
PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

MS P. SCOTT, Presiding Commissioner
MR J. WALSH, Associate Commissioner

TRANSCRIPT OF PROCEEDINGS

AT ADELAIDE ON MONDAY, 18 APRIL 2011, AT 8.59 AM

Continued from 15/4/11 in Sydney

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MS SCOTT: I think we might start. Good morning, ladies and gentlemen. My name is Patricia Scott. I'm the presiding commissioner for this public inquiry. John Walsh is joining us by Skype in Sydney. Even though we're doing a recording, we'll try and keep this as informal as possible, but it is important that you understand that it's not a public meeting in the sense that we're not going to ask questions from the floor or have comments from the floor. But I will allow a little time at the end of the day, if people wish, to come forward and make a short statement. Some of you that attended last time will remember that.

So if you do want to avail yourself of that, maybe you could keep your comments to just a few minutes, maybe five minutes, because if there's a lot of you, it turns out that we won't have sufficient time. You're not required to give an oath for this hearing, but you are expected to be truthful in your remarks. Because we've got a good response and we've got a lot of people attending and speaking today, I will be quite strict on ensuring that you don't go over your time, or otherwise that will mean other people will have less time.

The transcripts will be typed up and will be available on our web site at www.pc.gov.au, but allow a few days. And if you wish to follow the hearings in other cities, a number are up on the web site now and we'll be doing hearings in Perth shortly. Our report is going to be finalised by 31 July and presented to the government. It's up to the government to determine its release date, so I can't tell you what day it's going to be out. We require submissions from the public to be completed by 30 April, please, because you can imagine that we've got to revise the report as quickly as possible, continue our work on costings and then complete the report by 31 July.

Now I invite Robbi Williams from the Julia Farr Association to come forward, please. Good morning, Robbi.

MR WILLIAMS (JFA): Good morning.

MS SCOTT: We'd assigned 30 minutes for the association, so please allow a little bit of time for John and me to ask some questions.

MR WILLIAMS (JFA): No worries. John is not there at the moment.

MR WALSH: Yes, I can hear you, Robbi. The picture falls out.

MR WILLIAMS (JFA): Okay. G'day, John. Good to talk to you.

MS SCOTT: If the picture falls out, there's always the telephone recording, so we've got two systems working simultaneously.

MR WILLIAMS (JFA): No worries, thank you.

MS SCOTT: All right, thank you very much, Robbi.

MR WILLIAMS (JFA): Thanks very much. I speak on behalf of the Julia Farr Association, a not-for-profit, self-funded organisation working in disability research and policy. We had the opportunity of making our original submission previous to the draft paper. When the draft paper came out, in addition to our own analysis, we've also taken it round metropolitan and country South Australia through our Loop Conference format, which typically attracts between 200 and 300 people, so that a range of people have had a chance to hear about the main features of the draft report as we have seen it. We've offered that caveat to the participants. Those people have come from a number of regional centres including Mount Gambier, the Riverland and Whyalla.

Our contribution is prefaced by the notion of the common good. The common good essentially is what binds community and society together. We all work together because we can't achieve everything in our life by ourselves and, by working together, we contribute to the common good. The way we do that is through taxes; and taxes will come up later in this submission. The taxes essentially are for the common good and our reasonable, I think, collective expectation is that that common good - those taxes - is invested in a way that supports individual and community wellbeing.

With that in mind, we'd like to commend the Productivity Commission for its draft report. It appears to have worked well to its brief and the draft report contains many encouraging elements for the National Disability Insurance Scheme. If we were doing a five-second sound bite for radio we would say that the report confirms that current funding levels are grossly inadequate in Australia for people living with disability; and that there should be a national scheme of entitlement that helps ensure people get the necessary supports they need to be active citizens in our community. And if these are indeed the two main messages of the draft report, we agree wholeheartedly. We agree with the proposed functions of the National Disability Insurance Scheme, which seem to orient towards some themes of policy, of information and funded support.

Briefly, the elements that we're supportive of are as follows - and I'll then go on to the elements that we think could be strengthened and offer some suggestions about how so. The proposed arrangements being inclusive of all people currently living with significant disability we think is a good thing. That the proposed scheme would have a highly personalised focus, mindful of the person's strength and capacity with attention to that person's future as much as the present and with the expectation that people are contributors to their community and to the economy - we support that.

There is a strong expectation that mainstream services such as health and education will be properly welcoming and inclusive of all citizens including people living with a disability. The absence of a co-contribution mechanism makes sense, because we appreciate it's a complex topic, on the assumption that the method of revenue generation for the proposed scheme means that higher income earners will be making higher contributions through their taxation or other levy.

We are supportive of the idea that the proposed scheme would offer coverage of all reasonable and necessary support. We are supportive of the idea that the proposed scheme would include a focus on innovation and we recognise and suggest that innovation can happen in two ways - in other words, there are two imperatives to support innovation to emerge, because it's hard to buy innovation per se. One is to make sure that the individual planning assessments that people get do indeed support people to imagine for themselves an ordinary, valued life and how this might be achieved, as this line of inquiry would set the tone for innovative thinking.

Our experience has been that, for many people living with disability and their families, the many years' experience of receiving conventional services has resulted in a suppression of personal horizons and that might need to be re-stimulated. The second way in which innovation could be supported to emerge would be for the scheme to set aside funds for genuine innovation, recognising that innovative thinking can come from anywhere, not just government or service agencies but anywhere in the community.

Continuing, we support the three options that are mentioned for distributing a personalised budget, these three options being through cashing-out, through a third party agency operating as an intermediary or through a direct relationship with a trusted support agency. All of those are highly legitimate choices and reflect the typical features of individualised funding models operating successfully in other jurisdictions. We think it is important that plans get signed off quickly for people; and that's good. It's good that people can add their own resources to the plan and that they can transfer up to 10 per cent into the subsequent year.

The consideration of employment of family members is a thoughtful one and a positive, good idea. It would be very important to consider how best to still meet the emergence of best practice including new agencies to assist people to plan and orchestrate their supports. We recognise that that imperative is signalled in the draft report. We think it's good that there is accountability and risk management with the considerations being simple and accessible.

We value the mechanisms that are described for reviewing the work of a new scheme, both externally through independent reviews and also internally through a robust complaint mechanism. We think that the information database online makes good sense for people who are interested in purchasing services and support. We like the focus on additional funding for early intervention, though we would make the point that intervention is an unfortunate word. It's one that's well used in the disability support sector, as well as other human service areas, but it places the power squarely with the professionals in people's lives, because it's an intervention and we would recommend using the phrase investment - "early investment" - instead. So we support the idea of additional funding for early investment services.

And we're very supportive that the funding that is encapsulated in the National Disability Insurance Scheme is protected through whatever legislative mechanisms are necessary to ensure that people living with disability are able to connect into the future with a full and reasonable cost of their supports. That summarises what we think are the main positive features, and the following comments are things that we think need to be strengthened; all of these comments in the context that we think overall the draft report is extremely encouraging.

We think there's a risk of a separate national injury insurance scheme because, unless those two agencies are strongly collaborating on best practice, then two different classes of citizens living with disability could emerge, as happened in New Zealand following the introduction of the Accident Compensation Corporation no-fault insurance scheme which I have some close familiarity with, where people living with disability who are entitled to access ACC funds because of their disability coming from an accident were able to access a certain line of funding. People who got their disability through other causes, including being born with a disability, had to compete through a separate mechanism. It created two different types of citizenship with disability in New Zealand, so we would recommend the reconsideration of a separate scheme.

We understand there might be some complications there around the way insurance runs at the moment, particularly around motor traffic accidents, between states and territories, but we would recommend the reconsideration of that division or, if that is not possible because of the complex mechanism of insurance, then we would recommend the consideration of a timed merger at a single point following their separate establishment.

The age threshold of 65 seems a little arbitrary for people to start making co-contributions, though we recognise it's a feature of the aged care funding mechanism, although the age 65 doesn't necessarily mark a common point of capacity change for people, other than being the notional age of retirement, which one can imagine will be increasingly ignored as the average age of Australians changes and the workforce numbers change.

We understand the rationale. However, given that the outcomes for disability support and for support of older people are inherently similar, we believe it is possible to run a unified scheme. There will also need to be the same commitment, therefore, to personalised funding and supports in aged care, and we know there's a separate Productivity Commission inquiry into the future of support for older people and we've made similar comments there.

The current wording of the draft report appeared to convey the impression that people of Aboriginal heritage would be assessed for co-contributions sooner because it's assumed they will experience age-related health changes sooner than other people. That's unfortunate. I imagine it's not intended that Aboriginal [people] be assessed for the co-contribution earlier. It may also be an issue for people living with disability to have age-related capacity change earlier, so we think there needs to be some further detail on how that threshold for co-contributions happens in reality.

We think there's a question about what "reasonable and necessary supports" actually means. Who decides what the ceiling is for reasonable and necessary support? We noticed in the Productivity Commission's terms of reference for this inquiry that the words "where possible" were included "provides support for people to participate in employment where possible". I think the words "where possible" are unfortunate and we think that it would be best to avoid such limits being applied to people without them having a go, so we would be supportive of an expansive view of people's ability to participate in the economy and in the life of community and that "reasonable and necessary supports" is seen in that context. We do query the purpose of the one-off payment at the start. We're not sure we're clear on the purpose of that. Don't necessarily feel we need to debate it today, but it would be good to have some clarity on the whys and wherefores of it.

There's a comment that some activities may fall outside the scheme because their clinical impact is somehow not proven. We're wondering how that would work, because who decides whether a particular therapeutic intervention is beneficial to the person or not? Even the placebo effect could be regarded as having benefit for people who need reassurance. Our view would be that it would be quite complicated to manage the boundaries of what is a proven or not proven therapeutic methodology, and our view would be that people should have full flexibility for how they use their personalised budget, on the basis that it doesn't involve anything illegal, doesn't involve anything that's directly to do with gambling, or anything else that might be construed as contributing to disability or disadvantage, and we're aware that those coordinates operate in other jurisdictions where personalised funding is in place, and they seem to operate well.

We query that if there's an expectation that mainstream agencies and employments, education, et cetera, are expected to be welcoming and inclusive, then why would that not apply to other mainstream providers such as taxi companies and housing developers? We think there's a great opportunity for the Productivity Commission to give stronger voice on such matters in its final report, because I know one of the questions that the Productivity Commission raises is around the extent of taxi subsidies and how that can be kept within check. In our view the most appropriate way to go would be to capacity-build across the entire community by insisting that all new taxis are accessible, as is currently happening I believe in Queensland, and certainly happening in the United Kingdom, where I think pretty much any cab you get in London and Birmingham, for example, is accessible.

We have a query around the assessment process because, like everything else, a good idea is at its most vulnerable during implementation - that's called Wilagan's Fact - and we wonder how an assessment might be conducted. Our view is that it should be simple, accessible, co-participated by the person and the family in their life, if their family is in their life, and that it be non-intrusive. We recognise that short-form co-participation assessments may not yet have a large body of research on their effect, but we would also argue that you could also say the same thing for the larger, more conventional technical assessments.

They may have elements of validity and reliability in terms of professing to measure a particular thing, but that doesn't necessarily mean that those assessment tools have a goodness of fit with the work of the proposed National Disability Insurance Scheme. We feel they have a tendency to be over-engineered; they are intrusive; they ask essentially the same question many times over; and they're expensive to run because they will require professionals with particular skill sets.

Our view would be that unless there is a compelling body of evidence that shows that the short-form assessment tools - for example, those used in a number of jurisdictions in the UK - are less effective than detailed tools, then it would make more sense to use those short-form tools because they are easier to run and they are cheaper to run, they will provide good-quality census-style data without having to operate an overly complicated database and they, critically, involve people living with disability and their families at the heart of the journey towards a personalised budget and personalised supports.

We think it's important that people are supported to make an informed choice, especially where a choice is a crossroads in terms of inclusion and marginalisation.

We think careful attention needs to be given to the mechanism for supporting people to describe their support needs and to convert these support needs into a range of choices made and plans crafted. Many people living with disability and the families in their lives have had their horizons shrunk by those around them - service agencies, medical professionals and others - albeit absolutely with the best of intentions, but we can see this in human history and we think it's critical that if the personalised budget framework is to be a real success that brings people into the economy as productive citizens and participants in community, then it's really important that people are supported to grow into a view of what is possible in their own lives within the context of the values in the United Nations Convention on the Rights of Persons with Disabilities.

We would note here, for example, the difference between safety and safeguards. There is still a tendency, speaking as a psychologist, for professionals to focus on duty of care and to take it in its most cautious form, which is to ensure that there is safety in a person's life. Unfortunately, if we focus purely on safety we tend to close people off from experiences that bring people into community, that bring people into growth and into learning.

We all have risk in our lives and it would seem unfortunate if we chose to set up a framework that excluded risk from the lives of people living with disability. Better instead to focus on the notion of safeguards, which is to look at a person's strengths and capacities and their aspirations, to look at the opportunities they might wish to engage with in the community and in the economy and to look at how that can happen as safely as possible, and that would be what we would call a safeguard. So we would like to see that the final report make a more robust statement around people being supported into ordinary valued lives through mechanisms that safeguard rather than through mechanisms that take people away from experiences in the name of safety.

The governance arrangements: we note the proposal for a national disability insurance agency and that the board of that agency would comprise people with a range of skills - that makes sense - in insurance, in finance, management and so on, but we think there is an important skill that's missing from that board and that would be the lived experience of disability.

If the entire scheme is anchored on the place that Australians living with disability have in their inherent value as citizens in our communities, their inherent value in participation, the authorship of their own lives, then to have a board of governors who are the former leaders for this proposed system that does not comprise people living with disability would seem counterintuitive. So we would encourage the reconsideration of the proposed make-up of the board so that it includes people living with disability. We think that could be crafted through an arrangement, for example, where the advisory council has nominees from its number who are on the board.

In terms of a quality mechanism, quality is a very important thing. Unfortunately in human services we have a tendency to try and measure it from the wrong end. If you imagine a process where you have inputs, processes, outputs and outcomes, we have a tendency to go to inputs first: look at what, for example, qualifications we might expect people to have, if it's work in an industry like disability support. But from the experience of people living with disability, particularly the people who talk to us, they'd rather it start from the other end - just from outcomes.

So we would hope that in the final report there is a commentary around how a quality assurance mechanism will indeed focus on quality parameters that are based on the outcomes in people's lives and that those parameters are designed in partnership with people living with disability. We think the time frame could be shorter because South Australian funding for disability support is known to be low and we would like to see it higher sooner and so we would be all in favour of a tighter, more aggressive time frame because I don't think it can arrive soon enough for the disability community of South Australia.

We have a query around how the assessments will be commissioned. We found ourselves wondering what the future would be for currently employed, by the state, caseworkers. Sorry about that; bad sentence - so the people who are currently employed in casework brokerage roles by the state government. In South Australia, they're called "service coordinators", in Western Australian they're called "local area coordinators" and so on. We were wondering what their role will be in the future and imagined that it would be the National Disability Insurance Agency that would employ a separate workforce of people undertaking these assessments and related functions, in which case what's the relationship between those government offices, or might the National Disability Insurance Agency seek to outsource the trained assessments and associated activities to those workers currently working for state and territory governments? We're interested to see some more detail on who those personnel will be.

But I think more importantly what we're interested in seeing is, in the new agency, how will its culture, its organisational culture, be calibrated so that the people who work for that agency understand the importance of a vision in a person's life, understand their role on behalf of the formal agency in that person's life and that it's not to take over but to facilitate and to be a pilot guide, how to support people to connect with supported information, to connect with material resources and to move into support arrangements that bring the person living with disability into fellowship and connection in their local community?

Those elements I've just mentioned relate to a model of assessment and support that was authored at the Julia Farr Association. It basically covers five areas that we think are critical if people living with disability are to be supported into full roles of citizenhood in their community. We have some miscellaneous remarks in relation to the questions that the commission puts at the end of the draft but I'd like to pause and offer conversation - - -

MS SCOTT: Yes. You've got about six minutes left, so we might go to discussion, if that's all right.

MR WILLIAMS (JFA): Absolutely.

MS SCOTT: All right. Thank you very much. Thank you for a very systematic and comprehensive run-through of parts of the draft report that your organisation supports and those bits where you consider there should be reconsideration of proposals. I don't think we'll have time to go through all of that, but maybe we should concentrate, John, on some homework we can set the association in relation to some of those reconsiderations because it's very useful to have material that would address those. John, is it all right if I start off and then maybe you come in?

MR WALSH: Yes, you go on, Patricia.

MS SCOTT: So, for example, you've asked for a stronger focus on outcomes rather than inputs - that's eminently sensible. Of course, as you know, people often resort to measurement of inputs because outcomes are so hard to measure, but we have on chapter 8 potential indicators, sources of evidence, about service provider quality. We particularly would welcome your association's comments on whether these indicators, which go to outcomes - some of them go to outcomes, like serious incidents, infection rates, evidence of harm, evidence of satisfaction, consumer surveys of evidence of complaints. If you could go to that and just see what you could do to suggest changes to that area, that would be most welcome, possibly drawing on any evidence you have from overseas. That would be very useful.

In relation to safety versus safeguards, if there's material that you can suggest to us in relation to the draft report, we'd welcome that. On the people having their horizon shrunk, I think this is a theme that we tried to pick up when we were talking about passivity. John, do you want to discuss that with Robbi, and then maybe see where your interests go next?

MR WALSH: Yes, it's something I was going to pick up on anyway, Patricia. I think it's a critical issue, Robbi. We have almost an inevitable transition period between a setting in which people have got almost learned helplessness; even worse than that, learned lack of horizons. We're envisaging a world where people determine their own - I think you call it fellowship in the community. That's a big transition, and any work you've seen or done on how that transition might be facilitated would be really useful. We're very well aware that just installing a market won't do it, so people won't have the ability, won't have the capacity to participate fully in a market, given that they've had no experience. But that's where we want to get to eventually, so if you've got any literature on that, that would be really useful.

MR WILLIAMS (JFA): Certainly.

MS SCOTT: Robbi, you've stressed the importance that we have an expansive view of employment rather than stick to the terms of reference where it talks about employment "where possible". We are interested in doing some further work in this area, so we'll review what your association has said earlier but, again, if there's something you can add to the material that you've previously provided us, we'd welcome that. We certainly have had some engagement, some visiting experts from overseas that have stressed the fact that employment prospects in Australia are set so low for people with disabilities within the sector and within government, so whatever you can offer on that we'd welcome. I might make a few remarks, just to throw a few challenges back, if that's all right.

MR WILLIAMS (JFA): Sure.

MS SCOTT: I think we discussed last time your interest in people having as much personal choice as possible and I think a lot of that is reflected in the report, but you're drawing our attention to the fact of who decides what therapeutic interventions are suitable or not. I think we have to acknowledge that the community is very diverse and that some people are interested in homeopathy and crystal solutions and swimming with dolphins and new approaches. Not all of those are proven clinically - in fact, I think I can say with some confidence a number of those are not - and therefore I think it's reasonable for taxpayers' funds and even for the interests of the individual that careful consideration be going into that.

So I think we've got to acknowledge that people don't always make wise choices when it comes to therapies. There's potential for over-servicing and so I just throw that challenge back to you. We're suggesting that effectively there be a group of people, well regarded in a sector, that would advise the NDIS on therapeutic assessments and treatments, that people are assessed by allied health professionals but, ultimately, when it comes to clinical decisions about therapies, that it not entirely be left up to the individual. So I might throw that one back to you to have a further think, and maybe you want to respond to my comments in your submission.

On the different classes, it's true that in New Zealand people do want to get into the accident scheme if possible because of the alternative, but I guess what we're suggesting here is that both schemes have high standards and both have confidence of funding, something I don't think the New Zealand system reflects in relation to the non-accident scheme. So I wonder whether your point of comparison is really fair in relation to what we're suggesting in the report.

MR WILLIAMS (JFA):   It's not a perfect comparison, I think, just because it's a separate mechanism. It's partly done in a sense because, as you say, there's not the same robustness of people who don't get the disability through an accident in New Zealand. It's more just a note of caution because of the danger of two separate systems being in place. Unless they're closely aligned, there might well be a mismatch of standards and practices.

MS SCOTT: Maybe one last comment from me and then, John, you can take over. A lot of people initially referred us to the UK experience and we did look at that very significantly, as you would have seen in the report, in numbers of reference. But in relation to self-assessment or short assessment, we have acknowledged in the draft report that for some people short assessment would be quite appropriate. But where people in some states have not had assessment for some time or services are clearly inappropriate to their circumstances, it might actually be in the interest of the individual that there is a longer assessment of what they need and what their aspirations are.

In the UK - I think the suggestion in our report is that many people have probably a rose-coloured glasses assessment of what the UK system actually delivers, compared to sometimes what's in the documents. If it turns out you think we've got that wrong, by all means suggest areas where we should go in our research, but I do suggest some caution in terms of putting our eggs in the UK basket. I'll stop there. John, is there anything further you want to say?

MR WALSH: Yes, I've got a couple, Patricia. On the two schemes, Robbi, I think you make a good point about New Zealand. The other way of looking at it - and you're not the only person who's [indistinct] of only having one scheme, so it's one we need to look at. The other way of looking at it is that having a parallel accident scheme which is also well funded may serve as a safeguard, using your words, against the whole system being drawn down to a lower standard. So if you [audio interruption] schemes delivering high-quality benefits, it sets the benchmark for the non-accident scheme to achieve the same benchmarks.

The other thing I had is still about this ‘building horizons’, which I think is critically important, and building people's horizons will be dependent on building community as well. London and Birmingham I think have fully-accessible transport systems. There's a lot more community infrastructure that needs to be developed and any examples you've got of places around the world that have taken forward community transport, housing, education would be useful.

MR WILLIAMS (JFA): Right.

MR WALSH: That's it for me, Patricia.

MS SCOTT: Okay, is that all, John?

MR WALSH: Yes, thank you.

MS SCOTT: Robbi, thank you very much for coming along today. It's very encouraging to hear that you've had good participation in the loop. Was I right in thinking that you had between two and three hundred participants?

MR WILLIAMS (JFA): That's typical of what we'll get in any given year.

MS SCOTT: I see. You're still going through.

MR WILLIAMS (JFA): Yes. One or two venues had to be rearranged because they clashed with Easter.

MS SCOTT: Okay. Again, thank you very much for being so comprehensive in your commentary. I didn't draw attention to all your comments because I've written them down or have the transcript, but we welcome your participation and thank you for your efforts today.

MR WILLIAMS (JFA): I appreciate that. Can I just say, just for 10 seconds, on the subject of assessment we're not necessarily saying that a UK model should be accepted holus-bolus. It's more around, I think, the sentiment of co-participation. Whatever assessment mechanism is adopted in Australia, it's sentiment and its mode is that people with a disability and their families are partners in the way that tool runs.

MS SCOTT: We did want that to be the theme and I think I can probably find places in chapter 5 that do that, but if you don't think that's enough, by all means you can actually suggest fair dinkum drafting changes to us. How's that?

MR WILLIAMS (JFA): No worries.

MS SCOTT: Because we're going to run out of time.

MR WILLIAMS (JFA): Okay.

MS SCOTT: All right, thank you very much.

MR WILLIAMS (JFA): Thanks very much. Good to see you, John. Thank you.

MR WALSH: Thank you.

MS SCOTT: To those that have just arrived, good morning and welcome. You'll see that John is appearing on Skype from Sydney. Please don't be worried if it temporarily cuts out at some stage because he's also got a telephone link here to Adelaide. Are you able to hear us okay? People at the back, you're nodding all right? Yes, okay, that's good. All right, thank you.

Now, I also understand that there are members of the media present. We do have protocols regarding the media, so I'm sure they'll adhere to those and we certainly welcome their involvement in this inquiry, but I'd just ask them to note the protocol arrangements. We're almost on track on time, so I now invite the Australian Lawyers Alliance to come forward, please, and to make their presentation.

MR KERIN (ALA): Good morning, commissioners.

MS SCOTT: Good morning, Tony. Please feel free to call us Patricia and John.

MR KERIN (ALA): Thank you.

MS SCOTT: We've assigned 20 minutes to your presentation but you might allow just some time for us to ask questions.

MR KERIN (ALA): Certainly.

MS SCOTT: Please commence when you're comfortable. For the transcript could you state your full name, and I understand you are representing the Australian Lawyers Alliance today.

MR KERIN (ALA): That's correct. My name is Anthony James Kerin and I'm the state president of the SA branch of the Australian Lawyers Alliance. Patricia and John, I'm certainly aware that you've spoken to a number of my colleagues elsewhere in Australia and I'm one for efficiency. We have a similar view in South Australia, as you've already heard from members in other states. We deal with the big picture process in a way because of the very vast task which the commission has undertaken. We do appreciate the significance of it.

In South Australia in particular ALA SA has some connections with aspects of the disability sector through its work and generally, and we are well aware of the very great need that exists for the disability sector in South Australia and indeed elsewhere. The presentation of the draft report really has provided to us, as an organisation, a challenge in relation to the way the system works in Australia currently. There is no doubt that it is time for a national disability insurance scheme or structure that makes for a far more cohesive and streamlined approach to the issue of funding for the needs of this sector. It has been ad hoc to date and it's been observed from afar that there are many great needs not being met. The sooner it can occur, the better.

The Australian Lawyers Alliance also is aware of your recommendation for a national injury insurance scheme. We have a number of concerns about such a scheme, particularly given the tone and tenor of chapters 15 and 16 of the report, which tend to in our view not fully adequately appreciate the benefits of the common law system and the tort based systems that exist around the country. It is certainly our position, speaking generally - I'll come back to it in a moment - that that system should not be dismantled and that it should co-exist with an NDIS for the benefit of the entire Australian community. So as an overview, whilst we commend the NDIS concept - and undoubtedly there will be some finetuning that will be needed to the recommendations that have been made - we don't have the same degree of support for an NIIS.

ALA is an organisation which deals every day, through its members, with the injured through various mechanisms, not only through motor vehicle accidents but medical negligence and other forms of injury that are caused through human activity in a negligent way. We are fully aware that the common law system has been modified in a number of states and that there are different jurisdictions. There are also different methods of supporting those jurisdictions, given the different population in each of the different states. New Zealand, for example, as a completely opposite example of how systems work, is a much smaller population than the Australian mainland and Tasmania, and we are of the view that it provides a stark contrast to the benefits of the injured as received under our common law tort system.

The Australian Lawyers Alliance will be presenting a unified paper in response by the end of the month, to you, as I'm sure you are aware, and it will canvass in more detail some of the concerns I'm about to raise with you. In respect of the NDIS, there is a concern about it taking some time to come into fruition. In South Australia the need, as expressed by other organisations with which we've had contact, is immediate and increases yearly. We appreciate that there will be delays and it will take some time, but it is important that the transitional period is one that is not neglected and that mechanisms are put in place. What they are I leave to others to suggest, but I echo the concern that the need in South Australia is particularly great.

Our concern with the NDIS also extends to the issue of assessments. The report refers to assessments of disabilities being as objective as possible. Whilst this is an appropriate aim, it needs to take into account the concerns of all that are associated with the person being assessed. It needs to take into account those considerations and come to an appropriate conclusion and, if that conclusion is disputed, there needs to be an appropriate dispute mechanism. Whether that be an internal one initially or whether that layer of the scheme is stepped aside, there needs to be an independent review of all of those assessments where someone objects to it.

Ultimately, this would result in decisions being assessed by a body such as the Administrative Appeals Tribunal, where the courts essentially can assess what's occurred in relation to any activity. This is very important for a number of reasons, not least of all a sense of autonomy and the personal choice to be able to challenge decisions which are not agreed to or agreed with.

I was also concerned about the fact that mental health appears to be an issue that will not be included in the mechanism of an NDIS. We see it in a number of contexts in the community, not just as a consequence quite often to physical injury but also in other sectors or areas where we work. Mental health is an extremely important causative issue in criminal behaviour in the community. To exclude it now, when we have an opportunity of including it and dealing with it, would seem to be an opportunity lost. We appreciate it's a vast problem and a significant one, and that the criteria for mental illness creates challenges in itself, but it should not be one that's overlooked. As I said earlier, the complaint system needs to be objective and independent, with an ultimate review mechanism that people are going to walk away satisfied from. That is the purpose of an independent authority to deal with issues.

I turn to the National Injury Insurance Scheme. As indicated, ALA is opposed to a no-fault based scheme replacing all of the schemes that exist around the country, by 2020, if that is the intention of the report. We appreciate that initially the long-term care of the catastrophically injured in motor vehicle and other types of injuries is what's contemplated. We appreciate that this has been based, in part at least, on some of the considerations of the New South Wales scheme and I'm aware of some of the concerns about that scheme which need to be taken into account.

At this stage, ALA would suggest that that scheme is somewhat young and there needs to be a thorough review of it and of its downside. There are three basic problems with it, as I'm advised. As I say, fuller submissions will be provided. ALA will probably not be opposed to such a scheme if it is adequate and addresses these concerns, such as that the scheme does involve a right to representation and advocacy, doesn't minimise the use of lawyers and indeed insurers who have rights and interests, isn't coercive, and is optional, and can be a matter of choice for those who are injured rather than being forced upon them.

Those issues are significant in terms of that particular scheme but we, as I say, will be presenting a more fuller submission which will hopefully assist in further advancing that particular type of response to a particular type of significant injury. The costs involved will be significant, and that is a matter that I know you've had addressed to you by others and our inquiries are not complete in that area, but it will certainly be a concern that any such scheme will create difficulties in being fully funded.

The issue of autonomy in that situation is one that cannot be given too less a weight. It is extremely important for the injured and those with disabilities to be able to make decisions for themselves. I've referred to the need for advocacy and for representation and for a dispute process for decisions which, in the scheme in New South Wales, only exists in relation to matters of law. It needs to be merits based. There needs to be a complete new hearing, if that's necessary and if that's what it takes.

The Australian Lawyers Alliance works with the most vulnerable in the community, at the worst times of their lives, when they are injured and when things are stressful. Not having assistance just compounds those difficulties and needs to be taken into account when final conclusions are made from this report. As I say, independent judicial review is a vital aspect of any of these schemes and we reiterate that wholeheartedly. We are also aware that there is a need and a problem in some instances in the rural community in the provision of services under the New South Wales long-term catastrophic injuries scheme. We understand that there is a lack of provision of those expert enough to provide the care that's required.

Our further concerns are particularly in relation to the funding of this NIIS, even if it were to be eventually implemented. The duplication of similar schemes would also appear to us to give rise to inefficiencies potentially, which could be avoided if there was just the one NDIS approach. The NIIS, if it existed at all, should be an opt-in approach, but we are of the view that it's not something that has merit in terms of a review in 2020, which will require a correlation of all of the schemes in the country being put into one basket.

There will be a number of vested interests in relation to such a proposition, if that were to occur down the track, because there are certain funding benefits that apply to a number of corporations and entities involved in those schemes. Rather than waste time, effort and funding on a scheme which has a lot of dissent towards it, and will do in due course, and has a lot of interests, those funds should be better spent in implementing, setting up the structure and dealing with the NDIS, and we hope to be in a position to talk more comprehensively about figures in our final report and submission to the commission.

We also say that, in chapters 15 and 16, the commission has undervalued the benefits of the common law tort based system. There is a regulation of conduct in the community through this system. It has existed and evolved and, despite having gone through some transition of some magnitude in the last decade, continues to be of great benefit to the community in regulating the behaviour of activities that are antisocial and cause injury. It has had a broad-based effect in areas such as the asbestos disputes. It has significant assistance to make the world a safer place, and that is but one example. In a no-fault scheme, the incentive to be careful disappears to a large degree, and in any event it is a good thing to be held accountable for your actions and ALA is certainly of the view that a negligence based system is not one that should be dismissed, which is certainly referred to at the end of the report as a possibility.

I can give an example of that anecdotally, where a doctor speaking at a medical negligence conference in the year 2000 commented that the New Zealand system was some years behind the Australian system in terms of its developments and the reason for that was that there was not the same degree of accountability and every time that they went to operate, if a mistake was made it was covered under the no-fault scheme. They didn't have someone looking over their shoulder. I mention that by way of illustration as to the significant ability of the common law to regulate, improve standards and contribute to a healthier community.

MR WALSH: I hope we're not going to run out of time for questions.

MR KERIN (ALA): I've finished, sir. I'm happy to take any questions.

MS SCOTT: John, would you like to lead off?

MR WALSH: I'll lead off, yes. Tony, thank you. I'm very interested in your analysis of the New South Wales Lifetime Care scheme. Just for the record, there are currently about 500 participants in the Lifetime Care scheme, predominantly people with spinal cord injury and brain injury, who are receiving care and support, are receiving rehabilitation and having their needs met. About half of those people would receive nothing if not for the Lifetime Care and Support scheme.

In addition - I mean, you talk about the benefits of the common law - there are many people in New South Wales who had their injury before the Lifetime Care scheme came in who are entitled to the common law and who are still waiting for anything. So I think it's a bit hard to argue the benefits of common law for those people who would have received nothing, who are waiting for benefits when they had those accidents before the Lifetime Care scheme. I think they might find some disagreement with your concerns. It's a young scheme, yes, and it's still growing and still learning. No-one would dispute that.

I'd also now like to turn to the TAC scheme, which is funded on similar principles and has been going for much longer, which is also a no-fault scheme and in which people receive entitlements as they do in New South Wales. I'm going to your point that these are expensive schemes and hard to fully fund. The TAC scheme has been operating for (audio interruption) years I think, with very stable premiums and premiums which are less than those of South Australia. I believe the South Australian CTP scheme has premiums which are the highest in Australia, in a common law environment. So I'd like you to just explain how it is that you feel that a scheme like the TAC, which is a no-fault Lifetime Care scheme, doesn't have a funding problem, while the South Australian CTP scheme actually has higher costs and doesn't provide any compensation to those who can't prove negligence.

MS SCOTT: John, you cut out just while you were explaining how long the TAC has been operating, so if you could just say the number of years again, and I think your point was that it was a very stable scheme in terms of its premiums. We just missed that figure.

MR WALSH: I believe it's been going for nearly 25 years.

MS SCOTT: 25 years. Okay. Thank you.

MR KERIN (ALA):   I understand that.

MR WALSH: So did you hear my question, Tony?

MR KERIN (ALA):   I did. The schemes in each state are different. The TAC scheme, whilst a certain emphasis is on no fault, there is a common law aspect to that system and it can be accessed.

MR WALSH: Just before you go on, I'll just chip in there that I believe the common law component of the TAC is that which is escalating in cost most significantly at the moment. I believe there is evidence to support that.

MR KERIN (ALA):   We'll certainly review your remarks about that. I'm not aware of that scheme, but we do have - and I am aware that the Victorian alliance member has spoken to you about or has made a submission in relation to the benefits of that scheme. The TAC scheme does run well in terms of its performance. However, the benefits on average are not always as easy to access as the CTP scheme is in South Australia. Secondly, it is a very bureaucratic scheme. There are a number of hurdles one has to get through to get the benefits, and some of the delays are caused - in my submission, the delays caused in the motor vehicle collision area are predominantly as a result of the injury taking time to stabilise, not necessarily because of whatever scheme is in place.

However, the costs aspect is something that requires close analysis and we will certainly be providing you with further details and I'll answer that question in the course of the fuller submission that the alliance puts forward. I'm not familiar enough to be able to answer for you the benefits and pros and cons of the TAC scheme, other than to say that I'm parochial and I think the South Australian scheme works well with the size of population we have here and with its funding ratios being very stable over the last few years.

MR WALSH: Would you be able to just provide some evidence on what has happened in the CTP premium (audio interruption) Australia since say the year 2000?

MR KERIN (ALA): Yes, I will certainly take that up and provide you what we can on that. There are different considerations in every state, but I'm certainly happy to get the material together as best we can and to let you know if I have any difficulty.

MR WALSH: And just on the issue of hurdles that you mentioned, with the TAC it's pretty hard to get benefits because of hurdles - - -

MR KERIN (ALA): I didn't say it was pretty hard. I said that it is more difficult to access because of the number of procedural hurdles that one has to jump, which don't exist in the common law system in South Australia, for example.

MR WALSH: No, but for example, in a common law system wouldn't you regard it as a significant hurdle that the need to prove negligence excludes half of the people that have injuries?

MR KERIN (ALA): I don't know that the number would be as - I don't know what the percentage is. The way I look at it is that it's better for the injured in those circumstances to have rights that have evolved and not to be taken away. The criticism that the system faces is what you point out: that the other half say, "Well, that's unjust." But there are other aspects to the common law system that you're trying to regulate: the behaviour of those involved in the incident causing the injury, as opposed to those who get some injury or disability through some other mechanism. There are other ways of looking at it other than saying, "It's just unjust."

MEL: Excuse me, this is - - -

MS SCOTT: No, no, sorry, Mel. This is not a public meeting, and I explained that at the start. We're taking a recording and we have assigned time to John to talk to us. If you wish to make some comments, you can do so at the end of the day. Sorry. Would you like to proceed.

MR KERIN (ALA): Yes. I was saying that the benefit of the negligence system - proving negligence is a hurdle. I can't run away from the fact that you have to establish your case, and the difficulty that has existed to date - and hopefully your report is going to remedy that - is that there hasn't been a safety net of sufficient adequacy. Medicare, Centrelink, are inadequate in their current form to cope with what your report talks about as a deficiency. The two can exist side by side, and in our view should, because not only is it appropriate that those rights not be dissolved or taken away or abolished but the money that would be required to run an NIIS can be put back into an NDIS, if I've got the nomenclature right.

MS SCOTT: It turns out we have just a little bit more time, John, because our next presenter will not be appearing, so I just want to take the extra little bit of time just to explore this.

MR KERIN (ALA): Certainly.

MS SCOTT: As we've been travelling around Australia, I think it's clearer what the Australian Lawyers Alliance is suggesting, but I just want to check my understanding. For those cases where people can't prove negligence, are you suggesting that the Medicare and Centrelink system be strengthened to assist them or are you suggesting that those people would be in the NDIS? Can you just say which of those two you prefer?

MR KERIN (ALA): I don't think it's as simple as that. There are a number of options and one of them is the one you mention: strengthening those two systems. But surely if that were to be done, you would do it in conjunction with producing an NDIS which works cooperatively with such agencies.

MS SCOTT: Okay. So I just want to clarify this. You would see that someone who isn't able to bring forward a case proving negligence would be reliant on the NDIS for the sort of services we've outlined in the report?

MR KERIN (ALA): It's going to be ALA's final position, I suspect, and I speak without that being formalised yet.

MS SCOTT: All right. So we haven't got total clarity on that. And for people who go through the process of seeking an outcome using common law, if they were unsuccessful, would you see them falling back to the NDIS, in your mind?

MR KERIN (ALA): Again, that's not something that's been considered in detail, but I see no reason why that shouldn't be the case.

MS SCOTT: I think it would certainly help us if we could establish what the Australian Lawyers Alliance sees as happening to individuals who cannot bring cases or are unsuccessful in bringing cases. Then, having been critical of the New South Wales scheme and pointing to that, whatever you can provide in terms of outcomes from that scheme versus what people would have got through common law - I think that's what John is referring to - that would be quite useful. You've pointed to the fact that it's a very new scheme, and that's true; therefore, maybe your association can look at the TAC scheme which has had a considerable length of time to point that out.

But I'm going to go to another remark that you made, Tony, and that was about mental health. We have specifically asked people to provide feedback on the boundaries between the mental health sector and the NDIS, and we have actually included in the report some provision for the daily support costs, not clinical services, of people with severe mental illness in its preliminary cost estimates.

MR KERIN (ALA): I do recall that.

MS SCOTT: So just for the record, I didn't want people to read our transcript in future - - -

MR KERIN (ALA): No, I accept that.

MS SCOTT: - - - and think that we haven't included some. So we welcome your feedback also on that issue, because clearly it's one that we're grappling with. You can tell even from this morning that people would like to include in the NDIS - I think the previous presenter wanted to basically bring the aged care and the disability sector together. You seem to be arguing for the greater inclusion of the mental health sector. It does pose questions in terms of feasibility and cost.

MR KERIN (ALA): Yes, I accept that.

MS SCOTT: So if you can go to that issue, we'd welcome that. John, I think I've exhausted my questions.

MR WALSH: I just have one more, Patricia. You asked Tony to provide advice on what would happen to people who couldn't establish negligence but who had attempted it. Tony, I'd also like to ask the question of what happens to people who do successfully achieve a negligence action and get a common law lump sum, who extinguish that lump sum while they're still alive? Who pays for the care of those people once their lump sum is extinguished?

MR KERIN (ALA): As I understand it, they would fall back onto the public purse. It would be the Centrelink and Medicare systems.

MR WALSH: And the NDIS, presumably.

MR KERIN (ALA): And the NDIS.

MR WALSH: So that's an extra cost that needs to be taken in as well?

MR KERIN (ALA): It does, but we'll attempt to ascertain numbers in regard to that. Whilst there are always stories about claims that money is misspent upon completion of claims, the detail of what that represents in terms of overall numbers is not known. But certainly it's an issue that we will grapple with and respond to.

MR WALSH: Just for the record again, we understand from Centrelink that there are people receiving Centrelink benefit who have fallen through the compensation system.

MR KERIN (ALA): I don't doubt that that occurs, sir. Of course, that's still a prospect with NDIS, if you don't satisfy the criteria.

MR WALSH: I'm sorry?

MR KERIN (ALA): Well, you're still going to have to qualify for NDIS by way of assessments and other things, so there may still be some aspects of need that are not met. That's what I'm saying.

MR WALSH: That's an issue for the final report.

MR KERIN (ALA): Certainly.

MS SCOTT: I think if we were saying that someone who had paraplegia wasn't able to bring a legal case, then undoubtedly their reasonable and necessary needs would be met by the NDIS, and I guess if someone received a payout through a common law case and the money was exhausted, possibly exhausted through inappropriate use of expenditure, then I thought there had been some suggestion from others in your alliance that they would then, if there wasn't a preclusion period, fall back to the NDIS. Anyway, we look for clarification on that from your membership. That would be very useful. Are you okay, John?

MR WALSH: Yes, thank you, Tony.

MR KERIN (ALA): Thanks, John, Patricia.

MS SCOTT: Thanks for coming along today. Thank you for your contribution.

MR KERIN (ALA): Thank you.

MS SCOTT: I now invite Ian Thompson to come forward, please. Good morning.

MR THOMPSON (NCS): Good morning.

MS SCOTT: Thank you for coming along today. We have assigned 20 minutes to your presentation and our questions. For the record, could you indicate the group you're representing, please.

MR THOMPSON (NCS): Yes. I'm employed by Novita Children's Services. I'm the company secretary.

MS SCOTT: Thank you very much. Ian, would you like to now make your statement.

MR THOMPSON (NCS): Yes, thank you. I thank the commission for giving us the opportunity to make a statement today and I would like to record Novita's appreciation of the draft reports by the commission. Those reports give disability a national profile and a significance which we consider is warranted and long overdue. I also welcome the commission to South Australia, where I think even our state government now acknowledges that we have the least amount of funding per disabled person compared with any other state in Australia. We welcome measures to overcome this situation in South Australia.

Specifically, Novita agrees with the broad brush of the Productivity Commission's draft recommendations and, in particular, the establishment, or proposed establishment, of the two arms: a national disability insurance agency and NIIS, the no-fault injury scheme. Specifically, we agree with the concept that's been put forward of separate time frames for the introduction of those two arms, particularly noting that NIIS may have implementation issues around legislation delay, transfer of powers between state and the Commonwealth, uniformity issues and others. From our perspective, from the disability perspective, let's get on with the NDIA.

Novita made a submission last year to the commission. It is submission numbered 560. Generally, the features of that submission included an aim to describe very broadly the history of service delivery in South Australia to children and young people with disabilities. Novita was previously the Crippled Children's Association and it has existed in various forms since 1939. Our submission set out to describe the range of critical services that are delivered to children and young people with disabilities, particularly in allied health, in assistive technology, rehabilitation and equipment, research and other areas, and also to note the extensive links into other mainstream areas, particularly children's health, education and recreation.

Our submission deliberately stayed away from the high-level strategic and policy approaches and, at that time, we thought it best to describe what we do and what we're partly funded to do for children and young people aged zero to 18. Primarily, they are young people with physical disabilities. A lot of them have dual and multiple disabilities and some have acquired brain injuries. Because the issues relating to children and young people with disabilities are unique, and our concern was that they might not be well understood, we thought it was significant that the gains which have been consolidated particularly in the last 20 years be recognised as we would seek to consolidate them and not have any of them lost or overlooked in the implementation of a new system. We will provide a further written submission on a number of issues that the commission has mentioned in its draft reports which I won't go into today.

I just, if I may, briefly want to touch upon issues around eligibility and assessment; about interaction with other systems; about quality, and about fees; but particularly, and really only, in the context of children's issues and issues for young people with disabilities. There are two main points that we seek to emphasise in relation to eligibility. The first is to emphasise that in our view all children and young people with a disability should be eligible for the NDIS.

I take as an example cerebral palsy. CP takes different forms. It has different impacts with a different toll for children. No two children are identical and no two children will be impacted in exactly the same way; suffice to say in our submission that for every child with CP that condition is severe. Whether it's one limb or two limbs or three limbs or four that are affected, or whether it's speech, vision - whether the young person is ambulant or non-ambulant, whether it's interference and impairment with gross motor skills or fine motor skills, we would put forward the proposition that that disability is severe.

The condition, as you will be aware, is lifelong. There is no cure, so by definition we can contend it's a severe disability. In whatever form a child or young person has cerebral palsy, there will be different impacts for each child and young person at different stages of a child's development.

MR WALSH: Patricia, could I just ask a question?

MS SCOTT: Yes, please proceed.

MR WALSH: Ian, thanks for that. This is one of the issues that we're struggling with. I don't in any way question your assertion that any child with cerebral palsy has a severe disability. I guess the question for us is about support needs. If there is such a thing as less severe, at the least severe end of the spectrum what might the support needs look like for a child with a mild form of cerebral palsy?

MR THOMPSON (NCS): Well, it will change over time. In very broad terms, it will probably be quite intensive early on through initial assessments and working out what supports are needed. It may be in relation to physical impacts. It might be in relation to physical impacts and behavioural impacts. It might be in relation to social issues and education issues. So it is going to depend. If the child is ambulant and is attending a mainstream school, as many of them are, then really the supports are going to fluctuate over time. It's likely with most children with CP that there will be a series of medical interventions and some of those interventions might be quite substantial, involving hospitalisation and a period of rehabilitation after that.

So it is difficult to generalise but even in the more moderate cases of CP the intermittent but significant health service interventions will be a factor, and then the continuing but probably diminishing allied health interventions as the child grows older are again going to be significant.

MR WALSH: Thank you.

MR THOMPSON (NCS): Can I just touch on issues around eligibility and, in particular, raise the question about when eligibility is going to be determined. There is an example on page 15 of that part of the draft report which refers to a newborn with a severe disability and it's a reasonably nice little story which, if it worked out, would be good. We would just make the point that in reality issues around an early diagnosis and eligibility are much more difficult to determine than appears in that example and I appreciate it's only but one example.

The point really is this: it is critical to get an early determination of disability and it is critical to get an early determination on eligibility, but what does tend to happen frequently in our experience - in the first one to two to three to four years for many families with a newborn or a toddler with a perceived disability - is that doctors frequently decline or are unable to provide a diagnosis. Whatever the cause of that might be - and it may be that they are concerned about the prospect of litigation in relation to delivery, in relation to birth, or it may be a concern about the prospect of litigation in relation to diagnoses or alleged misdiagnosis - families are often left in this situation of limbo where there is no diagnosis.

In more recent times there has been a sanitised description of "global development delay", which is a description given frequently to toddlers and infants in relation to their condition. Sometimes that descriptor will be put in writing and sometimes it might be associated with verbal reassurances that things will get better. Be that as it may, our experience is that the trauma for families in not getting an early diagnosis is a significant trauma for them.

So in a situation where it might not be possible to get an early diagnosis, if that's going to have an effect on determination of eligibility for services, then we have a concern. In practice Novita, alongside Disability SA, has developed processes which enable provisional assessments of eligibility or time-framed assessments of eligibility to be implemented so that appropriate services can commence, which might be particularly services around physiotherapy, OT and speech therapy.

In addition, in relation to intellectual disability, our experience is that it's all but impossible to get an accurate diagnosis in relation to intellectual disability in those very early years, zero through to three to four. So in that sense we are asking that some thought be given to the extra difficulties and the nuances around problems with early diagnosis and getting eligibility because it is critical that services can be accessed under an NDIS even in the absence of a substantive diagnosis.

MS SCOTT: Ian, could we just pause here and have a discussion of this?

MR THOMPSON (NCS):   Yes.

MS SCOTT: I just want to see if I understand it correctly. You're right, our cameos can't possibly take into account all the complexities that may arise. I guess we did give ourselves a bit of room because in this example the child was born with physical disabilities as well that were evident at birth. But you're correct to say that many people have to wait some time before final diagnosis of their condition. We've received a number of representations on that in relation to the issues paper. In the draft report we do make reference to conditions in terms of trying to cost the number of people that will be in the scheme and estimate the cost of the services that would need to be provided, but we're not proposing that eligibility into the scheme be condition based.

MR WALSH: The eligibility for the scheme is very much core activity based or, alternatively, intellectual disability diagnosis based, or the third gateway is where early intervention would lead to a positive outcome. I think there's a way into the scheme for most children who would demonstrate some type of disability. Is that where you were going, Patricia?

MS SCOTT: Yes, that's right. I'm taking it that in cases where there's a clear need but not necessarily a clear diagnosis, the child or the family will be assisted, but I just wanted to check - having provided that comfort, I just want to check. Is your concern that doctors are unnecessarily hesitant in making a diagnosis? I just wondered if that was the extra layer that you were adding to this issue.

MR THOMPSON (NCS):   I think the point that I'm making is that there is a perception amongst families in these circumstances - - -

MS SCOTT: They are unduly - - -

MR THOMPSON (NCS): - - - and others agencies that there is that perception, but it may be an understandable matter.

MS SCOTT: All right. That's quite useful, thank you. I think that clarification was desirable. Would you like to proceed?

MR THOMPSON (NCS): Thank you. If I can just make some brief comments about assessments. In our view, they must be empowering processes and not designed to shut out individuals. We would like to see them enabling the sharing of information appropriately across other departments, particularly Centrelink and Health and, dare I say, across Commonwealth and state departments. We would certainly urge avoiding multiple assessments, if that can be done. There is core data which can be obtained early on, which should not have to be repeated over and over again.

As I have inferred or said, children and young people with disabilities frequently have multiple admissions to hospital over the years and multiple contacts with other health services and systems, so there are numerous stages where they do have to go through information provision processes. Can I say something about what the report refers to in chapter 3 as "intersections" with other areas and crossovers, particularly in areas such as education, transport, health and mental health, and we have dealt with them in some of our submission. The point that I just want to emphasise today is that, for children and young people with disabilities, those crossovers are multiple and they're critical.

In broad terms, they might start with a child care agency, with a kindergarten, with a primary school, a middle school, with vocational education and training, and they do change in their nature and in their intensity as children get older and when they have major surgery. We recognise that there are complexities in all of this. The draft at 4.19 seems to acknowledge that an NDIS would have a role in meeting some needs of individual students, and the example was used for the provision of hearing aids, wheelchairs, and that's something that would have an application for the individual in the education sense that would be provided irrespective of education.

However, unlike the provision of a ramp at school, which might come about because of the needs of one person and then endures for other people, our point is that there are education disability-specific needs for particular individuals and only for those individuals. In our submission we gave as some examples disability support to negotiated education plans, disability support to oral eating and drinking and care plans, and disability support to issues around transfer and positioning care plans. So many of those inputs - and they do include advocacy as well - into the mainstream services come from disability services, and sometimes their significance might not be broadly seen and understood from afar. So we're asking that there be an awareness of them and, if there is a need to further examine them in the next stage of this process, that that happen.

We are very concerned that, if these sorts of issues are left to be driven by mainstream services, they will actually wither on the vine and get lost. So the disability-specific impacts in those areas, including education and health, we would like to be seen as added to draft recommendation 4.5, which is about funding and being overseen by an NDIS.

MS SCOTT: In relation to that, Ian - I'll have to go back and look at your earlier submission - would you actually have words that you could suggest that we consider in terms of the drafting of that recommendation? Being that specific would be quite helpful for our deliberations.

MR THOMPSON (NCS):   Yes, we can certainly do that.

MS SCOTT: Thank you.

MR THOMPSON (NCS):   Thank you. Can I just touch briefly upon mental health. Obviously for children and young people - or some of them - with disabilities, there are crossovers and particularly for those with a dual diagnosis. The submission that we have made in the written submission is that disability is not a mental health condition, and that's our fundamental premise. That's a point made by the National Disability Services and also by Yooralla Services from Melbourne. In the report at 3.26 they talk about treatment for mental health being the responsibility for the health sector.

We agree with that view, and we note the draft recommendation 3.4 which we agree with, for MOUs to be in place with the mental health sector so that individuals do not fall between cracks in the system. Having said that, those of us who have been in the sector for 20 or 30 years have heard about individuals not falling between the cracks in the system and it seems to be something that's bedevilled the system and not been addressed successfully over three decades. So there is work of quite an intensive nature that needs to be done in that regard.

The commission has asked for feedback on which system is best placed to meet daily support needs and not clinical needs of individuals with a disability, arising from long-term mental health conditions, and I think schizophrenia was mentioned. Again, our concern with that kind of proposition is that it takes us into the realm of so-called, in recent times, psychiatric disability. The point that we have made in our submission and in other submissions is that we think this is potentially a dangerous misdescription, and we think that the fundamental premise must be that disability is seen as an impairment and not as an illness or as a manifestation or consequence of a mental illness.

If we get that premise wrong or if we get it blurred, then the history of services over 100 to 150 years, where boundaries between disability and mental health have been blurred and have not been clear, have shameful aspects of history which in blunt terms is disability in the mental asylum, and that's going back as recently as the 1960s and the 1970s. Even now with blurring, we have young people with disabilities who are accommodated in aged care residences because there is nowhere else for them to go.

MR WALSH: Ian, can I just chip in there. So your issue here is that you don't want people to be branded as having a mental illness - is that right? - and therefore inappropriately supported.

MR THOMPSON (NCS): It's the inappropriate support and treatment that is the critical issue.

MR WALSH: Yes. The other thing we're hearing from some mental health and illness advocates is that people with mental health issues don't want to be branded as having a disability.

MR THOMPSON (NCS): Yes.

MR WALSH: We have an interesting set of historical labels going on here.

MR THOMPSON (NCS): Well, we do, and labels are ultimately only labels. Our submission is in no way an argument for reduced funding for mental health: on the contrary. Particularly with dual disabilities, the issues are very difficult to address and need to be supported. But our issue is about different conditions, different diagnoses, different support services that are required, and mixing them up because of a symptom can lead to disaster.

MR WALSH: Thank you.

MS SCOTT: It does leave you, though, with a quandary - at least it leaves me with a quandary - because if we go down a very conditioned base diagnostic approach, so that, "You have this condition. It's on a list. You're in the NDIS," and I look down the list of conditions, "You're not in. You don't have this condition. You're out," if you go down that road you get these problems with misdiagnosis or, in the case you were alluding to before, where conditions aren't stable or doctors are hesitant to make a diagnosis, you get people who don't fit easily into a category and certainly we've had people present to us who have had significant - or their children have had significant neurological degenerative conditions. It just hasn't been easy for the medical profession to work out which condition it is.

So if you go down a conditions route you could exclude people with mental health. If you go down the needs route, the route that will look at their functional capacity and this person cannot look after themselves, they need assistance with self-care, then you could find people with severe permanent mental health conditions meeting that criteria. So I guess I struggled with this initially when you were speaking about people without diagnosis. I was thinking it sounds like you're a supporter of the functional approach but when you come to mental health it sounds like you're a supporter of the conditions approach. I just wanted to see if that's - I'm probably not being fair on your presentation. I just want to know where you do lie. What is your position on that difficult quandary?

MR THOMPSON (NCS):   I wouldn't necessarily see that as an inconsistency. I would get back to diagnosis and the critical importance of correct diagnosis. If that is done appropriately then that will lead to the correct streaming of service, irrespective of how they're funded. So that's the essential part of it. Where the crossovers come in, there will be situations where, as you've alluded to, the doctors may not be able to provide the ultimate answer in terms of a diagnosis. But in practice what will happen - in our experience quite frequently - is that the various allied health and other professions who are involved with the individual will share information and work out, as best they can, the nature of the condition, the nature of the impairments and the way in which that's going to be addressed.

Now, the reality is that under an NDIS those sorts of situations are going to appear and it's not always going to be easy to go down that list and get the right box ticked, so the assessments and the capacity of the trained assessors, and the interactions with all of the professionals who are involved, will be critical to that.

MS SCOTT: Okay. Thank you.

MR THOMPSON (NCS):   But I do urge great caution in trying to just get a strict delineation in these areas in the way that you've described; that if it's a consequence it might be dealt with equally by mental health or by disability. Can I just say something about quality? We strongly endorse the comments in chapter 8 of the report about the recommendations for a quality framework for disability providers. Novita has had ISO endorsement since 2002. We have the HACC national service standards appraisal endorsements, also in relation to OHS and NATA. So we strongly believe in the importance of quality assurance processes in services for children and young people and we strongly support the development and the implementation of nationally consistent standards.

We note that the Commonwealth in many senses has led the way with this and in relation to disability employment standards, some nine or 10 years ago they introduced quite rigorous independent mechanisms to monitor compliance with standards. In South Australia the state did not follow that approach and they adopted a more generic approach through a service excellence framework. We believe that that's unfortunate and we are strongly in favour of an emphasis on disability standards, that they are national and they're uniformly and independently monitored in addition to self-monitoring.

Finally, can I just say something about the controversial topic of fees and co-payments? We agree with the recommendation and we agree very strongly that there should be no income or asset test for obtaining funded NDIS services. We don't agree with the draft recommendation 4.3 about payment of front-end deductibles or issues of co-payments, and we are concerned about those draft recommendations.

There is comprehensive evidence, and we can summarise it for you in a subsequent report, about the extra financial hardship that families with a family member with a disability have to put up with. There are many single-parent carers of sons or daughters with a disability and there are many examples, in our experience, where a primary wage earner in the family needs to cease working at various stages when their child is undergoing serious or major surgery in hospitals and then going through a period of rehabilitation which might take several months.

There are examples, as you will be aware, of families having to move from country to city to be able to access services. So those extra financial burdens exist in any event in relation to having a child with a disability, and our submission is that front-end deductibles and co-payments will be seen and felt as another harsh penalty for giving birth to a child with a disability, so we do urge reconsideration of that recommendation.

In conclusion, we do emphasise that particularly in the last 20 to 30 years there have been significant gains in services for children with physical or multiple disabilities. Over the same period there have been marked changes and improvement for children with intellectual disabilities. The moves into mainstream education and employment for people with disabilities is a sign of those significant improvements, but the bottom line in all of this is that the work has largely been left, in the main, to the individuals themselves, to their families and to the not-for-profit sector. The government has done its bit but it's substantially been through subsidies to the not-for-profit sector.

So we don't want the gains that have been made to be lost but we do welcome and we're particularly grateful to the commission for this very substantive work that is before us.

MS SCOTT: Thank you very much, Ian, for such a comprehensive presentation. Just for the record, because other people will read the transcript, in terms of the 4.3 recommendation about deductible, we do suggest in the draft report that of course it be waived where families have already contributed significantly through unpaid care. I think it is all right to say that this recommendation has been drawn to our attention by a number of organisations and we're very open to the idea that we'll need to go back and have a further look at that recommendation. So that's fine.

If it's okay with you, John, I might just have the floor for a little bit. There's something you said that I wanted to ask you about. It's this idea that if we're not careful, the considerable learnings and the considerable practice that your own organisation and others like you have got over 20 years in developing resources, in developing good practice and so on could be lost. I wonder whether it's possible for your organisation, in a tentative way - maybe you don't want to call it your organisation, just an organisation - to indicate how you might see your functions operating in a world where there is a well-funded ongoing NDIS. For example, clearly John and I are not interested in seeing a diminution in the not-for-profit sector and NGOs, but we do think that circumstances will change because more resources will be available; the doubling of funding. More people would not have to have such rationed arrangements.

I guess it would be highly desirable for us if you could again maybe, as I said, just talk about an organisation rather than your own. I'm not asking you to commit to something, but you would look at how you would see yourself positioned in that environment. Is it the case that you would very much want to be in the role of providing information? Would you see that you would very much be in the role of providing services? Would you provide services of a specialist nature, that you'd see opportunities in new areas? I would be interested to have some sense of what are some of the issues that an organisation would have to think about in terms of positioning itself for that environment, because I think that would be extremely useful for us.

If funding could be more certain and ongoing, where would an organisation that's got a proud history- where would you see yourself going in a better world? I think that would be very good. So I might end my questions there, and leave it to you, John.

MR WALSH: No, I'm happy, but I echo Patricia's request. I think that would be a useful piece of work.

MR THOMPSON (NCS): Yes, we can certainly do that and would be pleased to.

MR WALSH: Thank you.

MS SCOTT: Sorry, one more thing; a bit more homework. You made the point that it's easy to make statements about no-one falling through the cracks but it's actually harder to achieve. I welcome your reality check on how that could be done. What would you need to have as your basic set of principles that would ensure that that high-sounding statement could actually become a reality?

We're hoping that the local person on the ground, the DSO, could be the person always in the individual's corner, always saying, "Wait a minute, this doesn't seem to be right," "Why isn't the education sector providing that service?" or "Why is the mental health sector not giving you the assistance required?" So we had thought of it from that perspective, but maybe you could think of what else needs to happen right at the outset for departments and organisations to work together to develop protocols. That would be good.

MR THOMPSON (NCS): Yes. In principle we'd strongly support that. In a way, what you are talking about is coordination and referrals, but if the point of coordination sits in one part of the system, it will coordinate it well within that system, but when you're going across systems, they don't coordinate quite as effectively, and that's the challenge.

MS SCOTT: We are expecting that that coordinator would be across various systems.

MR THOMPSON (NCS): Yes.

MS SCOTT: In fact we envisage that that would be a key element of the local person's role.

MR THOMPSON (NCS): Yes.

MS SCOTT: Anyway, we're looking forward to getting your submission, and thank you very much for coming along today.

MR THOMPSON (NCS): Thank you.

MS SCOTT: It might be the case that, Dom, if you've got a couple of minutes, you might like to talk to Ian about his work on the interface with education.

MR THOMPSON (NCS): Thank you.

MS SCOTT: We're now going to break for morning tea. We're going to resume at 11 o'clock. Thank you very much.

MS SCOTT: Ladies and gentlemen, we may now resume the hearings and I welcome to the table Dr Lorna Hallahan and I understand you're representing the Minister's Disability Advisory Council.

DR HALLAHAN (MDAC): I am.

MS SCOTT: For the record, I'll ask the individuals at the table to introduce themselves as well for transcript purposes. Don't be worried, John is actually listening in, in Sydney. You're there, aren't you, John?

MR WALSH: Yes, I'm here, Patricia.

MS SCOTT: Okay, and we'll re-establish Skype shortly. We've assigned 30 minutes to the Minister's Disability Advisory Council to present to us today. But again, Lorna, you're an old hand at this. We'd welcome some time to ask questions as you go on. So please commence now.

DR HALLAHAN (MDAC): Thank you. Do you want the introductions now or can I just do a brief introduction and then introduce the members?

MS SCOTT: Entirely up to you.

DR HALLAHAN (MDAC): Okay, thank you. I'd like to start by saying that the South Australian Minister's Disability Advisory Council welcomes this opportunity to present to you on this matter. We consider this a major policy initiative nationally. We also acknowledge that we meet on the land of the Kaurna people and pay our respects to elders past and present. As is our convention when we meet, we also acknowledge those people living with disability who are dealing with lack of or inappropriate services and supports, such that their lives are unnecessarily limited and confined and may never find themselves with the opportunity to participate in forums such as this.

I'd like to introduce the other members of the council who are with me. Dr Evdokia Kalaitzidis, who has a sister who lives with disability, has a very strong background in professional ethics and lectures in nursing at Flinders University. To my right, Mr Mike Taggart, who has a background in local government and a very very strong appreciation of issues around government interface and is particularly interested in picking up issues today around advocacy and assessment, which is really the focus of our overall submission, and Mr Neil Lillecrapp, who is also the deputy chair of the council and has a very long experience as a social worker in this area and current experience working with people with spinal injury, and a very sharp appreciation of many of the issues that people face, particularly when they don't have compensable injuries.

MS SCOTT: Okay.

DR HALLAHAN (MDAC): I think that you will find that this is a group of people with considerable expertise to bring to the table.

MS SCOTT: Thank you.

DR HALLAHAN (MDAC): I'm just going to do a brief opening statement and then I invite you to ask us questions and follow up with us in any way you wish. The areas that I wish to address relate to your questions dealing with chapter 8 and chapter 5. That sounds back to front but you'll understand it when I lay out our argument in this. These are two distinct yet we think quite related topics. One is about safeguarding vulnerable individuals and safeguarding service quality and the other one is around the issues of assessment, advocacy planning and brokerage.

The council operates with a policy appraisal tool that we developed about three years ago that asks a set of questions that we bring to any policy. We look at legislative, structural and policy alignments and then we have what we call the big questions, and the big questions are the things that we've used today to have run a lens over the draft report and recommendations. I'll just run very quickly through those questions and you will get a clear sense of where we're coming from.

The first one is: does this policy proposal help individuals to build a future that is rich with relationships, opportunities, rewarding experiences and high-quality support when needed? Two: does this policy proposal open doors to community participation and contribution for South Australian citizens living with disabilities and their families? Three: does this policy proposal strengthen the existing family and community based supports within the person's life?

Four: does this policy proposal provide openings for those people who are most vulnerable to further social exclusion, including people without family support or with aged, ill or much-stressed family and carers; people resident in institutions, prisons, special residential facilities and Indigenous peoples? And five: what other dimensions might be added to this proposal to give it structural resonance, philosophical coherence and implementational efficacy? So we approach the draft report and recommendations with these questions in mind, and I'll just present a number of points that have arisen for us as we looked at it.

The council has recently provided the South Australian disability minister, the Honourable Jennifer Rankine, with a detailed advice we called Inclusion and Protection. It was sought by the minister because of her growing concern about accounts of abuse against people, most often with intellectual disability or dual diagnoses, resident in group homes currently funded under the Disability Services Act (Commonwealth) 86 and Disability Services Act (South Australia) 93.

On the basis of evidence available to it, the MDAC strongly affirmed the personalisation agenda, which I think is clear in your draft report and recommendations, as central to developing a clear and unremitting focus on the individual, their rights, needs and welfare. This agenda is likely to be served by the introduction of a national disability insurance scheme, such as that presented in the draft report. Therefore, the council affirms the direction taken by the Productivity Commission.

We believe that the proposal before us offers much potential to individuals and their families, where appropriate, to experience reduced waiting times, to exercise more choice about the nature of their supports, and to direct supports to life goals, not just day-to-day survival needs. I should say that the minister gave us permission to come and talk with you about this today and if you wish to have a copy of the report that we gave her, we can share it with you as well.

MS SCOTT: We'd welcome that, thank you.

DR HALLAHAN (MDAC):   However, also upon the evidence available to it, as well as drawing on the combined and considerable experience of the members of the council, all of whom are people with lived experience of disability or have a family member with disability but also bring relevant knowledge and skills in strategic policy advice and development, the council has formed the view that without explicit attention paid to safeguarding aspects, a reliance on market mechanisms, even with the proposed quality assurance mechanisms presented in the draft report - just relying on those mechanisms to drive service quality may expose many people to low-grade and possibly dangerous services.

Article 19 of the UN convention affirms the rights of people with disability to live independently within the community and to exercise choice. I think that's a very good starting point for us. Articles 14, 15, 16 and 17 affirm rights to liberty, to live free from violence and abuse, neglect and exploitation, to the right to respect for the integrity of persons. There is a sense that if we too heavily favour choice we may undermine the protection of those most vulnerable, such as those with much more intense support needs deemed to have limited capacity to act autonomously or to pursue their own rights and interests or to exercise free and informed choice.

The council does not affirm a view that we hear too often expressed, at least in the South Australian community, that protections can only be assured by segregation. The weight of evidence is against such congregated and segregated settings. However, there is a growing concern that community living can translate into locational disadvantage, abandonment, neglect and increased vulnerability to abuse and exploitation, especially in instances where supports provided are not linked to a clear casework strategy, to the development of the skills and the capacities of the person, to the development of relationship networks and community connections.

Small-scale assistance with the tasks of daily living from low-paid and low-skilled workers or poorly applied behaviour management strategies, such as medication and isolation, can translate into service level abuse and it may not be seen because it looks like support. These individuals are most unlikely to pursue complaints and, where they do not have family or other people in relationships daily monitoring their safety, they can become increasingly disempowered and vulnerable. For example, people can lose their homes and find themselves drifting into the corrections system. You will note that in the National Disability Strategy there's actually attention paid to the rising numbers of people with intellectual impairments in the corrections system.

At this stage we do not have access to data to illustrate this and it would be fabulous if we could have much more clear data pointing to this but it is supported by key informants in the disability sector, including my most recent conversations, this time last week, with Prof Hilary Brown, who's the designer of No Secrets and related programs in the UK. She expressed a clear concern based on data there that the individualisation agenda doesn't always lead to the best services and protections for people.

The council does not support a view that conscious safeguarding, that is building what we think might be necessary, and national integrated dynamic, systemic and systematic adult protection system is paternalistic or impinges on rights. Indeed, such an approach is a defence of rights. The council acknowledges the array of formal mechanisms identified within the draft recommendations to guide service quality and to pursue complaints and to carry out regular quality reviews and evaluation of outcomes. The council found that while these mechanisms are necessary, they are not sufficient.

The council believes there's scope here for a much more nationally coordinated approach to adult protection. The council therefore suggests that the development of the NDIS be directly associated with the development of a national safeguarding approach which adopts a public health model, layers of safeguards, developmental, preventative and corrective safeguards that are related to service quality. It takes an ecological or systems approach, recognising that no one safeguard is reliable but that the system must distribute resilience through all layers and levels of the service system so we don't just rely on one thing. All of those layers and levels of the service system are obviously related to service design, implementation, delivery, monitoring and review.

Safeguard in theory recognises the potential for cascade failures in service systems and we've had evidence before the council of groups of individuals being subjected to declining standards of liberty and communication connection as service providers implement strategies under the rubric of occupational health and safety. Therefore, a redundancy of safeguards is required to ensure that mechanisms are in place to ensure that oppressive practices do not proliferate. To this end the council affirms the potential loss of certification and funding for serious breaches which is signalled in the draft report and also thinks that complaints and serious case reviews such as those conducted in the UK could provide a necessary feedback loop back into service design and so on.

These things relate to safeguarding service quality. The other, and related, section relates to safeguarding individuals. The same principles of distributed resilience, safeguard redundancy apply here but must be woven into the assessment process. While it recognises that assessment must occur to establish funding eligibility, the draft report recognises also that assessment is a real piece of work with a person, but the council is concerned that an assessment and planning industry may emerge that is technocratic, tool driven and unable to accurately and sensitively assess risk in the person's life, as well as to identify existing protective factors.

Taking this approach moves on significantly from a debate about diagnosis versus functionality or the place of natural supports. Both of those things are flagged within the report. It does, however, affirm the place of family and other associates in assessment, goal-setting and planning, as well as offering ongoing support. Further, this national adult protection system could be linked to other protective approaches such as those directed at elders and at prevention of violence against women. This would also need to ensure effective approaches to protection during natural disasters and other times of large-scale community disruption.

The council is not in a position to recommend a particular assessment tool except to say that those that we have seen that are currently being developed for this assessment market industry do not appear to offer much in the way of developing a safeguarding plan associated with a support plan driven by life goals and aspirations, rather than gaining an understanding of functional impairment. This brings me to my final point, which is a concern about the location of advocacy programs within the general scope of specialist disability services within your schemata around this.

The council is strongly supportive of the role of independent advocacy as a key but not the sole safeguard, especially aimed at rights protection and promotion. It's not just a form of service brokerage which it can become attenuated to. Access to independent advocacy may therefore feature within a person's safeguarding plan. We do not believe that the person should have to pay for this service out of their allocated funds. Advocacy should be high-profile, located accessibly, independent from the NDIA and from other services. In conclusion, I thank you, the commissioners, for this opportunity to raise these issues with you and look forward to your questions to me and to other members of the council.

MS SCOTT: Thank you very much. John, I've already got questions in my mind, but if you'd like to lead off, feel free.

MR WALSH: Okay, I'll lead off, Patricia. I've got one, but I think it's a big one. Lorna, I'm going to go straight to your issue about assessment and that the potential to build an assessment industry is really focused on tools, and you used other words, but tools and processes. You went on to talk about that assessment process needing to also include appreciation of risk and safeguards, and I don't disagree with that. What you didn't mention and what is mentioned in the report is that we're hoping that the assessment process will also take into account the individual's potential for growth and participation, and I see some conflict between the protection argument and philosophy that you're asserting quite vigorously and the need for people to be able to take risk to realise their potential, their participation. Do you want to comment on that?

DR HALLAHAN (MDAC):   It's a big one and I agree that that element of the assessment stuff was in the report. I think I referred indirectly to it when I said that it's a piece of work where you actually work with the person. I think this is not so much about people taking risks as - if you have a look in the literature around resilience and what it is that helps people have the capacity to take those life-stretching risks to which you refer, there are some things that undermine it, and I guess we've got a problem here with terminology, but if we have a look at the sorts of factors that reside in people's lives, where services particularly start to undermine freely given relationships in people's lives or where they don't have those relationships, they're at much more risk of violence and abuse.

So when I'm talking about risk assessment I'm talking about looking for those sorts of factors present in a person's life which must be ameliorated so that they have the right sorts of things in place to be able to step into that much bigger life. If we don't get a strong appreciation of aspects of the person's life which might undermine every time they take those life-stretching goals, we will not be offering them the right sort of support to be able to do it. So it's about ensuring that people have the right support to pursue those much bigger goals in their lives. I don't really think there's a conflict here. I think that we've probably got a problem with language that says that the fun and the good side of taking risk is quite different from those things which undermine protective factors in people's lives.

MR WALSH: I've got a follow-on question and then I'll hand over to you, Patricia.

This is an important debate I think. My follow-on question is: where should the protection sit? Is it a proactive protection so that when the person is designing, with help, their life plan, for example, is risk management involved in that so it could in a way be seen as a constraining factor, or does it sit as a protective safeguard so that the person takes the risk but knows they have a safety net should they fail, as we all do every day?

DR HALLAHAN (MDAC): I think obviously the second option is the preferable one, where people can step out into unknown territory in their lives, knowing that they're not going to be abandoned when things don't work out as they want, and I agree that that is absolutely consistent with a normative approach to it. We all have those protections. There's nothing scary about that. But, having said that, we also know that there are individuals within the system who need something which is much, much closer to them as well, and I am not talking about restrictive practices here, I am not talking about oppressive practices, I'm talking about those things that we know from the resiliency literature that add protection to people's lives.

They may not be mechanisms. They may not be support workers. They may be things like attending to a person's health, because one of the things that helps people to be resilient is to have the best possible health care. It may be things like ensuring that they do develop a set of relationships external to the service system. Those are the things which we all rely on to protect us when we reach out into parts of our lives that we haven't previously explored. So this is a much more subtle thing than just looking at mechanisms. It's actually an approach which is deeply informed by the literature about what it is that helps people flourish, and generally that's called protective factors. They should be part of the plans that we help people develop. The paradox of it all is that it's a protective factor to be able to take risk.

MS SCOTT: Yes.

MR WALSH: Yes. Thank you.

MS SCOTT: Lorna, if I had to give a one-minute summary of your presentation, let's see how I go.

DR HALLAHAN (MDAC): Yes, that's great.

MS SCOTT: Okay, here we go. You started off at the outset by drawing our attention to the fact that you recently had done work relating to people who had been subject to abuse in care, and from that basis you have provided commentary and advice to the government in your role, and in some ways that was now framing some of the response you're giving to John and me, and you're drawing our attention to the fact that some of the most vulnerable people who will be part of the scheme, if governments accept our proposal, need a set of safeguards that you couldn't find in the report as it's currently structured, and you're drawing our attention to this very significant issue because we shouldn't presume the families and other friends around people exist or that people necessarily have a capacity to assert their rights and protections.

DR HALLAHAN (MDAC): Yes. Only one caveat on it: I think that there are quite a number of those safeguarding mechanisms throughout the report.

MS SCOTT: Okay.

DR HALLAHAN (MDAC): And so it might be that there are things that can be sort of brought together and then judged to see whether or not that's a thorough, integrated and systematic approach or it has gaps in it.

MS SCOTT: Okay, good. Now, I'm very keen to set your council some homework. I know you've done this earlier work for your minister and I am keen to get it and I'm sure John is too, and the team will look through it carefully, but I guess what I want to do is take stuff from your reference to academic literature and convert it down to very practical things on the ground, because I'm sure you've got a very practical group of people in your council.

We have to explain this proposition to a very wide variety of people: people who have disabilities but they're barristers and are very assertive of their rights and wouldn't want to think that somebody is ticking a box on them, right down to people who are feeling quite threatened by any change. They might not live in a perfect world, but change can be threatening and they're not necessarily going to look forward to changes in routine or the option of having choices if they want to take those up.

So I'm interested in how you would suggest we go about this. Is it a case that we would have a charter? Is it a case that we would have a set of questions to ask someone? I'm going to refer you in particular to chapter 5, because I think is where it comes up, and I'm just going to show you a page in chapter 5 - and your group might have to think about this for a minute or two - and then I wouldn't mind asking you just a few questions about that. John, it's page 5.26 if you're interested.

MR WALSH: Yes.

MS SCOTT: Now, I'm going to explain it a little bit, just for the group here in front of us and for the people at the table. On this page 5.26 we set out what we thought should be the assessment process. The first thing is that people would get information about what the process is and what's available. That's obviously the first thing that needs to happen. Then they would make contact with the scheme. They might actually be invited to make contact with the scheme because they might be one of the early groups coming into the scheme.

There will be a short list of questions about whether they're likely to be eligible or not. Some people would then be referred to other services. But if it looks like the person is going to be eligible, they would provide information on the self-report questionnaire; the idea that people would start indicating things themselves that they'd like to see, their needs and so on. I won't go through all the steps, but it's quite concrete about each of the steps in the process. One of the things we have is that there's a meeting between the person, their carers, the trained assessors; it's not an assessment done on the paperwork; it's not an assessment done on diagnosis. It's an assessment involving the individual and hearing from them or learning from them what they're interested in doing and what support they currently get, and where there are inadequacies, and what they would like to do and so on.

There's also a visit by the local case manager - maybe you don't like that phrase, but local coordinator - to actually visit the person in their home setting, to understand their circumstances. It might be that that report comes back saying, "Things are pretty dysfunctional." It might say "a warm and loving environment that's a bit overprotective", or it might say "a warm and loving environment that's very keen on the person achieving all they can". So you can see we've got a few protections here: listening to people; asking them; engaging with them, visiting them.

DR HALLAHAN (MDAC):   Yes.

MS SCOTT: But you may have things that you think should be added. I'd be very keen to go from the academic literature to the very practical things that you think should be added to this process or added to the report. Maybe you can think of something right off the top of your head, because you've recently written this report for the government, that would fit the bill; you know, protections and safeguards. Could you just go to those now, or maybe I'll invite other members of the panel to say something. If you do say something, could you just identify yourself for the transcript.

DR HALLAHAN (MDAC):   I'll just briefly speak, and then the others might. Two things: we've also done an advice to the minister around individualised funding, and we had a look at some of this at that time as well and were very impressed with the process that started up; with people making their own self-assessment in a very concrete way. So it's good to see that as part of this process and also good to see that it doesn't stop there. We had a look at the British Columbian model, which I don't have here in front of me, but I think that that's got some really good pointers about how to deal with this planning for safety as well as for a big life. I would need to go back and have a look at that, but I think it's got some pointers.

MS SCOTT: Thank you. Now, the practical suggestions.

MR LILLECRAPP (MDAC): Neil Lillecrapp. One of the issues that I'm confronted with is when people are in institutions, and I may see something that I would consider to be abusive, and yet they are afraid to speak up about that because they feel in a less powerful situation. I don't know what the solution is unfortunately. That's one that's been with me for some time; that people just feel that they'll be victimised if they do speak up. It's within the institutionalised setting that this seems to occur. That doesn't offer a solution unfortunately.

MS SCOTT: You mentioned earlier, Lorna, resilience. Would training for the individual about, "This is your right. You can expect this level of service, this level of support," would that help, Neil, do you think?

MR LILLECRAPP (MDAC): That is one element of it. The other element is working in the institution and who is working within the institution and what are their attitudes towards the people that they work with.

MS SCOTT: Yes.

MR LILLECRAPP (MDAC): It is those attitudes that tend to make these people think, "Oh, it's okay to behave like this." Yes, so it's in the training.

MS SCOTT: Okay.

MR WALSH: Can I ask a question?

MS SCOTT: Sorry, John, just before you do, I think there's going to be some other responses here.

DR KALAITZIDIS (MDAC): Evdokia Kalaitzidis. I've just got a quick comment about that, and I don't have a solution to this, but I think domestic violence is something that we're familiar with, maybe not personally but we're certainly familiar with it as a culture, as a nation, and we know that it's often hidden and it's often the most functional-looking couple or family that it can happen in. I don't know, other than trying to encourage the person to speak out. What we seem to be doing as a society is changing the culture, that it is unacceptable, so we're bearing pressure on systems and individuals that it is unacceptable because the alternative is that we step in paternalistically and take over the woman's life or the man's life - whoever the victim is - and deal with it that way.

We know that hasn't been successful, not with domestic violence. What seems to be having some effect is changing the whole culture within the service industry, within individuals, within families, within whole communities, that certain behaviours or the way you deal with someone is unacceptable. That will take time to happen, I think.

MS SCOTT: Yes.

DR KALAITZIDIS (MDAC): I don't think there's a quick solution to it, just like there isn't with domestic violence.

MS SCOTT: Maybe it goes to that educative role that the scheme or other NGOs could have. Mike, did you want to make a statement?

MR TAGGART (MDAC): Thank you, yes. Mike Taggart. I'm just thinking, in the flow chart there, in the assessment process of course, that's at the commencement of a person's relationship with the National Disability Insurance Authority but it's also an ongoing thing. In all of those times of assessment, from the very first throughout a person's life, to reduce the vulnerability and to maximise the chances for people to actually become who they are capable of and want to become, it's important we build into the assessment testing-out sort of questions which lead people away from choosing to restrict the extent of their social contact with other people. I'm not just talking here about people who are living in some sort of institutional setting, like group homes or whatever it might be, but somebody living on their own, with their family or whatever.

We know that the ability to cope with change, the ability to cope with the negative consequences that we all face when we experience risk, our ability to cope is going to be improved the more networks we actually move into and are supported to be part of. So partly it's in the actual assessment process, to probe and tease out people's awareness about: "Well, there may be opportunities to move into parts of this world that I haven't done before."

I think the other side of it is, as a consequence of the assessment, there's a practical side; that is, that we don't want to end up with a service or support system which drags people back into a cocoon, in a sense. Rather than having those multiple external relationships which build both the capacity to feel I've got someone to go to if I'm having a difficulty with support, say, that my carer, my family, service agency, the local neighbours are providing, I've got somewhere else to go and also that it is right that I go somewhere else.

I suppose an assessment process is, in a way, a conversation. I think that an essential part of that conversation is, "How many links do you have with the wider community?" be it our neighbours, sporting, whatever - and are there ways that we can build on those?

MS SCOTT: Yes. John, you've got a question?

MR WALSH: I think it's pretty much been answered. I was really going to explore - I think Neil was talking about, particularly in institutions, being scared to speak up. I think both of the other guys have now talked about that. I think that extends to community and family and part of the solution might be in the choice under the assessment process. But I think, Patricia, there is also a confidence and capacity-building component that we can't forget.

MR TAGGART (MDAC): And it's not just in that very first assessment. This is a relationship and it's a journey, so to me it's important that the assessment process builds that in and helps to identify those things which strengthen people's resilience.

MR WALSH: Yes.

MS SCOTT: It's certainly a challenge. One of the examples we use in the report is that of a person who had an individualised funding package in Victoria who was able to vastly change what services and supports they received; so, rather than going off to a day care centre, was able to go off to the movies. It still involved community participation but it was a whole lot better for them because they found day services boring and they liked the movies and looked forward to it. There's an element of risk because instead of having the bus - this person had intellectual disability - picking you up and then taking you to a day care centre and bringing you safely home, it meant that she had to be trained to use public transport; sometimes the buses don't turn up, so you had to be trained about that; and had to go off and then sit with people when, you know, you can't be certain who someone is going to be sitting next to you in a picture theatre. But it made a quality of life difference.

I guess what we're looking for is your very practical guidance; if I can encourage you to think about the most practical ways we could meet this issue because you're right: a number of people have raised with us what safeguards will there be, especially when people are non-verbal, have got intellectual disability and have been subject to abuse. Just on the individualised packages, I think we have or are about to put up the detailed attachment appendix, on some of the cash and counselling studies in the US, Lorna, and some other locations, and it did look at the instance of reported abuse in individualised funding arrangements versus block funding arrangements. I'll leave you to read it, but we are interested in this subject, if you can suggest any other studies we need to look at. But if I had to again summarise very quickly, I think I'd say that the individualised arrangements suggest that they're less likely to be subject to abusive arrangements because people can actually walk away from the - - -

DR HALLAHAN (MDAC): That's certainly our expectation and that would be why we strongly supported individualising. With your example of the woman attending the movies, the sad history of disability services is that she's more at risk in the day program than she is catching the bus, and it's that thing that we have to be able to puncture; that thinking that cloistered services provide protection. They don't, but there may well be some other things that we need to put in place to ensure that people can get on with much better lives.

MS SCOTT: Mike, do you want to just finish off now, thank you. Please go ahead.

MR TAGGART (MDAC): I think there are things other than assessment we want to talk about. But this assessment thing seems so important to me, that we not just focus on obviously - and the report doesn't - simply types and levels of impairment and things like that, but the person's life context. I'll just use an example of somebody of whom I've been aware in the last few weeks who actually is supported by a current disability services provider. The person obviously has said that they want to go and participate more in the community and that's fine. What I suspect the discussion that went on in that process didn't include - which I'm strongly advocating that this national assessment process should include - is, "Well, okay, you want to go and get involved in some activities in a community centre," for example, or visit a library or go to a local market or something - "Also let's assess how resilient your social and support networks are at the moment. If you feel scared about something, who do you have to turn to?" Nobody; one body; two bodies; all in the same family; beyond that.

This particular woman was dropped off at a community event, which most people in the community would wander through and be satisfied and enjoy it and go off in half an hour, three-quarters of an hour. Because she had limited transport options, she was dropped off and left there for four hours and became quite disruptive. The community couldn't cope with her disruptiveness. To me, an initial assessment would be, well, okay, you don't do such a silly thing - to dump somebody in a situation that nobody else would ever be dumped into - but she had nowhere else to go except for a particular transport social service provider. Now, if it's going to be a resilient assessment process - assessment of resilience - we need to accompany people's wishes and ambitions - and they might be small at first - with understanding well the resources that they have available to them from what they say, from what we can observe.

MS SCOTT: Okay, that's very clear. Thank you, Michael. John, if it's all right, we might now draw this to a close. Are you comfortable with that, John? Thank you very much for attending today and we look forward to your submission and also the opportunity to read the report you'll make, and particularly I'd encourage you on that very practical element; we'd very much welcome your guidance. Thank you very much.

MS SCOTT: Margie, would you like to come forward now. Thank you. Hello, Margie.

MS CHARLESWORTH (WWDSA): Hello.

MS SCOTT: Welcome to our hearing. Thank you very much for also providing some notes and questions for John and me. John, Margie has already set us some questions to think about. We've assigned 30 minutes to your presentation and I understand that you're representing a group today.

MS CHARLESWORTH (WWDSA): Yes. We are Women With Disabilities South Australia. We've only been around for six months and this will be our very first public appearance.

MS SCOTT: That's great. Thanks for coming along and representing this group. This is therefore an historic presentation. Thank you.

MS CHARLESWORTH (WWDSA): Can I just say that people may not understand every word I say, but if people can pick up my pattern they will be able to piece words together in that way. I am here on behalf of a group of women with disabilities with (indistinct) and we have a few more practical responses to matters that other people have already said. We wholeheartedly agree with that suggestion.

But I know there are other aspects that most people may not recognise and the first would be that often women with disabilities are also carers for family members and this is not recognised until women are at their wits' end and need to go to quality intervention. We acknowledge that unless women over-represent their disability, they don't get the support that they need and so they fall through the cracks. And I know that other people have spoken about the issue today. We don't have answers but we hope that the inquiry might come to a point of maybe finding answers.

The other point that has also been brought up a couple of times is the issue of mental illness and, while mental illness is not a disability, we argue that women with disabilities are more likely to develop mental illness and this is because of lifelong experiences that they haven't been able to stand up for themselves (indistinct) I think it is important that mental illness be recognised as part of a person's disability - not all disabilities; but it is an issue that needs to be recognised.

MS SCOTT: Yes.

MS CHARLESWORTH (WWDSA): We were also concerned about - unless we self-manage our fund, would we still, or if we went through a broker or had a manager, would we still need help to (indistinct) of current policies. At the moment, the test that's so frustrating is equipment service. It's grossly underfunded and we've also been put in (indistinct) with aged services, and we think that is unacceptable. It's unacceptable that we have to put up with second-hand mobility devices.

MS SCOTT: This is your concern about - I think in your paper you've got someone who was told to - or someone given a wheelchair that had been used by someone else?

MS CHARLESWORTH (WWDSA): Yes.

MS SCOTT: And you're concerned that steam-cleaning is not sufficient.

MS CHARLESWORTH (WWDSA): No, because a person in a wheelchair is in a wheelchair for 80 per cent of the day and there are all sorts of hygiene issues that are bound to happen (indistinct) we just find that totally unacceptable. We are constantly told, "You have to wait for equipment. You can't have a brand-new wheelchair. You can't have brand-new crutches." I find that highly insulting, that we have to walk around with second-hand stuff.

MS SCOTT: Okay, got that.

MS CHARLESWORTH (WWDSA): That's that point. The other point to that is that it is not necessarily our concern but because of the second-hand equipment, there are a few services and companies that have gone out of business.

MS SCOTT: Yes.

MS CHARLESWORTH (WWDSA): Because they're only supplying three types of wheelchairs. Not only is that affecting our choice; it also means that someone who has used a wheelchair all their life and they know that they have faith in that brand or that company - that that's no longer available. So it does affect our quality of choice.

MS SCOTT: Yes. So this is the idea that people should be able to have choice in the wheelchairs that they - - -

MS CHARLESWORTH (WWDSA): Yes.

MS SCOTT: Right.

MS CHARLESWORTH (WWDSA): Whatever we need we should be able to get, because everyone is different. We all have a lot of personality and why should that be taken away from us?

MS SCOTT: Got you. Okay.

MS CHARLESWORTH (WWDSA): I guess my questions to the inquiry - and please forgive me if they're already answered - - -

MS SCOTT: No, I don't think so.

MS CHARLESWORTH (WWDSA): - - - when we read the full report. I guess what we would want to know is, if we use a broker system or a case management system, does that mean we give up our right to choose what we do, where we go and how we use our funding?

MS SCOTT: Okay. Are you okay if I answer the question there?

MR WALSH: Yes, you go, Patricia.

MS SCOTT: And you will correct me if I've got it wrong.

MR WALSH: Yes. I've got the paper here too, Margie.

MS SCOTT: All right. Let's see how I go, Margie. It might be the case that someone wants to manage their whole package; they really want to be in charge of every aspect of their package. They won't be given necessarily a whole lot of choice about therapies, because we're hoping that people will be advised by their allied health professionals the therapies that are available, and they might say, "Well, I'd like to use this much physiotherapy," and someone might say, "Well, that's more than we would normally suggest be available," but people would have a lot of choice about the non-therapeutical part of their package. They still might, of course, have quite a bit of say in particular therapies.

But anyway, getting back to the non-therapeutical part of the package, people would have a lot of choice. So that's for those people that want to manage their package, but we indicate in the report - and I appreciate that 800 pages is a lot for anyone to have to read, but a lot of people in the UK don't take up that total "I'll manage everything". They in fact use a broker or they nominate the services they want, and I think people could have a combination of some of those. For example, your example of people wanting to use a particular brand of wheelchair that suits them: provided it's within the funding agreed, then I can't see any problem with them being able to choose a particular brand of wheelchair.

They may not want to hire their attendant carers themselves. They might choose a particular attendant care company. They may wish to get services from someone else and they could arrange it themselves or get their broker to arrange it. So you might find that individuals, in some areas of their life, take particular decisions; others, they're happy for the fine micro detail to be left to a service broker or their nominated provider. Are you happy with that answer, John?

MR WALSH: Yes.

MS SCOTT: Have I been clear, Margie?

MS CHARLESWORTH (WWDSA): Yes, that's fine. Another question that I wrote down in my notes is about people who end up in hospital, need rehabilitation and are out of action for some months, and when they finally go home they actually need a lot more support than what they have in the original package. What if their needs are different from the package they might have taken, for unforeseen needs?

MS SCOTT: Okay, I got that. So the question is, what about when someone's circumstances change? What happens when they get sick or are in hospital and their circumstances change and the original package they got didn't perceive the change in circumstances? In the report it says that if a person's circumstances change, they can apply for having their needs reassessed, and we talk in here about people in crisis or emergency supports, someone who needs emergency accommodation or emergency services in terms of respite or care when, say, a family member dies or someone becomes sick, or they become sick.

I think you should rest assured that the way John and I are thinking about this, when things change in life, things that you know are going to change, like people leave school, leave university, start school, at those transition points it would be very important for the scheme to look at whether their needs change, and if things happen in their life - illness, sudden time in hospital - that might mean they need more attendant care at home than they would normally need. So the report does allow for that.

MS CHARLESWORTH (WWDSA): And I must add that as you were saying that, I remember reading that. As you were talking, I suddenly remembered, yes, I read that.

MS SCOTT: That's good. Great. Also, we acknowledge that in some - well, most hospital systems, the attendant carer would need to provide services actually in the hospital, because many won't necessarily look after all the needs of the individual in that circumstance. Margie, there was something else you said at the start which I thought worthwhile commenting on. I think you said that people - women in particular - with disabilities - you know, will they miss out if their needs are episodic, or will they miss out if they're not in tier 3, and remember we say that tier 2 is for people who may need referral to a service.

They may need to come in and say, "Look, this has happened. Am I eligible for an individualised package?" Maybe not, "but let's make an appointment for you to have a meeting with this person who's in another department, another area" - maybe an NGO that offers services. So you might want to have a look at that part of the report when you get time, just to see whether that meets your organisation's concerns. I'm just conscious that Dom is about to tell me we've run out of time. John, are there any comments you want to add, or ask Margie a question?

MR WALSH: No. That was very helpful, Margie. Thank you very much.

MS SCOTT: Thank you for coming along today, Margie, and thanks, we look forward to maybe a short submission from you if you get time. I'm a little behind schedule, John, but I'll just tell the audience here not to worry. That just means our lunches are all a bit shorter. I'll make sure people still get their allocated time.

MS SCOTT: I now welcome to the table the Royal Society for the Blind, and I'd ask you to identify yourself for the purpose of the transcript and then to make your opening statement. We've allocated 30 minutes for your presentation, but I'm sure you'll allow a little bit of time for us to ask questions as well as clarify things.

MR DALY (RSB): Have you got a copy of the presentation?

MS SCOTT: I'm just going to check that I've got the right one.

MR DALY (RSB): We've sent the draft submission as well as a copy of today's presentation.

MS SCOTT: Mine is dated 13 April. Is that right?

MR DALY (RSB): I doubt it, because I only just sent it an hour ago.

MS SCOTT: All right. There must be a further one.

MR DALY (RSB): We've got extra copies.

MS SCOTT: Thank you very much.

MR DALY (RSB): There's no extra charge for extra copies.

MS SCOTT: You won't mind if I ask you a few questions, going back to your earlier one.

MR DALY (RSB): No. Please. If I may, I'll just introduce my staff that are with me. Firstly, good afternoon, ladies and gentlemen.

MS SCOTT: Thank you.

MR DALY (RSB): On my left is Margaret Brown. Margaret is our community services manager. On my right is Tony Starkey. Tony is our government and ATSI adviser. I'm the executive director of the Royal Society for the Blind and my name is Andrew Daly. I just thought I'd commence the presentation by speaking, just a little bit briefly, about the RSB and what we do and perhaps use that as a lead-in to my further comments.

The RSB is the primary provider of services to people who are blind or vision impaired in South Australia, a quality endorsed organisation currently providing the full range of rehabilitation services to over 11,500 South Australians. It is also the only blindness agency in South Australia with regional offices. The RSB is committed to enabling people who are blind or vision impaired to become and remain independent, valued and active members of the community.

Eligibility for the RSB services is anyone diagnosed as being or likely to become legally blind. This definition enables the RSB to intervene early and reduce the impact of vision loss on an individual. Satisfaction rates, as independently assessed, are extremely high. 97 per cent of clients surveyed stated they are satisfied with the RSB services; that's 94 per cent on a 15-year average. 98 per cent of clients surveyed stated they are satisfied with the manner of RSB staff and volunteers, a 15-year average of 95 per cent. 89 per cent of clients surveyed stated that the RSB services had improved the quality of their lives; 83 per cent 15-year average.

In South Australia over many years the RSB has created a system whereby every ophthalmologist in South Australia refers to the RSB's low-vision clinic, LBC. Once referred, independent research has confirmed that 97 per cent of people attend the LBC within 12 months. Accordingly, the RSB believes that the vast majority of people newly diagnosed with vision loss will have contact with the RSB at the time of their initial diagnosis. Through early intervention at this point, a crisis can be avoided and, for many, no further services are required until there is a change in their life; for instance, further vision loss, death of a partner, or moving house.

The RSB has provided a draft copy of its written response, on 14/4/2011, to the Productivity Commission for their perusal and to provide some background to the RSB's views. The RSB expects to formally present its submission following this presentation. Given the RSB has forwarded the full document, this presentation will be just a quick recap of key points, and we welcome any questions or comments at the conclusion. The Australian Blindness Forum - ABF - of which the RSB is a member, has also forwarded its submission, and the RSB is fully supportive of issues raised within it.

The RSB commends the Productivity Commission on its draft report and strongly supports the recommendations supporting an entitlement to services, noting that the disability sector as a whole is broken and doesn't work; the injection of significant funding, the acknowledgment of early intervention, and the focus on the individual. For people who are blind or vision impaired, whilst not meant to be a definitive list, their service requirements tend to be episodic, predominantly revolving around information, understanding and acceptance of vision loss, access to information, built environment and specialist equipment, transport and specialist rehabilitation services.

The RSB does have a number of concerns with regard to the draft report, including the use of generic case managers and generic assessment tools, which will lead to the same dependency based models of the past, where people are forced to demean and exaggerate their disabilities to receive the quantum of service they are seeking, rather than a system focused on independence and community participation, or a genuine no-fault system. The proposed system, given its focus on personal care and holistic services, will force people who are blind or vision impaired to fall through the cracks, or create a sub-class of people who are blind or vision impaired within the aged care system.

As 80 per cent of people who are blind or vision impaired are over the age of 65, the artificial separation of services between ageing and disability is exacerbated by the Productivity Commission on Caring for Older Australians, making no provision for people with disabilities in their recent draft report. Accordingly, the RSB believes that these two reports can't be considered in isolation. Indeed, the Productivity Commission needs to create interfaces and safeguards to ensure a person with a disability, irrespective of their age, has an entitlement to the same level of services at the same cost.

The concept of trade-offs and realistic versus aspirational services: the RSB is firstly concerned at the language, which it considers to indicate a rationing of services based, as noted above, on a generic assessment from a generic assessor, which will exclude consideration of the specialist needs of people who are blind or vision impaired. Accordingly, it believes a template needs to be created to objectively assess what is considered a reasonable service. This may include remaining independent in their accommodation of choice, preparing to find employment, participation in community activities, forming and maintaining social relationships, and exercising their right of citizenship.

The RSB believes that, as with any undertaking seeking to educate and engage with the community, a dedicated global strategy for community engagement rather than linking this to tier 1 will provide economies of scale and provide a global strategic template for change of community attitudes. This, we assume, is similar to the motor accident campaigns that allocate a certain component of their budget to awareness-raising campaigns.

The RSB believes, rather than committing all funds to a tier 3 type of arrangement, significant client and economic benefits can be achieved through funding specific services and activities; for instance, peer support, systemic advocacy, print disability, adaptive technology and low-vision centres, research and benchmarking and volunteers. Excluding support for public educators, talking newspapers, et cetera, the RSB last month provided over 260 individual volunteer services which, over the space of a year, the cost for delivering this infrastructure, generic assessments, which I assume would be required at each request, would be substantial. By utilising volunteers, the costs are minimal and enable the RSB to deliver this service in an ongoing manner.

I have attached a report at the rear of these notes, if you're interested, just with regard to the services delivered through our OT centre and LVC for a month and don't believe they would be supported through the brokerage model suggested, given the specialist nature of the service, or they would be deemed not eligible under the proposed tier 3 arrangements. However, they will prevent people, through access, by not requiring tier 3 support.

Given the episodic nature of services to people who are blind or vision impaired, and the fact that they will enter and leave the system at various transition points for what may be very short interventions, that the current tier system be amended to include, subject to establishing appropriate eligibility criteria, the creation of trusted intermediaries for short-term or low-term cost interventions, a fourth tier be created to fast-track people into specialist services, or the continuation of block funding be considered. An alternative tier structure is suggested below.

The proposed tier structure as noted channels the bulk of funds via a series of generic assessments to eligible people under tier 3, which in effect excludes anyone else from accessing services and also, in some ways, is in conflict with the concept, in my view, of early intervention entitlement. The proposed tier system can be summarised briefly as tier 1 around community engagement, tier 2 to referral to a mainstream provider, tier 3 a funded package. As with the current system, this will in effect only assist people in times of crisis, encourage dependence, and requires people to demean themselves in order to obtain a service; that tier 2 is only effective if mainstream providers are willing and prepared to make their service accessible, something that is normally not the case. Within our submission I've noted, for instance, libraries and access to public libraries, which I'm happy to expand on later if you wish.

Given that any application for services we assume can be appealed at no cost to the appellant, and for those deemed by generic assessment not eligible, the inability to provide any meaningful response will result in a large number of complaints that would potentially clog the system. A suggested alternative is to modify the proposed structure to focus on triaging and, in the process, avoiding unnecessary generic assessments and overheads through the introduction of a quick assessment to determine the most appropriate referral pathway.

From this triage, people will be excluded if ineligible; for instance, a health-related issue rather than a disability issue. The tier structure could be amended to: tier 1, provision of information on disability and mainstream supports; tier 2, provision of restricted service intervention - this could be early intervention or minor service requirement; and tier 3, as per the proposed Productivity Commission's report.

We would also, with respect, suggest to the Productivity Commission that they review objectively the previous options coordination model, discontinued in South Australia, and the satisfaction of disabled people in South Australia with Disability SA which was created from this and is architecturally similar to what is being proposed. The South Australian government has commissioned the Social Inclusion Board to review the current situation and they are due to report in June this year, but we are sure that they would be prepared to discuss their research with you.

It was acknowledged during the Options Coordination era that this was not a model for people who are blind and, indeed, very few people who are blind would have any contact with Disability SA. This also raises a further issue on which the Productivity Commission is silent - namely, the future of government services, interfaces and funds currently allocated to individuals and agencies. Eligibility for tier 3 needs to be assessed on medical evidence, functional impact and likely progression, for the purpose of early intervention.

It has been the RSB's experience that the degree of vision loss is not the sole determinant in a person's ability to remain independent and participate in the community. The RSB recommends to the Productivity Commission, given the specialist needs of people who are blind or vision impaired, that either a tool to assess their specific needs to be created or the new system outsource this function to a specialist agency.

Further, the proposed system is heavily weighted towards other disability groups requiring holistic and personal care models, with the gatekeeper being a generic assessor using a generic assessment tool. Traditionally, people who are blind or vision impaired, given their unique and episodic needs, have their needs overlooked with generic assessment tools. Specific issues that may require consideration include the physiology of different eye diseases; the functional impact of an eye disease, including consideration of comorbidities; emotional impact of vision loss; strategies to overcome vision loss; services and technologies available; environmental barriers.

The RSB and ABS responses include case studies that demonstrate both this issue and a number of others noted below. It is the RSB's view that this needs to be assessed by a specialist with an understanding of vision loss and interventions available. In any assessment, the true cost of the disability also needs to be considered and, for people who are blind or vision impaired, many of these are unique to the disability; for instance, the additional costs of power associated with good lighting; the need to purchase a property near public transport.

The RSB fully supports the creation of benchmarks and the identification of best practice. However, this should be measured more broadly than just a cost-benefit analysis based on a researcher's perception of an average. In addition, clearly in measuring any benchmark there needs to be sufficient research to ensure that the same criteria are being assessed and creating standards, particularly given the NDIA will at least initially be the price-setter. Services need to be created to a standard, not a price.

The RSB fully supports a global investment in research and doesn't believe, as noted in the report, that a chronically underfunded sector should bear the cost of meeting NDIA requirements for funding. Randomised control studies also create a number of ethical dilemmas, as a control group is required from which services are denied and there is a requirement for a large group of very similar participants in order to isolate the impact of the intervention. For people who are blind, it would be very difficult, given variances in life skills, levels of vision loss, care networks and the environment, to create this homogenous group. If such a group is created, given the wide number of variables, the dosage provided to the homogenous group does not necessarily reflect the needs of others in any event.

The RSB believes innovation needs to be encouraged, rewarded and shared, rather than considered a competitive advantage, a danger in circumstances where innovation equates to intellectual property. The needs of people who are blind or vision impaired are unique and episodic, requiring specialist responses from trained specialist staff. We do not believe it appropriate for someone that has empathy, patience and good communication skills to deliver orientation, mobility or braille training, or prescribe or magnify, any more than - whilst well meaning - this person should be to conduct eye surgery or prescribe medicine.

Accordingly, the RSB believes that there remains a need for the training of specialist staff to deliver specialist services, the removal of which will place people who are blind or vision impaired not only at risk of not being able to access the service but the service they access placing them at risk. Thank you for your time and patience and we look forward to answering any questions that you may have.

MS SCOTT: Thank you very much for coming along today. We've had very good participation from the vision sector and I think we've heard from a variety of groups on these issues. I wish in some ways that our systems allowed us to have more engagement early on, because I think we could have resolved some of the potential misunderstandings that are reflected in this paper. For example, we don't suggest there is a generic tool that everyone will be assessed against. In fact, the chapter explicitly says that there would need to be specialist tools and not a one-size-fits-all.

MR DALY (RSB):   Can I just say there that the experience of the past - and even within the Productivity Commission report - if you look at the outcomes that are going to be assessed in 2020, they're very much around personal care and holistic services. The RSB's experience has always been that, using snap tools and worker assessability tables, the specific needs of people that are blind or vision impaired are not incorporated, and I guess that's a bigger concern when we consider that the scheme will go ahead without having a perfect assessment tool. So I guess our concerns are that the tool - I've read the bit about the toolbox concept.

MS SCOTT: Yes, okay. I can see that you've got concerns about the proposals and I wouldn't mind using the rest of our time to discuss those - - -

MR DALY (RSB):   Sure.

MS SCOTT: - - - and where you suggest John and I go.

MR DALY (RSB):   I think you've just lost John.

MS SCOTT: That's all right. No, he's still always on the phone.

MR WALSH: I can see you guys.

MS SCOTT: He can see us and we can always hear him and he can always hear you.

MR DALY (RSB):   Would you like us to hide the camera somewhere else, mate?

MS SCOTT: In some ways, because we've got such strong organisation in the vision sector - you know, well organised, very well accepted in the community and very effective in generating revenue and services, and I acknowledge the very high satisfaction rates - I guess what I am conscious of, of course, and I'm sure you acknowledge, is that so many other parts of the disability sector don't have the organisation, don't have the effective membership, don't have the effective resources and so on. So, while there are general deficiencies in many, many other areas, I think what you're alluding to is that there are many strengths in this sector, in your area, that you're keen to retain, that are not lost, in say lifting up the other boats. You don't want to see your good work lost. So is there a way that you can see the Royal Blind Society effectively continuing your good work in a way that would actually strengthen your services or strengthen the services to your clients in a bigger system that also is, hopefully, better servicing people who have really deficient services? I mean, we wouldn't get figures like 97 per cent in any other sector, I don't think.

MR DALY (RSB):   Clearly part of the report is to look at incorporating everyone into one system. From the perspective of people that are blind or vision impaired, the issues are that the services tend to be very specialist in nature.

MS SCOTT: Yes.

MR DALY (RSB): You know, we're not going to see braille training rolled across hundreds of thousands of people.

MS SCOTT: No.

MR DALY (RSB): The needs are very episodic and they tend to change at times of - the terminology we use is "transition", which could be the death of a partner, could be moving house. It could be a whole range of things. I think where the system needs to accommodate people that are blind or vision impaired is obviously - and I'm assuming that this will be picked up under therapies in any event, but there needs to be a very timely intervention; that we can't have someone sitting in their house for six months while we wait for a further assessment to say that they need orientation and mobility training to get to the bus stop. That's the concept.

I've actually put two suggestions up there. I'm not obviously party to all your other research or anything else. One was the concept of a trusted intermediary or a fourth tier, which would allow that sort of - under the trusted intermediary concept, effectively NDIA would entrust or authorise or empower a specialist provider to be able to conduct an assessment to deliver an intervention, a short-term intervention or a capped-cost intervention fairly quickly, because most people have the relationship in any event. We get our referrals normally through the primary medical sector and that would seem to work well.

The alternative would be, as I said, a further tier or changing the structure of the current tiers as proposed, on which I've put a suggestion up and, as I said, I'm not quite sure how that fits in with the other feedback you've received. But rather than try to mix community engagement, which I think should be a separate strategy, if we're serious about allocating funds to actually change community perception, we should be doing that in a strategic manner. It shouldn't be just an add-on that someone else is doing.

I think that the tier system itself should be reflecting your service response and, to my mind, what I've put together seems like a fairly logical response - namely, that you have a triaging system which identifies whether people are eligible for any of the three tiers of services. The first tier really becomes one around information. For instance, for blind people: on diagnosis many people require a little bit of information about their eye loss, the prognosis, what service will be available, a little bit of reassurance, and we possibly won't see them again until there's a death of a carer or a change in vision loss.

Tier 2 is the concept of a restricted service or limited response which could again be time dependent, cost dependent, based on utilisation of a specialist assessment. Then tier 3 would be a person who's blind or vision impaired with complex needs or a requirement for ongoing holistic or personal care needs.

MS SCOTT: Margaret, you'd like to - - -

MS BROWN (RSB): Patricia, I think what you were asking before, would any of our clients be assisted by the recommendations - was that what you - - -

MS SCOTT: No, I was more drawing to the fact that while you've got a long history of services in the area of assisting those people with vision impairment, for many degenerative neurological conditions there's a dearth of services; for many people with physical disabilities there's a dearth of services. So in some ways, when we look at your organisation, you're a strong, well-established organisation and you're pointing to the strength in your current service provision, which is quite reasonable, but I'd say of the 604 submissions we received before we wrote our draft report, 95, maybe 97, per cent of those highlighted deficiencies in current arrangements. So in some ways you're a high-water mark.

MS BROWN (RSB): We think so.

MS SCOTT: Yes, a high-water mark, I'll acknowledge that - a high-water mark in service provision - and I'm trying to work out how to lift general service provision in many, many areas where the needs are quite specific to the circumstances of the individuals. Then we've got your high-water mark and I guess I'm just trying to work out how to not jeopardise your good arrangements while generally improving others, and that's what we're seeking to do.

MR DALY (RSB): Could I suggest that the problem is that we're trying to lump all individuals and all services into one bucket, and I think most of the submissions you would have received from the blindness sector is really saying that, for people that are blind or vision impaired, most of the service needs are fairly unique around, for instance, orientation and mobility - you know, guide dogs - magnification; that most of the responses are not holistic in nature, they're not ongoing, they tend to be very episodic.

Now, the model that's been created and proposed is very much around that personal care and holistic sort of care, which is actually what occurred with Options Coordination in South Australia, which is why I'm suggesting that I think it would be very worthwhile for you to review with the Social Inclusion Board their research and their experiences of what occurred there.

MR STARKEY (RSB): Also what we're saying within our submission is not that - we're focusing on the system more than the deficits in the current system. Currently, for instance, equipment is exempt under the independent living scheme for people who are blind or vision impaired. You can't go there and get a white cane, you can't go and get a magnifier or a talking computer type thing. Currently those are deficiencies in the system, so the new system we're hoping will improve those sorts of areas of equipment and options like that, while we don't want to try and lose a lot of the skills in the system that is currently working. We acknowledge it is working.

We think it's quite a good system at the moment, although it's not perfect. There are a lot of issues that - whilst we generate most of our own money in the sector, we are exempt from a lot of the disability funding that's around, a lot of personal support in lots of ways. For instance, we use a lot of volunteers to do shopping and things like that, whereas other disability groups get paid attendant carers to do that. Whilst, as I said, our submission focuses on the system just to make sure that the system will at least have us in the ballpark, there are a lot of deficiencies in the current system that we suffer from.

MS SCOTT: Thank you.

MR DALY (RSB): I might also just perhaps draw your attention to the separation between disability and ageing. I think you'll find most of the vision impairment submissions do raise the issue that the Productivity Commission in disability is looking at excluding people over the age of 65 from access to services.

MS SCOTT: I don't think that's actually what we're saying. That's not a correct characterisation.

MR DALY (RSB): No? Fine. I'm happy to be corrected.

MS SCOTT: Okay. Well, maybe we'll go to that, but just before we move off services, John, do you have any questions to ask the Royal Blind Society at this stage?

MR WALSH: No, and as you said earlier, Patricia, we had very positive submissions from the various blind associations in other places, so I think we've heard some of these issues.

MS SCOTT: So maybe just turning to that issue of the interface, Andrew, we are in part directed by our terms of reference but also, because of current arrangements, we have looked at those people who are already in the scheme being able to nominate, at age pension age, where they would like to receive their services, and we suggest that funding - as in most cases now - would come from the aged care sector after the age pension age.

Now, I think your group and a number of groups assisting the vision impaired have highlighted the fact that - and I'm sure your submission does the same - the incidence of vision impairment increases after age pension age and that you would like to see a different set of arrangements in place. That's a reasonable summary?

MR DALY (RSB):   To a point. I think what I'm saying is that irrespective of the funding source there needs to be some undertaking; that irrespective of the age the person has an entitlement to exactly the same quantum service delivered at exactly the same time. From an individual's perspective I guess they're not concerned whether it's the aged care sector, disability care sector or some other sector. The very real concern that certainly the RSB has is that we've got one report that came out after the aged care report, saying anyone over the age of 65 will need to rely on the aged care system, but we've got a Productivity Commission report on aged care that makes no acknowledgment of the need to cater for the needs of these people.

Now, my feeling is that I don't think you can look at these two reports in isolation. If we're going to say that one report will exclude people over the age of 65, then surely the other report needs to mirror the fact and say, "That's fine, we accept that and this is how we're going to basically accommodate these people." If not, it just becomes a cost-shifting exercise with very poor outcomes for people over retirement age.

MS SCOTT: Okay, good. Thank you. I'd be interested in just a little bit more information about aids and appliances. Thank you for the attachment here on what's available. When we were in Victoria - I think it was Victoria - we met a person there who presented on behalf of people who are deaf and blind who weren't able to get assistive technology worth $3000 which was to convert digital messages into braille. I'd be interested if you could highlight any new technology that you think should be available to your clients that you currently can't get. It would be very interesting to know what that would be and what the cost per items would be. If you've got a quick response now, Andrew, I'll take it.

MR DALY (RSB):   I think I can give you a very detailed written response. It might be the far superior way of going.

MS SCOTT: Okay, that's fine.

MR DALY (RSB):   Most strategies tend to be around vision enhancement or vision substitution, so we look at making things bigger or brighter or bolder or we change the format to be audio or tactile and there's a range of technologies that can provide that. I'm more than happy, if that's acceptable, to perhaps provide you a list with roughly the costs.

MS SCOTT: That would be great. That would be good.

MR DALY (RSB): I would just like to make one comment on aids and equipment, and Tony sort of alluded to it. People that are blind or vision impaired in South Australia are currently specifically excluded from accessing the state government equipment scheme. At the current time the only way that they're able to access equipment is if it's vocationally related under the Workplace Modification Scheme. To overcome that, the RSB has actually created a short-term loan pool scheme for people that have an immediate need, a long-term loan pool scheme if they've got no ability to purchase, an equipment subsidy scheme to help them to purchase if they have some ability, and a braille grant scheme in order to encourage the learning and acquisition of braille skills.

I'm not quite sure what the circumstances are around the rest of Australia, but I don't know that it would be much better for people that are blind or vision impaired, so I would wholly comment your recommendation around aids and appliances. For people that are blind or vision impaired, aids and appliances can make the difference between being independent and totally dependent. We've got the current situation now where potentially you could actually have someone come in and read your mail once a week for a fee, but the provision of a piece of equipment to allow you to do it yourself is beyond them. I would just stress the importance of that recommendation.

MS SCOTT: Okay, we look forward to getting that material. Thank you very much and thank you for coming along today.

MR DALY (RSB): It's a pleasure. Thank you for your time.

MS SCOTT: Okay, it's going to have to be a quick lunch, unfortunately. We'll be back here at 1.15, please. We've got nine more participants to hear from. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon, ladies and gentlemen. I'm now going to resume the hearings. John Walsh will be joining us shortly, but don't be worried about the fact that he's going to miss a little bit of your testimony, Margaret, because he will catch up with it through the transcripts. Thank you for coming along today. I take it at the moment we have no members of the media with us? We had some members of the media before. Okay, that's fine. Welcome to our public hearing, Margaret. I think you're representing yourself, aren't you? Are you representing an organisation or yourself?

MS SPRINGGAY: I'm actually here as an individual, but I am the South Australian representative on the National Mental Health Consumer and Carer Forum as well.

MS SCOTT: John is just five minutes away, so I think we will take a five-minute break.

MS SCOTT: All right, ladies and gentlemen, sorry, that was a false start before. We are now going to resume and I welcome to the table Margaret and I'd like you again just to identify the organisation you're representing. We have assigned 10 minutes to your presentation.

MS SPRINGGAY: Okay. My presentation today will be as an individual just to speak to the commissioners. I'm the South Australian representative to the National Mental Health Consumer and Carer Forum as a carer representative.

MS SCOTT: Thank you. Please proceed with your statement.

MS SPRINGGAY: I will read this so that I don't miss points I want to make. My presentation will focus on people with a mental illness and, in particular, the focus is where the mental illness results in a disability, and the term that I will use in this paper to encompass that is psychosocial disability, where the psychosocial consequences are a result of mental illness, and I'll acknowledge at the start that not all people with a mental illness will develop a psychosocial disability. The majority in fact seek out their own treatment and organise and lead their own lives with minimal assistance, and that assistance is mainly through the health sector.

Some of those with a mental illness have an episodic illness and will require assistance from a range of agencies to assist them at that time of an episodic occurrence. A smaller proportion of people with a mental illness develop a disability which can affect them in a number of ways: their cognitive processes and their capacity to manage their lives, find housing, negotiate with government agencies, for example. Some with a psychosocial disability are considered to have a lifelong disability unless improved treatments emerge from the ongoing research that is occurring and that will happen in future.

The term "psychosocial disability" has not been widely used in mental health and generally there has been a failure by the mental health services to recognise and address the disabilities resulting from severe mental illness. To use an example from my own family, when my son developed schizophrenia in his first year at university, we were advised to encourage him to continue his studies, take the prescribed medication, attend monthly meetings with his psychiatrist, and after four years of that, with him exhibiting declining functions, major family disruption, bizarre symptoms - awake, pacing at night, calling out to the sun or moon, obviously delusional - no insight into his condition, withdrawing, and isolated from friends and society, the capacity to study and the attendance at university dropped off, he had significant thought disorders, and when I sought help from the then psychiatric hospitals I was told he had to come in of his own accord, but that was an impossible ask because he had no insight to the fact that he was unwell. But that's typical of the mental health services at that time.

Eventually, because he was clearly getting no better - in fact, things were deteriorating - and the chaotic home life, the only way I could get him into a psychiatric hospital was to call the police, and it was only at that time, despite me having a background in health and working other than mental health - I really couldn't believe the mental health system when I discovered it. But he spent six years in a psychiatric institution, which is an indication of how unwell he really was, and we only really discovered that when he got in there, and how had he coped?

During that time I learned about the term "treatment resistance", which describes somebody who doesn't respond to standard medication or other treatments. He came home when that hospital closed and spent the next 13 years at home interspersed with frequent readmissions to hospital and some support as it's begun fairly recently with the PHaMs, the Day to Day programs, et cetera. I've been an advocate for mental health reform for that whole period.

Governments and mental health services have been slow to respond with appropriate services, despite the reforms that are now under way, and there are many in a similar situation to that which I describe. While research and services have improved since that time, the degree of psychosocial disability experienced by some people with a mental illness remains, and this is evidenced by the higher proportion of people with a mental illness who are homeless or incarcerated for minor crimes which could probably have been avoided.

There is no current cure for the more severe mental illnesses. Research and treatments have improved and innovations such as early intervention can reduce the level of resulting disability, but are not yet able to entirely prevent it in all circumstances. I understand that the commission sees that the broader service needs such as employment and housing are the province of other sectors and I therefore won't comment on those needs, but acknowledge them as part of the necessary components in a whole-service continuum.

MS SCOTT: Margaret, because of time constraints, I'm going to now take the next bit through conversation, if that's all right with you.

MS SPRINGGAY: Yes, okay.

MS SCOTT: John, Margaret and I were able to have a chat before we commenced the hearing. So, what services and who do you think should be in the NDIS? What services should be available for people with psychosocial illness and who should be in the system, as you see it?

MS SPRINGGAY: I guess it's not easy to define the range of disabilities associated with a psychosocial disability. I've mentioned the fact that they can be cognitive thought disorder, delusional at times, et cetera, and it's that type of disorder that means that the person will have huge problems negotiating day-to-day living. As an example, trying to initially get a disability pension: it's very difficult to negotiate with government agencies that really have little insight and understanding of what the disability is and, indeed, the person is not helpful in describing the fact that "I have a disability". So they may, because of their lack of insight, even need somebody to get them there and to talk them through the fact that it would be really good for them to get some income; so that sort of buddying system, if you like, to assist those people that are unable to negotiate themselves, on their own behalf.

It's very difficult for them to manage a household and in fact to organise things. You will frequently find - and families are grappling with this sort of thing all the time - that they don't answer correspondence, they don't respond to phone calls, at times may not use the phone because they see that as enabling some spaceperson to intercept the calls - you know, that sort of delusional thinking. So it's very difficult to confine into one neat package what the particular service needs are, but they will encompass a lot that will be accompanying that person through the maze of services.

Now, there's no way to make those services more simple. They are as they are. But it requires a considerable amount of skill to negotiate them even when you are completely well. But I think the critical thing to me is, mental health services have had a poor record in understanding the consequences of these disabilities and so the services have not met the needs. The community based services have just not developed in mental health to meet the need that is out there. The focus has always been on psychiatric beds and that is fed by the media that always picks up the stories and says, "Well, we need more beds," and it's a very easy goal for a politician to set because it seems to satisfy the public to a degree.

MS SCOTT: Margaret, that answers the first question, and now the second question. Who within the mental health community do you think should be in the NDIS?

MS SPRINGGAY: Which group would provide the service to do the assessment?

MS SCOTT: No.

MS SPRINGGAY: Sorry, I'm not quite familiar with your question.

MS SCOTT: Okay. A fair proportion of the Australian population reports a mental illness at some stage in their life - you know, this figure of one in four.

MS SPRINGGAY: Yes.

MS SCOTT: What proportion of those people do you think should be eligible for services from the NDIS?

MS SPRINGGAY: I would find it almost impossible to quantify it. I know the figure of one in four is used to describe the people that are affected by mental illness at some time in their lives. It is certainly a proportion of that - but point zero something, I would suspect. I think there are indicators, and I can do no more than point to the indicators that might give the commission some idea of the quantity and the magnitude of that need and the population which would be recipients of it.

I think the UK developments, with personal budgets, would be a part of that. I think the number of people with a mental illness currently on a disability support pension may also be part of that, as an indicator only; the services coming out of FaHCSIA, the PHaMs and Day to Day Living, although because PHaMs have allocated those services based on, I think, postcode they would be fully aware there is an unmet need and so far those services haven't been evaluated, so I don't know. They would nevertheless, I'm sure, have some idea of an unmet need there. I think they would be indicators.

MS SCOTT: All right, that's fine. John, we've run into time constraints. Are there questions that you've got for Margaret? She has provided us with three pages of notes on her presentation.

MR WALSH: No. Margaret, I think that's been very helpful. Thanks very much for that.

MS SCOTT: So, Margaret, we're going to have to close there, but thank you very much for coming along and thank you for your written material.

MS SPRINGGAY: Thank you.

MS SCOTT: I now invite Linda McGarvey to come forward, please. Linda, thank you very much for coming along today. Just for the record would you like to give your full name, and I understand you're representing yourself - is that right - and your family.

MS McGARVEY: Yes. My name is Linda McGarvey. I should also mention that I'm a South Australian peer volunteer support coordinator for Limbs 4 Life, so I guess my bias in terms of the commission is to talk in relation to amputees.

MS SCOTT: Amputees, yes, okay.

MS McGARVEY: I'll give you a little bit of personal background before I'll address the draft document. I am quite newly disabled. I'm a cancer survivor. My amputations happened in 2004 and 2005 and now I'm a hip disarticulation amputee. One of the things that I'd like to address in terms of my own personal experience - and it has been mentioned in the draft document - is that because I actually had some expertise in dealing with government agencies, I was better able to negotiate what was happening to me.

I was, I suppose, fortunate in the sense that I actually had time to research what the amputation would mean, met the rehab doctor, went to the hospital, had the OT out to the house beforehand, had counselling with another amputee. So I had accumulated a whole range of knowledge that enabled me to have some control in my life, and I guess what's important for amputees is that early intervention, before depression sets in, before isolation sets in.

We have done some questionnaires around how people feel when they go home and there is that great sense of depression and isolation - you know, "What am I going to do with my life now?" - and many amputees, and I know people have given you the statistics, are over the age of 65 and so are already retired and often do fall into the trap of depression and not knowing what to do with their lives.

For me there was all that early assessment, intervention, much of that instigated by myself; so to give someone that knowledge prior to an amputation, which is obviously a huge thing in someone's life and a great loss, and there's a whole range of - as you were talking about - psychosocial things that go alongside it. I was very fortunate and it did help my recovery process in that I had things like rails and ramps organised before I went into hospital, so I was not one of those people that gets left in hospital waiting for things to happen.

One of the things that I'd like to talk about is, within the scheme, I saw that in page 7 of the important points you mention aids, appliances and home and vehicle modification, and in brackets you have included artificial limbs. The way I think about it, an artificial limb is not so different from an artificial hip or an artificial knee; it is external, but I think it falls into the category of a replacement body part and perhaps when the scheme has its components put into it, that might be something that - because I know there's been the internal/external discussion. But I think it is a body part and even though it is external it helps people become more active in their communities, resume their lives; you know, work; pay taxes - all of those things that make us valued people in society. I think that's a really important point.

So partly the assessment process is what I'm concerned about, that there should be best practice, and I consider that I had best practice, so I think all amputees deserve that. The prosthetics is a huge issue around the artificial limb scheme and its disparity against insurance. So, say, if you sat me next to someone who is the same level of amputation as myself, they would get a leg worth $70,000 out of the insurance scheme. I might get a leg that's worth six. So there's a huge disparity. I think that this is also an opportunity to have a national artificial limb scheme so that that inequity of access is diminished. I think that's really important because how do you value one person more than another and give them a microprocessor knee and this next person gets the basic model.

I think that given the advances in technology, we certainly in Australia are quite far behind what other amputees in other Western countries have and it's there, it's out there. I personally researched my own. I went to America and actually went to Walter Reed, and of course they're making huge inroads and huge gains into how they do artificial limbs. So that was really a learning experience for me and I brought some of that back; brought it back to my prosthetist who, within the constraints of the artificial limb scheme, has embraced - and I should commend him for that and he is a relatively new graduate - some of that stuff and taken that forward.

I think that if you want to retain really good prosthetists in the system, you really need to give them adequate funds to do that; so I personally feel that early assessment, early intervention, decent prosthetics and - there was something else - that notion of equity and respect that amputees and anyone with a disability deserves and requires. Obviously equipment is an issue. I had organised all of that before I went in, and the other things happened while I was in hospital. Issues around equipment occur now when you want to change equipment, when you went to vary it, and I've recently spent six months trying to change the type of crutch that I use. Now I've learnt that we were missing a piece of paper, so my piece of paper has been found.

I wanted to change a type of cushion. That also has taken a great period of time because I think the system has its downfall in that there's a huge waiting list for OTs, so if you want to change a piece of equipment, you have to be given an appointment to see an OT and be assessed. It seems a huge waste of money.

MS SCOTT: Would it be all right if I interrupted your presentation and just asked a few questions?

MS McGARVEY: Sure.

MS SCOTT: Linda, it sounds like you didn't have much contact with the sector before your cancer meant that you had to have it. When you did have the contact with the sector, I get a sense that it's somewhat bureaucratic, but did it meet your expectations? Did you think, "Oh, right, well, this is a well-working system and this is how it operates," or have you been surprised by it?

MS McGARVEY: Because I as a peer support volunteer see a lot of amputees and I see the system as being very bureaucratic for them, I think a lot of it is a lack of knowledge, lots of paperwork. For me, because I had some expertise in that, I'm kind of a person that will say, "Okay, if that door is closed to me, I'm going to open another one."

MS SCOTT: Yes.

MS McGARVEY: But for many people in that situation, that whole notion of advocacy that you talk about in the draft I think is really important.

MS SCOTT: All right. We're just running out of time.

MS McGARVEY: Yes, sure. Sorry.

MS SCOTT: John, is there anything you'd like to ask Linda?

MR WALSH: Yes. Linda, you mentioned that Australia was way behind other countries in terms of - I forget what you said - quality or - - -

MS McGARVEY: In the quality of the componentry that's used.

MR WALSH: If there's any information you've got on places we might have a look at, that would be - - -

MS McGARVEY: Sure. I'll certainly give you that. I'd just like to say one more thing. I really do feel that this is a real opportunity for amputees to have equity of access and I certainly hope that that might come out of this commission, and I certainly will get that information to you around the componentry.

MS SCOTT: Thank you very much, Linda. Thank you for coming along today and for your material.

MS SCOTT: I now call for the South Australian Council on Intellectual Disability. It turns out they're not here. We might go to you, Leah, please. John, we've got some material from AFDO. I've got a statement outline. I don't know if you've seen that.

MR WALSH: Yes, I've got it, Patricia.

MS SCOTT: Yes. Thank you. Leah, thank you very much for attending today. Thank you for providing us with a statement outline. Would you like to commence your presentation, please, and anticipate that John and I have got some questions and I'll tell you when our time is about to run out.

MS HOBSON (AFDO): Sure. Would you like me to just go through what I put into the submission, put it back to you or - - -

MS SCOTT: Just for the public record, because we have other people presenting after us, maybe you'd want to pick four key points.

MS HOBSON (AFDO): Okay, sure. I think from our perspective the key points that are coming out from the consultations we've done around Australia have been who's in and who's out. There's a sense of some lack of clarity around some of the eligibility criteria. With regard to severe and profound disability there's a sense that perhaps that criteria isn't necessarily clear enough in terms of sensory disability. Those people experience particular requirements for assistance that may not be articulated so well in assessment tools.

In terms of the intellectual disability eligibility criteria there's a sense that basing that on a diagnostic group, rather than perhaps some of the functional issues for people within that group and outside of it, such as people who have acquired brain injury, perhaps people experiencing some kinds of psychosocial disability where there are issues with daily living skills, issues with maintaining relationships and expressing a need for assistance - would be more appropriate in terms of a category. We've also had a number of people concerned with the cut-off age of 65. In particular, I think there's a sense out there that the system becomes very either/or and that the aged care system doesn't necessarily provide adequately for disability-specific supports and so there needs to be some kind of support that is specific to disability expertise built into the aged care system if that's going to be the case.

In terms of psychosocial disability, as others have said today, the feedback we're getting from around the country is that it's very important to have that included. In particular, we're not seeing a lot of people with psychosocial disability at our consultations. We've had some conversations specifically with people from that sector and are continuing to do so, but certainly what people with disability are telling us is that when you have a dual diagnosis, when you have a psychosocial disability and you have another kind of disability, there's a lot of toing and froing between what, for instance, is part of your intellectual disability and what is considered an issue with your psychosocial disability, and who deals with what becomes very bureaucratic and is the cause of much blame shifting.

When it comes to assessment the concerns that people have been raising have been around - well, firstly, I guess at a basic level, but everybody is different and some of those needs in terms of an assessment context are going to be very different. So for people who are in crisis situations and who may need support very quickly, you don't want to spend the same amount of time and energy assessing that person. For instance, if you have somebody who is suicidal you perhaps want to do a very limited assessment indeed, as compared to somebody - - -

MS SCOTT: But wouldn't the person who's suicidal be in the acute mental health sector? They're not going to be assessed for their clinical needs in the NDIS.

MS HOBSON (AFDO): They're not necessarily going to be assessed for their clinical needs in the NDIS, yes, but if part of what's causing somebody perhaps with a disability to be suicidal is a lack of disability support, for instance, then obviously you want to take that into account when you're doing an assessment of somebody.

MS SCOTT: All right. Sorry, I interrupted your flow. Please continue.

MS HOBSON (AFDO): No, of course.

MS SCOTT: Maybe one or two more points, then we might go back through these and discuss and ask you a few questions about them.

MS HOBSON (AFDO): Sure. Certainly when it comes to assessment of people with disability we're keen to see some form of self-assessment. We're still having some ongoing conversations about what that might look like and what that might mean for people with disability. We've also heard some concerns from people that there's some ambivalence out there about whether or not an assessor should know a person and to what extent, because on the one hand it does, as the report says, alleviate some of those issues around your GP perhaps who's had a longstanding relationship with you, putting in a form for you that may get you better support where there's clear conflict of interest.

But on the other hand you have issues where people with disability maybe need to be speaking to somebody they can trust in order to perhaps disclose that they're being abused, or that they may need to spend some time with somebody in order for some subtleties of their disability to be observed. That may not come out in direct consultation with them or their family or friends but just take a little time to establish.

MS SCOTT: If it's all right with you we might pause there and go back through some of your issues.

MS HOBSON (AFDO): Sure.

MS SCOTT: Just on sensory disability - so we're talking about blindness and deafness. I'm on the right wavelength, aren't I?

MS HOBSON (AFDO): Yes.

MS SCOTT: Okay. Well, we have in our report an eligibility criteria which says "have significant limitations in communications, mobility or self-care". That would capture quite a few people with significant sensory disability, wouldn't it?

MS HOBSON (AFDO): It would, but I guess it depends on how you clarify that in any documentation that you're putting out through the system. Certainly when some of our member organisations first saw this their first question - - -

MS SCOTT: "Are we in or out?"

MS HOBSON (AFDO): - - - was "Are we in or out?" That was a particular concern for the sensory disability organisations.

MS SCOTT: This is where I'm in puzzlement, because on the one hand you say we should potentially have a list which says "sensory disability", right, and on the other hand you have trouble with us using the phrase "intellectual disability".

MS HOBSON (AFDO): What I guess I mean in terms of sensory disability is that there needs to be some articulation of the functional differences for people with sensory disability when it comes to - - -

MS SCOTT: Okay, that's fine, but isn't that then for significant limitations in communications, mobility or self-care? I'll be frank. I think you're arguing two sides of the fence on this stuff. On the one hand upset that we're using the phrase "intellectual disability" and on the other hand saying we haven't used something that would allow people with sensory disabilities to see themselves in our criteria.

MS HOBSON (AFDO): As I was just saying, I think the issue is not so much with the terminology you've used in that first criteria in terms of yes, it does cover functionality, and yes - if you understand the intent of the system you can read it as yes, this covers people who are blind or who are deaf, but for the layperson reading it, for some reason that's not coming across. So you would need to be looking at having some clear examples of what exactly it might mean for a person with a sensory disability.

MS SCOTT: Okay. Now, your objection to us using the phrase "intellectual disability", we did actually put this to a group of people who were intellectually disabled and said, "Are you comfortable if we use this phrase in our report?" and they were, so I'm trying to work out why we can't - given that you want us to be very precise in the first definition and you've now given examples - eg people who are deaf, eg people who are blind, eg people who are vision impaired or whatever - why do you have trouble with the words "intellectual disability"?

MS HOBSON (AFDO): I don't have trouble with the words "intellectual disability" but what we've been hearing from people in our consultations is that to set apart people who have an intellectual disability - for whom, yes, there are some different concerns to people who have issues with mobility, communication and self-care, because for people with intellectual disability, as I said earlier, it's more about building relationships - - -

MS SCOTT: Well, I've got shy friends and they can't build relationships either.

MS HOBSON (AFDO): Sure.

MS SCOTT: They don't actually necessarily have a disability.

MS HOBSON (AFDO): But there are a whole lot of other categories of disability which don't fall into that first severe and profound limitation in mobility, communication or self-care.

MS SCOTT: But we haven't used that phrase "severe and profound".

MS HOBSON (AFDO): In the first criteria?

MS SCOTT: No, we've used the phrase "significant".

MS HOBSON (AFDO): Significant, right, okay. So there are some groups of people with disability who don't necessarily fall into that category and I'm thinking particularly of groups of people like those with acquired brain injury where - - -

MS SCOTT: But wouldn't they have trouble with communication, mobility or self-care?

MS HOBSON (AFDO): Yes. Again this is another one where people aren't clear about whether or not that means they're in or out. Some people with acquired brain injury might be able to get up and shower themselves, they might be able to hold a conversation, they might be able to get out of the house under their own steam, but then they have trouble remembering what it is they're supposed to do or how they're supposed to interact with someone, or they become easily angered.

MS SCOTT: All right.

MS HOBSON (AFDO): So there's those fine distinctions.

MS SCOTT: Okay. John, do you want to take over?

MR WALSH: Yes. I was just going to ask, Leah, that second criteria where we've described it as "people with intellectual disability", are you suggesting that there may be other types of disability as well as intellectual disability that should fall into that group, such as people with acquired brain injury?

MS HOBSON (AFDO): Exactly - where some of the issues for people in different diagnostic groups actually look very similar even though they don't have the same diagnosis.

MS SCOTT: In relation to people with acquired brain injury, we have got them in the third category. We specifically say "autism, acquired brain injury, cerebral palsy and sensory impairments". We could use a whole lot of examples but, as you know, at the end of the day, if we use a lot of examples and your example is not down there, there's sure to be someone who will say, "But my example is not down there," which is why we have these general headings. Anyway, I'm still in a quandary about exactly how we go about meeting your concerns.

MS HOBSON (AFDO): I think some of this comes down not just to how the eligibility criteria are expressed but also how people within the system know to interpret them and know to express that to people who connect with the system as well, and that's true of a lot of systems that exist at the moment. So, if you are a person with a disability who goes to, for instance, a disabled parking permit scheme, whether or not you come away from a conversation with somebody involved in that with a sense of whether or not you're eligible is sometimes very much about the person you're talking to and about the information they're able to give you and the flexibility they have in seeing what your individual needs are. So some of that goes back to the information that's available from the National Disability Insurance Agency too.

MS SCOTT: John, a further question?

MR WALSH: We understand, Leah, that the assessment process for eligibility will require skilled people. We're struggling to understand what you're proposing that we should say is the eligibility criteria. Do you have any suggestions on how we would word it?

MS HOBSON (AFDO): In terms of the issues that we've talked about with intellectual disability.

MS SCOTT: Maybe you want to go and actually draft something for us to have a look at.

MS HOBSON (AFDO): Yes.

MS SCOTT: We looked at the ICF criteria about having trouble forming social relationships. There's a whole industry out there called - I don't know what they're called, but people who get people together - a social dating service. There are some people who have an industry in that. Having a criteria that says, "Have difficulty forming social relationships" it's just so broad; it covers so many people. Then you might say, "Have trouble making decisions." Well, that covers a fair few people, probably a few in political life as well as in ordinary life.

MS HOBSON (AFDO): Yes.

MS SCOTT: I guess what I'm looking for is something that could meet your needs of being functionally related but being not so broad that half of your social friends - - -

MS HOBSON (AFDO): Wouldn't actually fit into that category, yes.

MS SCOTT: Even though the people in the disability sector may say, "Well, that seems very odd. I didn't think resources would go towards them," at the end of the day we've got a highly under-resourced sector, so we have to have eligibility criteria that direct those funds to those most in need.

MS HOBSON (AFDO): Sure, and we would appreciate that. As I said earlier, this is about trying to see where there might be some unintended gaps in that.

MS SCOTT: Sure.

MS HOBSON (AFDO): So we'll go away and have a think.

MS SCOTT: That would be good. Look, I think some of the other points that you've made in your written presentation to us we've heard from other people, and we will have them under active consideration. Please don't be worried - the fact we didn't get to have you read them out.

MS HOBSON (AFDO): Sure.

MS SCOTT: I wanted to direct my questions to the ones that caused me the greatest concern.

MS HOBSON (AFDO): Of course.

MS SCOTT: Are you comfortable, John, if we wrap up now with Leah?

MR WALSH: Yes. Thanks very much, Leah.

MS HOBSON (AFDO): Thank you, John. Thank you, Patricia.

MS SCOTT: Thank you for coming along and thank you for the material.

MS SCOTT: I call for the South Australian Council on Intellectual Disability to come forward, please. Nice to see you again, Dell.

MS STAGG (SACIDI): Hello. Denice is the president of the Australian Society of Intellectual Disability.

MS SCOTT: Welcome to both of you. For the record, could you state your name, please, and your organisation, and if you'd like to make an opening statement, and I'll try and stick to a bit of a time constraint, okay? Thank you.

MS STAGG (SACIDI): Dell Stagg, president of the South Australian Council on Intellectual Disability and Michelle's mum, and Denice.

MS WHARLDALL (ASIDSA): Denice Wharldall. I'm the president of the South Australian Branch of the Australasian Society for Intellectual Disability.

MS SCOTT: All right. You're welcome here today. Would you like to make a statement, please.

MS STAGG (SACIDI): Yes, I would. SACIDI and ASID would like to take this opportunity to congratulate and thank the commission for a very thorough and comprehensive document which demonstrates a great depth of understanding about the issues with people with disabilities and, where appropriate, their families have to deal with. It was refreshing to be left with the impression that we have not only been heard but listened to. That being said, we just sort of made a note of some of the stuff that we thought needed a bit more attention.

MS SCOTT: Sure.

MS STAGG (SACIDI): One part of the document talked about "rigorous assessments". We very much like to operate using the principles of self-determination for people, which are freedom to live a meaningful life in the community, authority over dollars needed for support, support to organise resources in a way that are life-enhancing and meaningful, responsibility for the wise use of public dollars, and confirmation of the important leadership that self-advocates must hold in the newly designed system. That comes from the Centre for Self-Determination in the States. Tom Nerney has written quite a lot of stuff around self-determination. I've given some documents with this paper for you to have a look at.

MS SCOTT: Yes, thank you.

MS STAGG (SACIDI): He's a bit of a hero of mine.

MS SCOTT: Yes. All right.

MS STAGG (SACIDI): Then we talk about now, we believe it's essential that consideration be given to the provision of a form of self-assessment such as the resource allocation system from the UK. All evidence finds that most people do not over-assess; in fact tend to make savings. I think there have been three evaluations of the In Control program, and it seems that there are savings made almost by everybody that does this self-assessment model. It's a self-determining thing, if you can make your own assessment and tick off the boxes.

The RAS allocation system is a system of people saying, "I need help with" or "To go and meet my friends, I need support to do such-and-such," and they provide a points system. It depends on how much help you need to do it, how many points you get. I mean, that sounds awful, but I think it's the only way you can actually manage these things. Then there is a line of continuum, where people know how much money is available to them for the points that they attract for the support that they need. So it's open and it's transparent and they know what their allocation is. That's then their entitlement. Then they can sort out how they manage their lives.

MS SCOTT: Dell, I might return to this later, but let's get down the points that you think we need to consider before we finalise our report and then we might return to the ones that we consider to be most contentious. Would you like to move on to your next point, please?

MS STAGG (SACIDI): Yes. Same opportunities for all, and we believe it's essential that people who are currently living in institutions, group homes, supported residential facilities under block funding arrangements, should have access to a direct payment of an individual funding package over which they would be supported, if they required it, to self-manage using their current allocation; that is, what it costs for their current service now.

There was a program in the United States that was the Money Follows the Person, where people went out of institutions and whatever money was used to support them there went out and supported them in the community. I think the cost dropped off over the years because they didn't need as much money in the end. We just think that there's lots of people stuck away somewhere who really deserve to have the same opportunities that we have.

MS SCOTT: Okay, got that point, thank you.

MS STAGG (SACIDI): And the co-payments: it must be remembered that many people with disabilities and their family carers whose only income is a Centrelink income support payment are already seriously economically disadvantaged and usually have no opportunity to amass assets, liquid or otherwise, and live from fortnight to fortnight on inadequate payment. In light of the predicted future increases in energy and water costs, not to mention everything else, which for some are absolutely essential to maintain health and wellbeing, the requirement for co-payments would just add further impost to those already struggling to make ends meet.

MS SCOTT: Let's clarify that one now. We don't recommend co-payments. Some people have drawn our attention to the fact we have suggested that there might need to be a front-end deductible, a bit like sometimes with insurance policies. You have a little bingle on your car, you pay the first 500. But we do say in that recommendation that where people are providing care for a family, where people are really covering quite a lot of the cost anyway, that would be waived. I don't want you to leave here thinking that we've recommended co-payments.

MS STAGG (SACIDI):   I understood that, but I just felt that we wanted to say - - -

MS SCOTT: All right. You want to get it on the record just in case we change our mind.

MS STAGG (SACIDI):   Yes.

MS SCOTT: Okay, thanks, Dell.

MS STAGG (SACIDI):   Family carers: it's essential for the current propensity to exploit family carers as cheap labour force to cease. Supporting family carers in a tangible way, using NDIS funding to enable them to have such things as a break away for a couple of weeks a year, payment for work performed and the care of their family member, payment into a private health fund could make the difference between a carer's ability to continue their supportive role and of relinquishing it in an untimely and unplanned way. When you struggle with poverty and you struggle with not being able to go out the door because you can't afford the bus ticket, it just makes life unbearable at times and all you want to do is give up. Part of the payment of a person should include support of the family carer.

MS SCOTT: All right, I've heard that. We're going to come back to that one.

MS STAGG (SACIDI):   Adequate resources made available to the person with disability will enable their supported participation in the community and relieve the carer of the responsibility of full-time care, plus encouraging their own participation in away-from-home activities - a much healthier option for all. Payments: with regard to the payments, if we get to the stage where people are going to get an allocation, it says in there that it's recommended that monthly payments be made. It's our view that the first payment might make more sense to be of a three-monthly payment to cover such things as emergencies, enable a bit of planning, just so that there's something in hand in case somebody gets sick and they've got to pay for additional support for three weeks instead of three days. A month's payment is not going to cover that sort of thing.

With regard to any money remaining at the end of the financial year, we believe it must remain with the individual and be allowed to roll over for at least three years, so that they can plan - - -

MS SCOTT: And I think we've suggested 10 per cent rather than whatever is left.

MS STAGG (SACIDI): Well, if somebody wants to replace a washing machine or buy an accessible vehicle and they've had - slippage is a marvellous thing and it ends up being quite a lot more than you think it's going to be by the end of the year. If somebody in a wheelchair was finding it difficult to get out and they could see that there was going to be slippage, then in three years they might be able to buy an accessible vehicle or put towards an accessible vehicle.

MS SCOTT: I guess we envisaged that people that need vehicle modifications will get vehicle modifications.

MS STAGG (SACIDI): But they have to have the vehicle first to be modified.

MS SCOTT: Yes, that's true. All right, I understand the point you're making. Okay, are we towards the end?

MS STAGG (SACIDI): Yes, that's it. Thank you.

MS SCOTT: All right, so let's just check. Rigorous assessment, and you want it to be based on self-determination; same opportunities for all. Your concern about co-payments was discussed. Family carers: you want them to be able to get a break away for a couple of weeks.

MS STAGG (SACIDI): To have access to a certain amount of the disability funding.

MS SCOTT: Sure. Payments for work performed and payments into private health funds.

MS STAGG (SACIDI): Yes, that's just examples.

MS SCOTT: And then number 5: the first payment to be three months rather than just one month, to allow some flexibility, and then unspent funds to be rolled over for three years.

MS STAGG (SACIDI): Yes, and the same opportunities for people who live in institutions, group homes - - -

MS SCOTT: Yes, sorry, I did have that. I did have that down but I had it under 2. All right, so this is - even if you're in supported accommodation or an institution, that you still get to have an individualised package and if you want to be supported in that decision-making that it be allowed. John, do you have some questions for Dell?

MR WALSH: Just a comment really, Dell. You've described a very entitlement based scheme, I think. Have you given any consideration to what your proposals might do to the cost of the scheme?

MS STAGG (SACIDI): Well, I can speak from experience, John. My daughter lived in institutional group home arrangements before she became really, really ill and I brought her home. We get a bucket of money every year. In fact, we get a 12-month amount which goes into Michelle's bank account, which is linked to an agency so they can check that I don't run off to Bermuda. But I think over the last 20 years - I've done the numbers - I've saved the government $2 million because what it costs for Michelle to live in a group home, I think I'm saving them about $60,000 a year. I don't need that much money. It would mean the house would be full of people all the time and I would much rather have our privacy and the support that we need when we need it than just have money to spend. You know, it definitely has saved - - -

MR WALSH: I think you've described a scheme that is the scheme that you'd prefer. Our challenge I guess is trying to determine which of the things you've asked for are practically able to be implemented on a large scale. Not everyone is as diligent and as trustworthy as you are, so scaling these ideas up onto a large scale is the problem that we have challenges with.

MS STAGG (SACIDI): I'm sure if I did something wrong someone would be knocking on my door within about three days, if the bank balance didn't balance.

MS SCOTT: Okay, look, I want to go back to the self-assessment point, if that's all right, John. You talk about the UK experience suggests that we could put a lot of reliance on self-assessment. One of the themes in our report is that, notwithstanding that people have disabilities and that families and carers look after them, often with the very best of intentions, not everyone is an angel.

MS STAGG (SACIDI): Neither am I.

MS SCOTT: So we start on the basis that not everyone is an angel and our systems have to acknowledge that. We have in the report - and I admit it's in volume 1 of the two volumes, so you may not have got to see this, Dell, because I know you've got so many responsibilities, but in there we look at how accurate is self-assessment. I'd be interested in your views once you've had a chance to look at this part of the report. It's on page 518, 519 and then just over the page. Basically we've come to the view that although they talk about self-assessment in the UK a great deal and everybody in Australia talks to John and I about UK self-assessment, in fact it's a bit like the end of the rainbow. You go hunting for it and then you don't quite find it. You see signs of it.

We've come to the view that, while it's much talked about, it's not necessarily given a lot of weight when it comes to actual resource decisions, so if it turns out that this - you know, you think our studies we've referred to, and we've referred to a number in here - is dated, if you've seen something that's more current or something that takes a different view, we'd be happy to be corrected. But our view is that, on the basis of what we've been able to glean so far and on the basis that not everyone is an angel, while self-assessment can be part of the assessment process, at the end of the day for the system to continue to have the confidence of the public it's very important that there be some objectivity in it, so let's maybe get your reaction to that when you get a chance.

On some of your other points, well, in the draft report we have suggested a trial of payments for family members. I have to tell you, that hasn't necessarily had universal appeal. We've had some people that have been quite critical of that suggestion, haven't we, John, to us? So, look, in the report we touch on a number of the things that you've suggested. We haven't gone as far as you've suggested, and already we're conscious that we're posing what is a considerable call on budgets. But we've heard you today. It's good to see you back again and thank you very much for your material.

MS WHARLDALL (ASIDSA): I had a few more things, sorry.

MS SCOTT: Yes, please do, sorry. You've got a little bit of time, so please go ahead.

MS WHARLDALL (ASIDSA): We have a different view to the person that was here last, around the commission's recognition of the issues and complexities for people with an intellectual disability, and we do commend you for including coverage for those with an intellectual disability that are not easily covered by the definitions. I imagine there will be concerns with other groups and that they might well want to broaden the definitions to expand them to include other groups and we're really aware that in fact, if that were to happen, then it would probably include half of society when they're going through a bad stage of their life. We wouldn't want to see that happen, but we're really glad that it's in there. I guess the other group that might present some of those similar issues are maybe people with an acquired brain injury who, through their injury, are presenting very similar to these people with an intellectual disability. We really like that part of the report, that there is a recognition for that group of people.

MS SCOTT: All right.

MS WHARLDALL (ASIDSA):   So that was really good. The other area: with training, we have some concerns about the lack of training benchmarks, given that the scheme will bring about a significant increase in individual support, resulting in unsupervised workers. The vulnerability of those with an intellectual disability is considerable. We don't believe that it's an all or nothing. I'll give you an example. Within South Australia there's a specific government policy related to supporting people with health support needs and that has, as part of its risk management, some training benchmarks.

Say you have a person with an intellectual disability, living in a group home, that has nutrition via gastrostomy and quite frail health: there are some very specific training requirements you need to do. If, however, someone had similar health support needs and they were living in the community, they were able to direct their support worker, et cetera, then there would be an exemption from those training requirements. So we don't think that they're mutually exclusive, but it is a concern that they're not in there.

There is evidence research for people with an intellectual disability, for instance, with behaviours of concern, who may be very violent. The research tells you that more than likely, if you've got an untrained support worker who doesn't understand the person and their disability, that person will be restrained and their human rights will be violated. That's just a given. That is of particular concern, particularly given that we're going to move more and more into unsupervised settings.

Just in relation to what money can be spent on, I guess I was a little confused. For instance, in South Australia there's a really good respite support service called Holiday Explorers and - although I don't have anything to do with them - they offer a very good service. Their whole service is based on people going on holidays, who pay for their holiday just like you or I would, and the funding they get is spent on training volunteers, recruiting volunteers to go on the holidays, but the cost of the holiday is paid by Holiday Explorers.

That can be anything from a camping holiday, and certainly the Companion Card has assisted in those things, but it could even be a more expensive holiday, although they're not as often. So you're not paying for the person with the intellectual disability. But often the respite is much higher quality and probably better value for money than paying a support worker. So I guess there's an understanding that you've got to have some restrictions, but in fact the restrictions could get in the way, so I don't know how a program like that would fit into the new way of thinking.

MS SCOTT: I think it's quite in keeping with at least my thinking. I won't try to talk for John, but - - -

MR WALSH: I was just going to say the same thing, Patricia. I don't know that you'd find anything in the report that would suggest that that wasn't within our thinking. If you do - - -

MS WHARLDALL (ASIDSA): That's the impression I got, that you would pay, say, for a volunteer to go on holiday, the holiday cost. You wouldn't pay for the person with the disability, we understood that, but there are other ways of using money more creatively, so it was about having the creativity but having the safeguards in place.

MS SCOTT: Okay. We actually like the - we use the example, and I don't want to repeat it because I'm sure the audience will groan if I repeat it again, but the difference between day care versus going to a film.

MS WHARLDALL (ASIDSA): Yes.

MS SCOTT: Both can involve social participation. One could be boring and the other one could be a bit of fun. But, look, if we've created that impression, maybe you could direct our attention to the paragraphs that suggest that to you. It looks like Dom is going to find me the bit that says something contrary to that. Yes, page 4.3, again in the huge report. We actually have got down, "Rather than just thinking of it as respite in your home," et cetera, "recreation holiday programs where the primary purpose is respite".

MS WHARLDALL (ASIDSA): Okay. That's good.

MS SCOTT: Maybe we could clarify that.

MS WHARLDALL (ASIDSA): Sure.

MS SCOTT: But if there's some part of the report that you think would lead you to a completely different conclusion, let's have a look at that.

MS WHARLDALL (ASIDSA): Sure, okay.

MS SCOTT: And your earlier point, we'd welcome getting your written notes on that.

MS WHARLDALL (ASIDSA): Sure. And just one more thing: it's just the vulnerability of people with an intellectual disability; that most people would have someone in their lives to assist them, guide their decision-making where required, make decisions, but there are still a lot of people that don't have someone to guide them or even a person to assist. We just wonder whether there will be resources allocated to, for instance, reviewing living arrangements where, you know, they might be inappropriate, et cetera. That might be just in a once-off way when the scheme starts.

MS SCOTT: Yes.

MS WHARLDALL (ASIDSA): We are well aware of the large number of people that are quite vulnerable, with an intellectual disability, that really have got no-one to look out for them.

MS SCOTT: Yes, I think you're absolutely right. This gives me a chance to say something that I would have liked to have said with one of the other speakers but just didn't get the chance. We do see the role of a disability support organisation, if people want to have one of those, as very much being an advocate in their corner and we do think that the local area coordination, in the WA sort of world - - -

MS WHARLDALL (ASIDSA): Yes, that's a good one.

MS SCOTT: - - - would provide looking after the person. For any assessment process, we expect that local case manager will visit the person in their home. We're hoping that that would allow at least someone to get a glimpse into the setting that an individual is in: what are the natural supports? Where is the home located?

MS WHARLDALL (ASIDSA): Yes.

MS SCOTT: You know, give some sense of just how easy or hard it is, and it gives some better context for then the assessment process. Now, just on the disability support organisation, someone made the point earlier - and I know you didn't raise it, but it just gives me, as I said, a chance to correct the record. Someone said, well, they didn't think it was necessarily fair that a disability support advocate would be out of a person's package; but the package would include that as - it's not as though they have to trade off something else. If somebody wants that service, the family sees desirability, that would be an add-on, not a subtraction from. I thought I should clarify that.

MS STAGG (SACIDI):   And often you need independent advocacy, because people working in organisations are more likely to be loyal to the organisation than to the individual.

MS SCOTT: It's just natural, isn't it, yes? Are we finished?

MS STAGG (SACIDI):   Yes.

MS SCOTT: Great. John, any further questions?

MR WALSH: No. Thank you very much.

MS SCOTT: Thank you very much for coming along today. Is there a chance for us just to get the extra notes? All right. Thank you.

MS SCOTT: Can I just alter the schedule a little, and I'll invite Bruce McDonald to come forward now, please.

MR McDONALD (ADASA): Quicker than I thought.

MS SCOTT: John, Bruce is going to be representing the Attention Disorder Association. We're a little bit out of sequence, but this will make the rest of the afternoon, I think, flow more smoothly. Bruce, would you like to now commence your presentation?

MR McDONALD (ADASA): Certainly. My name is Bruce McDonald and I'm the secretary/treasurer of the Attention Disorder Association of South Australia. This is a presentation obviously to the Productivity Commission re the National Disability Insurance Scheme and the case for including ADHD. Firstly, may I echo the sentiments of the whole disability sector and community to note that it is imperative that we as Australians support the establishment of an NDIS. I would like to echo a couple of earlier speakers. Rob Williams said - and we endorse his eloquent, all-encompassing presentation, culminating in consideration of outcomes. He also mentioned clinical definition not being included and, in essence, this is the substance of my presentation, I believe.

Tony Kerin mentioned the report relating to mental health aspects. These are extremely causative contributors affecting society. The cliche "Many fall between the cracks" is sadly true in our culture. Then, John, you mentioned the scheme proposed to support early intervention for positive outcomes and we support this goal. It is important, we believe, that with all the evidence available the NDIS include ADHD in their planning to ensure the destigmatisation and support of those afflicted with ADHD, children and adults; to financially support those unable to access services, counselling, remedial education and medication; to support schools and institutions with projects to be educated to assist those individuals in need; to adequately train staff and counsellors to assist ADHD children and parents.

An example in South Australia we have is a school at Hamilton called Flato which encompasses the broad spectrum of disabilities that children have, including children with mental health issues.

MS SCOTT: Could you talk a little bit about the quality of that school? Is that something that you would endorse as a model that education departments could follow elsewhere?

MR McDONALD (ADASA): Say again, sorry?

MS SCOTT: You talk about this school in Hamilton, Flats, that - - -

MR McDONALD (ADASA): Hamilton Flato it's called.

MS SCOTT: Hamilton F-l-a-t - - -

MR McDONALD (ADASA): Flato it's called.

MS SCOTT: I'm sorry, Flato unit, which caters for children with disabilities. Do you find that's a very effective model?

MR McDONALD (ADASA): Certainly as a starting point, yes, because kids with autism, Down syndrome and other needs can be there and they can all get catered for, and at this particular school they had a couple of kids with ADHD as well and the teachers became aware of their needs and were able to cater for these, as they were for all of the other kids with Down syndrome, autism or whatever.

MS SCOTT: Thank you.

MR McDONALD (ADASA): I then say to support and educate Centrelink regarding the need for support for some. ADHD is a really tricky one with Centrelink. As this inquiry is in the context of productivity, it is worth noting that many people with ADHD have difficulties finding and keeping work but, with properly targeted services, their working lives can be consistent and productive. Attention deficit hyperactivity disorder, ADHD, is a common condition that has also been defined in the Diagnostic and Statistical Manual of Mental Disorders which is commonly known as DSM-IV, and in the NHMRC draft documents within Australia and endorsed by the Royal Australasian College of Physicians and other international guidelines within Canada, New Zealand, USA, so it's a worldwide phenomenon, very well known and recorded.

Not every person with ADHD will have all the symptoms, and the severity of the symptoms of ADHD varies. The level of impairment changes between individuals. In addition, ADHD symptoms and severity can change with age. One severe case in South Australia indicates the need for support that the NDIS could provide to overcome the endemic problem, and I quote part of the coroner's summation into the death of Jarrad Roberts:

> The counsel for the department has explained that this new policy -

this was relating to a South Australian one -

> as represented by exhibit C81 will make use of sections 19 to 21 of the act -

and this is the coroner commenting -

> to which I have already referred. There is an irony in the fact that this latest response is nothing more than a recognition by the agencies of the options which have been available at all times to Families SA for early intervention and investigations pursuant to those sections of the act. In effect, the new policy adds nothing to the tools that were always available to Families SA at all relevant times. When I pointed these facts out to counsel for the departments, he responded as follows -

and it is not clear whether this position from the counsel was for Families SA or DECS. The comment was:

> It's a tragic situation and equally so there will be other children who will be in homes and their situation won't come to light, the department won't be there and they will die and that is a simple fact of life.

I was at the coroner's hearing for all of that, so that brought a tear to my eye:

> Counsel said that if Families SA were to investigate every child who is not attending school on a chronic or habitual basis, then it would be unable to investigate child sexual or physical abuse.

The coroner said:

> In my view this response is simply unacceptable. It effectively amounts to a concession that Exhibit C81, the new policy which was proffered as a response to Jarrad's case, is no solution at all. I am left wondering why it was produced in the first place.

NDIS inclusion of ADHD is imperative to us to help solve associated problems, to assist people with ADHD and prevent further situations like the Jarrad Roberts one. Further deaths are unacceptable. For the majority of people with ADHD, the disorder will persist through childhood into adolescence and adulthood. This NDIS inclusion and assistance is imperative to offer these sufferers a normal life. ADHD is a disability. If undiagnosed or inadequately managed, it can be a handicap, but if NDIS includes it in the documents, treatment will result in early intervention and positive outcomes to reduce the likelihood of it being a handicap through whole of life.

It is in this way similar to autism and, like autism, is a disability that deserves to be included in a national disability insurance scheme. It would be positively supportive if the NDIS included ADHD within its support proposal, because the actual percentage numbers within the community treated is around 1 per cent, with the real percentage in the community who suffer between 9 to 12 per cent, and productivity in the community can be improved if this group receives assistance.

The adverse outcomes without assistance: these include academic underachievement, difficulties with interpersonal relationships, low self-esteem, all of which have potentially serious consequences for the individual, and the flow-on effects of ADHD can have significant impact on families, schools, workplaces and the community more broadly. The inclusion of ADHD in the NDIS and the resulting support would assist with and encourage best practice by professionals and teachers, improve the following and the associated productive outcome: parents and school-age children with educational problems and academic problems. Compared with non-ADHD children, many have poor results in reading, spelling, maths, and have to repeat classes or require remediation and tutoring to improve their self-esteem.

Improved relationships: they have fewer friendships, often poor relationships with parents and siblings. Their inattention may affect perception of social cues. Hyperactive and impulsive behaviour often results in social rejection by peers. By inclusion, it would help reduce accidents, reduce injuries as a result of impulsive behaviour. Obesity will be reduced by education. Then improve the medical assessment, workplace issues, substance abuse, reducing crime which I believe is significant. In Australia and elsewhere markedly more ADHD people are placed on community orders in juvenile justice centres and in prisons. This needs to be addressed, and NDIS could assist.

One source in SA, a gentleman by the name of Aldis Putnins, has written papers on this subject and is an internationally recognised expert. The predictions would be reductions of 35 per cent plus of prisoners with ADHD who would be incredibly productive and save massive dollars if they were back in the community. This saving could be reinvested in the community productively.

The personal experience of ADHD: general incidence of anxiety, mood disorder and eating disorders. How would inclusion within the NDIS assist the management of ADHD? Individuals with ADHD and their families and carers would be provided with information and education about ADHD, its impact and the advantages and disadvantages of potential treatment strategies. ADHD is not covered by the public health system after 18 years old - it's covered by the public health system up to 18 years old - leaving only private psychiatrists, who charge between $250 and $550 a visit. The majority don't bulk-bill. Not all medications are covered by PBS, unless adults were diagnosed before they were 18. It is a whole-of-life condition. We believe this should be corrected.

Multimodal therapy for the treatment of ADHD in all age groups: NDIS must include medication, behavioural therapy and education interventions as defined in the federal government NHMRC Guidelines Research Program - GRP - that supports the development and maintenance of high-quality clinical practice guidelines and evidence based products and defines optimal treatment for ADHD as a combination of medication and behavioural therapy, which should be funded by the NDIS to help people.

MS SCOTT: Can I just ask a question there, Bruce?

MR McDONALD (ADASA):   Yes.

MS SCOTT: Do you mind if we just interrupt your presentation for a bit. What is the rationale for the public health system not continuing to pay for therapies after a person reaches 18 years of age? What's the rationale they give?

MR McDONALD (ADASA):   I think it's fairly simple: that a paediatrician treats a child up to 18 and then a psychiatrist takes over from 18 on. The only thing you can get is if - you can tweak the system if the child continues education after 18 - let's say university; you can tweak it up to 24 under a paediatrician. But it's this paediatrician to psychiatrist link.

MS SCOTT: Okay.   And the treatments that a paediatrician would give to a child with ADHD would be cognitive therapies and, in some cases, pharmaceutical treatments?

MR McDONALD (ADASA):   Yes.

MS SCOTT: I know you're a layperson, but from your reading what's the evidence that those treatments are effective in reducing the level of impairment suffered by someone who has ADHD?

MR McDONALD (ADASA):   Again from a layperson's point of view - because, again, as an association we very clearly don't present ourselves as the experts.

MS SCOTT: Yes, I see that.

MR McDONALD (ADASA):   But from a hands-on experience of kids by the dozen, and I deal with seven a week phone calls - my best example is either an adult who was diagnosed at 46 and a 67-year-old lady who was diagnosed, that each of those rang me back again once they got onto using, in this case, dexamphetamine, and they said, "I can suddenly see the wood for the trees." The change is immediate in terms of their normalisation. Therefore a child, if the diagnosis is correct - again, I've seen numerous children who were disruptive, inattentive and all of that list of things - the medication works within half an hour. And if they get the right mix of medication, usually three times a day - morning, lunchtime and afternoon - they can basically be normal.

MS SCOTT: Okay. If that's the case, and it can be treated in many instances with pharmaceutical treatments, why would a person need to be in the NDIS with an individualised package over a long term? I mean, compare that to someone with significant physical disabilities or someone with significant intellectual disabilities. If this can be successfully treated with pharmaceutical treatments, why do they need to be automatically in the scheme?

MR McDONALD (ADASA):   I think we would like to see that ADHD is at least recognised so that it can be acknowledged and included. Currently it's not included anywhere. It's a difficult one. As I said, only 1 per cent are treated.

MS SCOTT: But in the public health system, you've indicated that - - -

MR McDONALD (ADASA):   Yes, but it's still got to be recognised. Very few GPs, very few specialists - I'll get to one other thing in a second, but it's difficult to find specialists or GPs who even understand it, let alone deal with it. So again, like the national medical registration system, that that links into the NDIS scheme, I believe, such that there's an education program to go on. We would hope it would get included in the NDIS so that it becomes part of this national recognition.

MS SCOTT: There are all sorts of ways it could be recognised. One of the things that we see as important is that people can be referred to the right sources of help. It might be a peer support group for some people. Somebody might be looking for assistance with budgeting. Other people might need assistance with decision-making. Some people might have a significant disability that needs an individualised package. If people were referred to units within the public health system that dealt with autism, if people got diagnosed accurately first-off in the health system, would that relieve much of the need that you're identifying in your papers?

MR McDONALD (ADASA):   That's the other end of the rainbow. Yes. Again, I lightheartedly say if I was the proverbial millionaire, we could achieve that.

MS SCOTT: Right.

MR McDONALD (ADASA):   Currently, autism - I can remember doing a deputation to Tim Fischer that did not achieve great success, because Tim Fischer as

Deputy Prime Minister had an autistic daughter and that got through a damn sight faster than ADHD did. The money spent on autism was quite massive. If we could get the same sort of both input and recognition for ADHD then there would be a greater community, clinician and specialist recognition, whose outcome would be of benefit to the people who are sufferers.

MS SCOTT: I'm conscious that we've probably got about another five minutes of your time. John and I have both got your written paper, so don't feel you've got to read every word of it. Just looking down the rest of your points, are there some key points that you want to include that we haven't addressed in our report that you'd like to see included?

MR McDONALD (ADASA): Yes. Out of those, I'll rip down that page and assume you can read that. Stigma: there is a high degree of stigma associated with ADHD, which is very sad and it's resulting from a public lack of understanding of ADHD. I believe the NDIS could assist with community education to reduce the aggravation the handicap creates for the individuals, their carers and families. I haven't put that in there but I have put it as a PS, because there's a false stigma because the medication has an amphetamine base. But a clinician's comment to me: for a child's dose of one per day, you would have to take 200 dex, or for an adult 500 dex, to equal a street dose of speed. There's a misnomer out there, but the media keep jumping on this and that really makes it very hard for ADHD people to succeed.

Public understanding, I think, is the biggest thing. You know, we're battling to succeed. One of the successes we had, we've been working for the past year and a half with the Royal Australian and New Zealand College of Psychiatrists and in 2010 succeeded in getting ADHD in South Australia at the Uni of SA as a one and a half hour lecture in the first year of the uni course. It's reinforced in the second year. That won't hit the streets for five years, but we have been part of starting the process of improvement. Things like that are little steps, it's little building blocks. I guess that's why I'm here today to try and tell it. Here's my story. If there's any way any of it can be included, then it becomes part of the building block/stepping stone to improving the situation.

The most amazing one to me is when you read all of the international data on how many people are in gaols who are ADHD because they never got treated. You get the Mark Spitzes of the world - and I'd love to quote. There's a book Start Small Finish Big written by the guy who started Subway. It has 25 other businessmen who again are trillionaires - the typical American story. What's critical is that five of these guys are ADHD bipolar. One of the things they each say is, "Without my mum's support, I wouldn't have got through school."

That again is sort of a silly, emotional comment, but it means that that's okay in their case. But we have situations in South Australia where every day I deal with people - east, west, and our majority of callers come from the south - because they are relatively comfortably-off, fighting, battling people, who are surviving, with two working in the family. But the north of Adelaide, which is the Housing Trust type income, I get a lesser number of callers because they're less educated, they're less persistent, they're less pushy. They don't get a lot of support from the schools, from the local area and community. We want to put an equilibrium in there.

MS SCOTT: Yes, fair enough. John, are there any questions you've got for Bruce?

MR WALSH: Just one, really. Bruce, I think you've made a very clear case of the need for appropriate support for ADHD. It sounds like the need for support is mainly met by medication. I'm wondering, what is it that the NDIS could provide to those people who need more than medication?

MR McDONALD (ADASA): We've just recently got a grant for 13 grand from the community support system to set up a support group; we really need $100,000 to do it. We're setting up a model for support groups in South Australia. That is one of the greatest needs: to support the mums with kids, all the way up to 18; generally mums, but a few dads in there. We need a support group network so that people can network and just understand their situation, talk about it, work out what they do next and swap stories. That would be really valuable. So the medication support groups.

I don't know how we're going to do it, but we've got to try and get the government to educate their teachers. You can find aware SSOs and teachers around but, out of the 720 schools in South Australia, I have 12 on the books.

MS SCOTT: 12 of them?

MR McDONALD (ADASA): 12 schools who are aware of what they can do for ADHD who have inquired about it, got all the data and everything. They all know we exist because I've written to them all, but the response is 12 out of 720.

MS SCOTT: Yes, I understand.

MR WALSH: I've just got one more question.

MR McDONALD (ADASA): Yes.

MR WALSH: Very early on in your presentation, Bruce, you mentioned I think it was Hamilton Flato School?

MR McDONALD (ADASA): Correct.

MR WALSH: It sounds like a school that specialises in a variety of types of disability.

MR McDONALD (ADASA): Yes.

MR WALSH: We've heard in other places that the approach for kids with disability is to try and stream them into mainstream schools wherever possible. Do they go from Hamilton Flato into mainstream, or is it - - -

MR McDONALD (ADASA): No. When they get to Hamilton they've usually come from not fitting in in a mainstream stream.

MR WALSH: Okay.

MR McDONALD (ADASA): Very few leave. Hamilton, to me, is broken up into three sections, basically - and don't quote me. In a sense, one section is fully disabled people who are two-to-one ratio care; the middle section, which are quite in need of mental support, et cetera, and medication and physical support in terms of washing and cleaning, et cetera; but the other third, which is slightly above a third, are kids who can participate in educational activities but at a lower level than the age group of which they are. They tend to be, as I said, autistic, Down's, Asperger's, bipolar, ADHD, et cetera.

MR WALSH: How many children are at the school?

MR McDONALD (ADASA): 60, 70, but there would be 12 or so in the higher-need ratio, 15 in the middle. That's 30. So you've got 40 in the top section; two classes of 20. That's roughly.

MR WALSH: Is that the only school of its type in South Australia?

MR McDONALD (ADASA): No. I think there are a number of others. It's just one of the ones I know because I got involved in that. I was on the school council for Hamilton as well as Mitcham Primary. When we heard earlier on from Novita today, the principal and I at Hamilton observed something that didn't occur there that occurred at a normal primary school, which is a silly example of mums and dads networking, when they meet kids out of their class and pick them up. At Hamilton they don't because everybody comes in by taxi. So we used to invite the mums in once a month for a coffee. Out of that, we tried for funding for an out-of-school-hours care program. We didn't get it. The next year, with Novita, we got an out-of-school-hours care program for the school holidays only, so we've had a win there in support for these people - more for the parents, frankly, than the kids.

MR WALSH: Thank you.

MS SCOTT: Bruce, thank you for coming along today.

MR McDONALD (ADASA): Okay.

MS SCOTT: Thank you for your testimony.

MR McDONALD (ADASA): Can I finish with one little thing?

MS SCOTT: As long as you keep it to a minute.

MR McDONALD (ADASA): One of my best examples is, I use the word "maturity". When people get to a mature age - ie, that could be anything from 18 to 30 - there are a number of ADHDers who, when they get to that age, can actually work themselves off medication by education and choose meditation or their own therapies. So there is a future for people like that sometimes. There's a positive end to this story somewhere along the line. Thank you for listening, very much.

MR WALSH: Thank you.

MS SCOTT: Thank you for your time. John, we might now go to afternoon tea. We're going to resume at 3.20, but can I just check. Is there anyone that is not on our official list who does want to speak this afternoon for a few minutes because they've been here listening to other people present today and want to take the opportunity to present? Is there anyone in that group? Okay. When we resume this afternoon at 3.20 we'll be resuming with the Community Support Inc. They will be first on. Thank you very much.

MS SCOTT: Good afternoon. We're now resuming our hearings and we're going to be hearing from Community Support Inc. So thank you very much for attending the hearings today. Thanks for coming along and as soon as you're ready, if you could identify yourself for the transcript, please, and just commence your statement. We've allowed 30 minutes for this presentation but please expect some questions from John and me.

MR GILLAN (CSI): Thank you. May I call you Patricia?

MS SCOTT: Yes, please do.

MR GILLAN (CSI): Okay, Patricia. My name is Brian Gillan. I'm the former, recently retired chief executive of Community Support Inc, and on my left is the chairman of Community Support Inc, Mr Phillip Beddall. I'm presenting our submission today because I voted. Okay, so ready to start?

MS SCOTT: Yes, please go ahead.

MR GILLAN (CSI): Look, I just want to refer to my notes but just start with a bit of a statement, and that is that Community Support Inc - or we're known mostly as CSI - believe that the current income support and service system is not meeting the needs of people living with a disability and their families. There are still unacceptably high levels of unmet need in the disability community. We agree with the Productivity Commission's findings that this sector is fragmented, underfunded and inefficient, and we therefore commend the Productivity Commission on producing this draft report.

CSI then would ask the commission to consider the following key issues in their deliberations. Primary consideration should be given to the person's living arrangements. Now, we say that because CSI is community based services, so we've got almost 2000 clients in South Australia who live in the community and in our experience we just want to press that point that we think in this draft review we should not lose sight of the fact that we believe that most people, where possible, should live in the community - therefore the preferred living arrangements, as I said. Support should be community based where possible and the disability national insurance scheme should, we believe, provide funding on a range of levels according to the person's care needs and not based on funding caps.

The system should be easily accessible with easily identified points of entry. Where possible there should be one assessment to avoid multiple assessments. As people age in the disability service system, the system should be responsible for ongoing support at an appropriate level, and certainly we see that in CSI all the time. As consumers get older you get into this duplicity around whether they come under the Commonwealth system or the state system and there's a lot of confusion there. We want to see that standardised and if the consumer is happy with the support, where possible that should be continuing care with minimal disruption.

We believe that the quality of service should be consistent regardless of the funding source, with the use of an overarching quality assessment process. Something that we think is being missed in the Productivity Commission is that there's no standard benchmark of servicing and therefore every state - and in fact, may I say, almost every service - has its own standards. It would be good to see some standardisation coming across so that there's a measurement of quality service. New models of service should be developed in response to changing community and consumer needs and they should be flexible and innovative, tailored to that individual's circumstances, rather than a one-size-fits-all.

Facilitation of continuum of care is seen as a necessary activity in caring for or supporting anyone accessing a community service. It should not be identified as another service type. Consumers should be provided with choice through linkages across residential and community services. We still, unfortunately - at least in South Australia - have a silo mentality around those living in the community and those not. There are different funding arrangements and what we're saying is it should be standardised, so there should be scope for sharing resources across a community centre and community and residential agreements to enhance the quality-of-life and care outcomes for the consumer.

Special needs groups require innovative, flexible models of care, including people with multiple disabilities, Indigenous people, those from diverse cultures and linguistic backgrounds, those living in rural and remote service areas. So in other words we're saying that there should be an individualised, tailored service rather than a standard service that can meet the needs of those consumers.

The key issue that we spent a lot of time discussing is the workforce. The workforce is one of the key issues to quality care services and we believe that staff must be well trained and supported. CSI believe that the consumers should be involved in the training process. Even with credentialled workers there's still often a lack of sensitivity around respecting someone's home or working with that person as opposed to in a residential facility where there are clearly standards, policies and processes and a supervisor. When we walk into someone's home it's a whole different environment and so we think that training in particular enhanced by consumers should be something to be considered.

As we understand it - and there was some ambiguity about this but the report appeared to suggest that government may be the only institution with sufficient infrastructure to manage and operate a national disability insurance scheme. CSI disagrees with that. We believe that the non-government sector, and in particular the not-for-profit non-government organisations, are best placed to provide support services to people living in the community. We understand that government, whether it be federal or state, have every right to set the policies and hold people accountable and set the funding and boundaries, but the actual service provision we believe would be better off provided by non-government organisations.

MS SCOTT: I don't think we're in disagreement there.

MR WALSH: I don't think we've got any disagreement with that.

MR GILLAN (CSI):   There is a section in the agreement that made the statement that government are best placed to provide the services because no-one else had the infrastructure.

MS SCOTT: If you can find us the reference we'll correct it.

MR GILLAN (CSI):   Okay.

MS SCOTT: But I assure you we have plenty of other places in the report that we indicate that services should be provided by a range of organisations. They may be government operations but they can also be non-government organisations and they can be - in fact probably the easiest place to see it is on page 32 in the overview. I'm happy to show it to you but I think it quite clearly shows that we envisage that there are all sorts of people providing services.

MR GILLAN (CSI):   Sure. If I may take you up on that, can I write to you with chapter and verse with that one?

MS SCOTT: Yes, that would be good. We did only think of one sort of service where it might be the case that it had to be operated by government, and that was services for people with very challenging behaviour, almost forensic needs; people where it might be the case that we thought it would be difficult for those services to be provided by NGOs. But since we have written that, we've visited Tasmania, and in Tasmania all the services are provided by NGOs, including high-level care for people with very challenging behaviour, two on one, 24-7 - people, as I said, bordering on forensic needs. If you've found more references I think - - -

MR GILLAN (CSI):   Okay. I think it's relative to the earlier point you made.

MR BEDDALL (CSI):   I think the fear is it doesn't matter who provides the service, as long as it's not the one agency providing the whole-of-life service, that it's not the one agency being the landlord and the service provider, that there is choice and the consumer isn't trapped in this sort of service provision where they only have one service provider, that they do have real choice.

MR WALSH: I hope the message has come across that the report is all about choice and you need have no fear of that.

MR BEDDALL (CSI): Yes.

MR GILLAN (CSI): Thank you for that. A point we'd like to just raise is we believe that the national insurance scheme, the actual name, is confusing to lots of people. If you consider in particular the National Injury Insurance Scheme, it's set within an insurance-type context around someone with an acquired injury through a motor vehicle accident or whatever. People understand the insurance context but to apply "insurance" to a national scheme we think is ambiguous and we'd ask the commission just to consider that. It almost in some areas smacks of the insurance stamps that you would get in some countries; it smacks of almost a welfare-type service. We understand that's not what it's meant to be but the name "National Disability Insurance Scheme" - - -

MS SCOTT: What name would you prefer?

MR GILLAN (CSI): Just National Disability Scheme.

MS SCOTT: Right.

MR GILLAN (CSI): Keeping "insurance" obviously for the insurance injury but not - - -

MS SCOTT: Can we discuss that, just so we understand each other a little bit more? Are you comfortable with that?

MR GILLAN (CSI): Sure, absolutely.

MS SCOTT: All right. So if I get you correctly, you don't mind the word "insurance" in relation to the injury scheme?

MR GILLAN (CSI): That's right.

MS SCOTT: But you don't like it in relation to the large scheme?

MR GILLAN (CSI): To the national scheme.

MS SCOTT: Right. I just want to establish a bit more, why is it all right with the injury scheme?

MR GILLAN (CSI): Because in the injury scheme there is often an insurance aspect. If someone has a motor vehicle accident and as a result of that they're left with a disability, there's a compensation payout. Whether it's the at-fault or no-fault status, there's a compensable element to that and there's an insurance element to that, whereas someone born with a disability doesn't have that option and the insurance context is somewhat different, we believe. It's just confusing, I think, for people.

MS SCOTT: Okay. Let's see if we can nut this out a bit more, if that's all right.

MR GILLAN (CSI): Yes.

MS SCOTT: Medicare used to have a governing body called the Health Insurance Commission and the reason why it had the word "insurance" in there was because there's a pooling of risk. Effectively there's a pooling of community responsibility and that's a key characteristic of what we're proposing - a pooling, a sharing of the costs of disability, so not all falling on the shoulders of the individual or their family. The other aspect of it is, we want the organisation to run to insurance principles. For example, it would look at the lifetime opportunities of the individual and look at the long-term liabilities, costs. It might then decide instead of something costing $5000 - and that isn't that impossible because of an annual budget - you might say, "Actually $30,000 of vehicle modifications might exactly be the right investment because we're going to take an insurance perspective," and an insurance firm would be prepared to invest up-front if they knew that there was in fact a better outcome and lower costs in the out years.

So we want this to be insurance because of the fact that it involves all the community, everyone is covered like Medicare and it has community pooling of shared responsibility, and it would operate with insurance characteristics. John, have I forgotten anything that I should add there?

MR WALSH: I think the other one, Patricia, is the prudential governance of it.

MS SCOTT: Yes, good point. The whole governance operation would reflect insurance principles. Would you like to speak about that for a minute or two?

MR WALSH: Yes. Phillip and Brian, the notion of insurance and in particular long-term insurance is that the scheme monitors the inputs, outputs and outcomes very closely so that it can make sure the insurance scheme is sustainable. Even though we're proposing that the funding of this - the national scheme is funded from consolidated revenue - because it's an entitlement scheme we feel very strongly that the sustainability of it depends on strong governance. The examples of that sort of governance are found in insurance systems.

MS SCOTT: We've also been thinking about why the disability sector is so underfunded now, so fragmented, and I think the fragmentation comes from the fact that autism is the order of the day, the celebrity concern, and there's an autism package and then something else happens and there's a package for that, and then something else happens and there's a package for that, so it's highly fragmented. We also think because people think disabilities affect someone else, not them; whereas if you actually use the words "national insurance" everyone has a buy-in, effectively. Everyone is covered. So while I see on one hand the point you're making, that's the arguments we've thought about on the alternative side.

MR GILLAN (CSI): Yes. Thank you, John and Patricia, for explaining that. Look, I really do understand the concept and the principles behind the early intervention and the need to get good resources in, and very quickly. In a past life I used to manage the state government's brain injury services and I worked with insurance companies and spent a considerable amount of time in the Transport and Accident Commission in Victoria, so I do understand the principles. The point I was simply trying to make is that some people - and in North American countries, or in some states, you pay welfare insurance stamps. In the UK you used to pay insurance stamps and it just smacked of the duplicity or the ambiguity between a national insurance scheme and a national disability service. All we wanted to do is point that out to see if you've heard that from anybody else or if you think it's relevant to the discussion. I don't want to be pedantic about it because at the end of the day it's about getting a good service.

MR BEDDALL (CSI): There is the broader issue around community education and, given the discussion that we've just had, it does show that there is a difference of opinion around that issue. It may be a lack of understanding of the community as to what we mean by disability insurance, so we need to think about how we sell this to the broader community and also how we sell it to the political masters going forward.

MR WALSH: Yes, that's a good point, Phillip.

MR GILLAN (CSI): Look, we've only got one more point to make and that is that the report recommends the establishment of a new independent agency, which we think is great, to run the National Disability Insurance Scheme. We just wanted to make the point that we would hope that people with disabilities would be included on the executive of such an agency. It just speaks to full inclusion and appropriate representation.

MS SCOTT: All right. Thank you very much. John, do you have any questions?

MR WALSH: The main message is about community support, community integration, I think. Is that a fair takeaway?

MR GILLAN (CSI): Absolutely, and flexibility in choice for those people living at home.

MR WALSH: Thank you very much.

MR GILLAN (CSI): No, thank you. Phil, have you got anything?

MR BEDDALL (CSI): Yes, the final comment I wanted to make was around the transitional arrangements. There are a lot of people in need now and four or five years is a long time away. We've got the pilot process that you've recommended that will be going through. We've got the target groups that you've highlighted and I have no problem with that. They're the right target groups to start off the scheme. But we do need to think about the transitional arrangements and dealing with the unmet need that exists now.

MR WALSH: Wheels of government turn slowly, so it's what's achievable, I think.

MS SCOTT: Yes. We have already in the draft report suggested that governments will need to increase funding in the interim, but there's a lot of complexity associated with transitional arrangements and we won't be able to nail them all down because we just don't have the time. But they're good points that you make, so thank you for that.

MR BEDDALL (CSI): The other point of support is for the Commonwealth to take more responsibility in delivering disability services. State governments will still have a role to play, but in terms of not being hampered by state borders and not having to leave your wheelchair or your equipment at the state border, or being able to move interstate and take your service away, is something that needs to be encouraged and strongly supported.

MS SCOTT: All right. Thank you. That's a good point. Thank you, gentlemen. Thank you very much for coming along.

MR GILLAN (CSI): Thank you very much.

MR BEDDALL (CSI): Thank you.

MS SCOTT: We now invite Antoinette, please.

MS EDGINTON: Good afternoon.

MS SCOTT: Good afternoon. Just for the transcript could you state your name, and I understand you're representing yourself or your family. Is that correct?

MS EDGINTON: Yes, but I'll embark on that. Antoinette EDGINTON. I'm a carer for two in my domestic situation, but I have also had and try to do as much as I can for various community organisations and government bodies and so forth along the way.

MS SCOTT: All right. Thank you. Well, Antoinette, would you like to make a statement.

MS EDGINTON: Yes.

MS SCOTT: And then we might ask you a few questions.

MS EDGINTON: Probably questions will come eventually. I'd like to put the point of being a carer, and then the carer of generations that are involved, or more than one person in a domestic environment that somebody is caring for. I mean, it is not uncommon to have two autistic children in a family, even three, and that makes an enormous pressure point for somebody that's looking after that family, and I don't have to go into the figures but, generally speaking, in two-thirds of those cases there is only one person in that family left to care for those people.

My immediate experience is dealing with the age of one parent and the age of a child, and the differences. I just happened to marry a man who is 17 years older, but this is going to eventually come in, because he was 50 when our child was born with a disability, and with parents having children later in life, it's going to become more of a problem. It was not fine, but it was manageable when the two of us were there to care for the child and to bring up other members of the family, but once my husband became, as well, needing full-time care, then it became an enormous problem.

Within that family - again, if you've still got the family intact - your other children still have their lives and their futures and therefore their own families to look forward to, and therefore they can't always - which is what everybody asks you: "What family do you have? What support can those family give you?" Well, that's not always possible. There can be distance. There can be young children that they are also bringing up.

There's a very big factor in the aged parent, and if you're looking at just one disability area, it is the growth, for instance, in younger onset people with dementia, and that onset comes within the middle of their growing family. One of the points in that diagnosis is that it is very common that that family can lose their home because, for instance, if one parent was the carer of a disabled person they might be providing perhaps a smaller income or a part-time income.

But the person that is having the early onset dementia is a much younger person. They are not 65 and retired. They are still in establishing their family and their family home and therefore it is devastating. You've got to then deal with the financial circumstances of what the consequences are. And people only think that dementias occur in older people. That is not the case in this day and age. But there are also many other areas of disability that can be imposed on a family within that framework.

Then there are the consequences of that generation and the consequences of the disabilities that that carer is then trying to deal with. The consequences of a child is one area, and a child in these circumstances, particularly where there's an intellectual disability, can be a fully grown adult but their developmental age is still only a child and therefore your care still has to be pitched at that level; whereas your spouse, male or female, you need to respect their disability. The conflicts that occur in that disability are enormous and huge: behaviours, the levels of care that are required, the levels of expenses that are required into that home - and that is an enormous problem, because the carer is not in a position to leave and have full-time work and maintain the family at the same time. The support is just not there to enable them to do it.

MS SCOTT: Antoinette, is it all right if I ask a question or two now?

MS EDGINTON: Yes, certainly.

MS SCOTT: In the report, we propose that assessment be based on the needs of the person with disability and that there be a separate assessment of the carer's situation so that it's not automatically assumed that the carer wants to continue with the care, can continue with the same level of care as they provided or that all is hunky-dory; and, I guess, in our thinking, discussion with the individual, a home visit, the encouragement of a person to fill out a little survey indicating what they want to see, what they're after, all these things would help to establish better the circumstances of the individual. Does that sound fair enough to you? Have you had a chance to - - -

MS EDGINTON: It's just one more form to fill out. Sorry, but yes, I have to be cynical about that. You fill out forms 10 times a week for both of them. I mean, somebody has to, but there's a multitude of those being done, and I think that comes under the splintered skills heading as much as anything else. But you're right. But they also have to take in the progression of that circumstance. When that form is filled in, that might be appropriate, but in four or five years' time that won't be appropriate and there needs to be some acknowledgment - and particularly if you're going to target funds for that person on, say, a five-year basis.

You need to have some form of recognition of where they are going to be, plus where is the carer going to be at that stage? Where is their emotional energy, their mental health, their actual physical exhaustion going to be in that position in five years' time? I'm not against what you're saying. I'm just saying it needs to look very definitely at future requirements and take into consideration that there is a third person in this position.

MS SCOTT: John, do you have any questions for Antoinette?

MR WALSH: No. I think, Antoinette, you made a very good presentation of the complexities that can arise when there's more than one person with a disability in a family and particularly when there's only one carer. I hope that the scheme is equipped, as Patricia said, through its assessment process, to identify these families and provide the support required, but if you've got any other suggestions of things that we need to cover off, please feel free to put in a written submission.

MS EDGINTON: Yes. Thank you, John.

MR WALSH: It need only be a page; just a few dot points making the same points that you made today, I think.

MS EDGINTON: I just think that there's not an age factor in disability, at all, let alone - and I haven't touched on the young person who then perhaps is in a sheltered environment now, or a service workshop, or day options or whatever. What happens to those when you've got perhaps two age groups that are also involved? That complexity is enormous as well.

I think from my angle, and from what I've understood and from what I've heard around the National - we're locally calling it, I think, the National Disability Services, but I understand its insurance aspect. I think from my point of view and from my experience that something has to happen. Something has to happen where there is proper respect within the community that acknowledges and gives dignity to people who have a disability, with the aged person who has a disability, and they're not recognised at all, really, and plus the younger person.

You and I can find ourselves, tomorrow, in a position where we've had a major stroke. It is quite devastating, the difference between you and I who can hold down a job and add to society to all of a sudden becoming the person who is dependent on society, and what you lose in dignity and respect is phenomenal - to all of a sudden no longer have an intellect and a brain, and that's quite often how it's looked at. Your funding in aged care and disability only has three years' funding, five years' funding, so there's no continuity.

I think that the national insurance disability or national insurance scheme has to come in so that, for instance - just one other area that I don't know whether anybody has said is where the parents' main concern about their child all the child's life is, "What is going to happen to my child when I die? Who is going to look after them? Who is going to fund them? What is going to happen?" As it exists today, if you willed that your home remain in that child's name, there is no guarantee that that child will remain in that home. There is no guarantee at all.

If you've got an autistic person that surfaces, and that person has lived in that home all their life, the whole community around them, the whole neighbourhood knows that they're there; rightly or wrongly, or badly or well, but they actually know that that person is there. Once you uproot them - and they've not only lost the parent or the carer that's caring for them, they've also lost the roof over their head - they've lost their environment that they know, and the aggression then sets in. And I don't have to tell you. You must have heard bucketloads about what happens when they hit out and the consequences of that.

Surely to goodness, in some respect there should be some form of continuity. There would be continuity for you and me living in society. Why isn't there continuity for a person with a disability? If the insurance scheme came into effect I think that, from a parental point of view, there would be secured funding, where you should have some more secure knowledge that there is funding and then services supplied after you can no longer do it. Either you've absolutely gone into a nursing home yourself or you have died.

It's very common for an aged parent to die with a disabled child still in their home and that child has never experienced anything else but that environment, and it's devastating to move that person. In this state, if you move that person, there is no guarantee that you can move them into even a proper house with proper care. They could be put into a hostel or a halfway house or a respite care house, and they can live from day to day in something different.

MS SCOTT: Yes.

MS EDGINTON: That, to me, is absolutely despicable. I think there should be some form of continuation in funding that the parent can see. The other thing that's very common in the aged community for this area is, "Well, if put myself to sleep and my child to sleep, then that takes care of both of us." That is a very common way of looking at things because there is nothing out there for them to at least even look at in any of this continuity. I haven't touched on the amount of energy you spend in looking for services.

MS SCOTT: Yes.

MS EDGINTON: Yes, I feel very strongly, in both my years of sitting on the board for IDSC and seeing the number of people that literally landed on our doorstep. We had no idea they were there. We had no idea of the age of the parent that was caring for them, and then the parent just died. This poor child - sibling - was just left absolutely - inability to care for itself. Nine times out of 10 they've actually been their parent's carer because the parent has actually trained them to be the carer.

MS SCOTT: I think there's a clear theme of the complexity in the arrangements and the need for something to be done to address this, and we accept that, Antoinette. The points you make are well made and have been made by a number of people in our inquiry. When you get a chance to look at the report, I think you'll see that we've tried to address the issue of people with disabilities having early dementia in some cases, the issue of complexity in caring arrangements, and the issue of people looking for certainty for their children as they age. I don't have any further questions for Antoinette, John. Do you have any further question? We might wrap up now.

MR WALSH: Yes. Thanks, Antoinette.

MS SCOTT: Antoinette, thank you for coming along.

MS EDGINTON: Thank you very much indeed.

MS SCOTT: All right. Jeff Filsell, please.

MR FILSELL: Firstly, I'd like to thank the commission for giving me this opportunity, as I came in very late on the advice of this event.

MS SCOTT: Thank you very much for coming along, Jeff, and for your interest in this. Thank you also for providing some notes in advance. Would you like to commence your presentation, and I'm sure we're going to have questions.

MR FILSELL: Yes. Thank you. Those that have seen my submission of around three years ago will note that I have concern for advocacy resources in South Australia, or a lack thereof. I guess this is one of the things that has been discussed by the commission. I don't know. I have to plead ignorant to that. But in this state it is a big problem, having timely access to advocacy for severely disabled people in particular, but for any person with a disability.

I've read the terms of reference - only today actually - and I have to say I have some concerns, in that there appear to be limitations as to just who among the sector are going to be eligible and the words "eligible" and "qualified" and so forth are mentioned a few times in there. I guess the fear I have is that the budget, which is headlining in the media at the moment, is talking about severe cuts. They're talking about also people on welfare being asked to work and that is a concern, particularly for those that are unable to work. On the other hand, those who do want to work find it very difficult to impress an employer and they remain on the long-term unemployed.

My concern is that the government will target certain groups and individuals. Will they be the right targets and will the actual reform be effective? I'm not sure if anyone wants to ask any questions at this point.

MS SCOTT: Not at this point.

MR FILSELL: One of the big frustrations is, as I say, the disabled that want to work invariably can't get it, while those with severe cases of individual disability at this particular point in time, I know for a fact, fear that they will be forced to work, and to me that's unacceptable. One of the solutions that I've touched on in my submission talks about the government calling expressions of interest for people with a disability to participate in the decision-making process and in this regard I've made mention of a consumer reference group or similar body, comprising predominantly people with disabilities. This is one of the reforms I would like to see introduced as soon as possible. Can I ask whether the commission is aware of whether the government is going down that path or just where it's all at?

MS SCOTT: Our terms of reference were settled by the government and we've been working on this project now since relatively early last year. The government's budget deliberations are entirely separate from us and we're not party to their work, and our work is independent. Once we're given the terms of reference, our work is independent, but the reason why we released our report is so that individual governments, individual government departments, individuals like yourself, and community groups can respond and we can take those into account.

So we try and do our work in a very open and transparent way so we're not hiding our ideas and if you get a chance at some stage to go beyond the terms of reference and have a look at the report, we'd welcome your comments on the report, up until 30 April. So it's really two separate processes. I'm not able to comment on where the budget process is up to. That's not our process.

MR FILSELL: I've mentioned in my submission about the government acting as a role model for people with a disability seeking employment. I'm not the only one, I know for a fact, that has submitted that proposal. Does the commission have any views on recommending such a proposal?

MS SCOTT: We don't have it included in our draft report at the moment, but would you like to talk about your idea? Basically, you're suggesting that the government has a policy to employ a certain proportion of its workforce with disability - - -

MR FILSELL: Yes.

MS SCOTT: Would you like to indicate, Jeff, what percentage you think would be appropriate and how they would be recruited and retained, and if supports need to be provided? Would you like to talk about that for a few minutes?

MR FILSELL: Yes. At the moment, I don't have any idea what the threshold is - the percentage of disabled people in employment, certainly in the government. I believe it may be somewhere between 2 and 10 per cent, but that's in ignorance really. I'd like to see it a lot higher than that of course; also participation in some kind of reference group that could advise the government in regard to the value that can be added by employing PWDs and just generally how much they have to contribute.

MS SCOTT: All right. John, I thought that was very clear. Is there anything you'd like to ask Jeff?

MR WALSH: No. Thanks, Jeff, for coming in.

MS SCOTT: All right. Thank you very much, Jeff. We're going to have a short break now. We have someone to present after we come back, but we'll just have a break for five minutes now and we'll resume at quarter past 4. Thank you.

MS SCOTT: John, we might resume now. I welcome to the table now Erin McKenzie-Christensen and Jeff Christensen. We have allowed 20 minutes for your presentation and questions. Thank you very much for coming along today. Why don't you commence now? I understand you're representing yourselves in this process.

MR CHRISTENSEN: Yes, correct. Looking at the draft report, there is a minor point I wanted to raise just before Erin starts saying anything. There's a recommendation to amend the Income Tax Assessment Act 1936. This is probably pedantic but it is rather close to my heart. The confusions that relate to taxable income and non-taxable income were actually in the 1997 act.

MS SCOTT: Okay, thank you for that correction.

MS McKENZIE-CHRISTENSEN: This is from my own personal experience. I don't know how to start this. Basically, a few weeks ago I was talking to Women With Disabilities Australia, of which I'm a member. I was just talking to them about something that happened, wanting advocacy support and they asked me to write a story for their newsletter, which is what I gave you. I'm going to give you the shortened version of it because it's quite long.

In 2006, I lost all of my hearing on one side and partially in my right ear. I was a musician so this was kind of pretty devastating. Through one thing and another, I went to Hearing Solutions, which is within Guide Dogs, and was able to try a system called an FM system, which has two boxes, like a microphone transmitter and a receiver, and the sound goes to my ear. I just totally fell in love with this. It's meant for conversations and stuff like that, but I just said to the woman helping, "I play viola and violin. Would I be able to use this system with this instrument?" She said, "The only way is to try it and find out." So I did, and it worked and my teacher was majorly impressed because my intonation improved and everything.

Then, as if that wasn't enough, then in 2008, after having an accident in 2005, I was being treated for chronic pain, specifically fibromyalgia. I was taking medications and these medications interacted, which caused this massive reaction, leading to me not being able to walk, leading to rehab, leading to being a wheelchair user. Like I said, this is the condensed version of what's been happening. So I lost all the strength that I had. I couldn't even lift my instrument out of its case. I'm like, "First I lose my hearing, now I can't even hold it up." That's when I approached Technical Aid to the Disabled, who made me a stand which basically fits round my waist and holds up my violin and my viola. I've been using that for the last two years and I was able to continue playing music.

Then, also in 2008 before all this happened, I was a member of the Tutti

Ensemble, and it was arranged that I was going to teach this woman with an intellectual disability violin. Unfortunately, one week before that was set to happen, this interaction happened with my medication and I was just too sick. I was never able to get back to Tutti to teach her. But ever since then, I've really wanted to combine music and disability.

Because before I was a wheelchair user I was actually a support worker for people with disabilities, I started Certificate III in disability studies and last year I actually finished it and I've done music at university, or music within an arts degree at university. So I just really wanted to combine these two fields and form a group, like Tutti, for people with disabilities to play music together, because I sort of figure if I'm hearing impaired and can't hold up my instrument, there must be a way for able-people being able to enjoy it like I do. I'd really like to be able to do this as a volunteer.

You're probably thinking, "This is an interesting story, but what's this got to with the National Disability Insurance Scheme?" But what I was sort of thinking was, on top of all this - and this is a bit of a confusing story, but basically within Domiciliary Care at the moment, I'm trying to get into Disability SA, and I don't really have the supports that I need to be able to do this music ensemble. This is what I really want to do - and talking about participation in society, going to work or volunteering or whatever, and I can't do it because I don't have the support to do it.

Amongst other things like personal care and a new wheelchair and whatever else, it would be really nice to have support to be able to participate in the community like that and to be able to fulfil my dream. That's the beginning. Then we wrote a submission on different points of the thing.

MS SCOTT: Good, thank you. John, do you have any questions for Erin or Jeff?

MR WALSH: No. You've had a rough few years, clearly. It's great to see you've made this new career, Erin. I'm interested to hear more about how it's going.

MS McKENZIE-CHRISTENSEN: How it's going? What, the process of it starting? Sorry, I'm a bit deaf, so I can't hear what you're asking me.

MR WALSH: You said that you've become passionate about music and disability and I'm just wondering if you've got any plans for how to put that into action.

MS McKENZIE-CHRISTENSEN: How was - - -

MS SCOTT: I think John is keen to find out how you propose to proceed with your ensemble work and how you propose to - - -

MS McKENZIE-CHRISTENSEN: How do I propose to do it?

MS SCOTT: Yes.

MS McKENZIE-CHRISTENSEN: That's a pretty good question.

MR CHRISTENSEN: She's already looked into the possibility of venues, looking at other teachers, considering the problem of finding support workers for - well, hopefully not so much for herself but for the students.

MS McKENZIE-CHRISTENSEN: For me as well.

MR CHRISTENSEN: Obtaining instruments to learn on, all that kind of thing. So we'll start on a small scale, I would expect, probably in a community centre fairly close to home.

MS McKENZIE-CHRISTENSEN: Yes, I was looking at a community centre that's only 750 metres up the road on my street, so that's not too far to go, and I was hoping to sort of run it as mostly a volunteer because I know that people with disabilities don't have a lot of money, so they can't really afford to buy an expensive violin or something. I'm hoping that maybe a music store or something might donate instruments that we could use, something like that, and, like Jeff said, definitely involve other string teachers and that sort of thing.

I guess the thing that's putting me off at the moment is that I'm, for want of a better word, fighting to get a new wheelchair. It's taking up quite a lot of time with all the emails back and forth, and kind of, yes, trying to get more assistance at home. I think once that happens, it will be much, much easier to be able to start thinking more heavily about this. And I guess my doctors are still in the process of working out what's wrong with me, for want of a better way of putting it. They think it's genetic but they're not quite sure.

I'm sort of a bit cautious to start too many things at once, with so many things going on, but once all those work out, I would love to do this. I would so love to do this. But yes, like I said, I just need the support to be able to do it. I'm hoping to start with maybe three or four people or something, but sort of build up big.

MS SCOTT: Okay. Jeff, you've obviously very carefully looked at the recommendations in relation to the tax changes. Is there any other comment? We have taken down that correction. I'll get you to give it in writing, just the change of the act, please, to Dominique, who should be just outside the door. But is there any other aspect of the draft report that you would like to comment on? We're only three months away before we have to finalise it, and you've obviously had a look at it. Is there any other issue you'd like to raise with us?

MR CHRISTENSEN: There was a point - I think it was page 12 - where it referred to people who would be better looked after within a normal health system. Now, it gave an example of people with musculoskeletal conditions. I think we have to be careful that each case is looked at on its own merits, that we don't just say, "Musculoskeletal problem, therefore that means the normal health system, therefore we don't want to know them." I mean, anybody who's in a wheelchair probably has some kind of musculoskeletal thing because if their skeletal muscles worked the way they were meant to, they wouldn't be in a wheelchair. But there are many causes of that, and that's the kind of thing we have to consider, not the ultimate symptom.

MS SCOTT: Okay.

MR WALSH: I think that's a good point. Just for the record, Jeff, there are many tens of thousands, probably hundreds of thousands, of people who report as having a musculoskeletal health condition but only a small percentage of those would be those you've described, and if they satisfy the core activity support needs they would certainly be eligible for the scheme.

MR CHRISTENSEN: I'm sure it's important to stick to the principle and not blindly follow this particular example. If care is being taken in that area, that's exactly what I'm aiming for.

MS SCOTT: All right. Are there any other comments you want to make on the draft report?

MS McKENZIE-CHRISTENSEN: Yes. We've got a written thing as well.

MR CHRISTENSEN: We should possibly avoid using terms like "serious and profound" because they relate, I believe, to the severity of a particular condition and what we're talking about here is a need. If you need something, you need it. I don't think it should necessarily be put into a particular classification of severe or profound.

MS SCOTT: Okay. Well, I think we're in agreement with that.

MR CHRISTENSEN: Yes.

MS McKENZIE-CHRISTENSEN: I know there was some kind of choice about this or something, but I think somebody else mentioned it earlier: if you have a disability, it doesn't really matter what age you are, and I don't think there should necessarily be a switch so that when you get to 65 you automatically go into a different system. If you've got a disability, you've got a disability. Perhaps if you're over 65 and then get a disability it might be different, but it's not really that much different, to me, and it might just get a bit confusing.

MS SCOTT: Okay. Just for the record, because other people will read the transcripts and I don't want people to be confused: Erin and Jeff, what we're suggesting there is that if you're already in the disability sector and receiving individualised packages you could choose at pension-age which system you want to provide for your services, but we think that the funding should come from the aged care sector. We had an alternative option, which is this joint funding, but that does become more complex because you actually have to assign cost: is it because someone is aged and frail or is it because someone has a disability? So that's a very difficult assignment task.

The government gave us our terms of reference and they talked about non-ageing-related disability, so that's why we have the age sector and the disability sector. Certainly we've heard today from a number of speakers, and during the break someone also spoke to me, John, about their concern about the age sector being distinct from the disability sector. This is a very problematic issue. Some people have said to John and me that the cost of this scheme is considerable but, of course, if it encompasses the whole age sector it's an even larger cost. It's certainly a cost that exists now, but it's an even larger cost, and it means many, many, many more people in the scheme, so economists think about things like diseconomies of scale: when something becomes so large, it gets to be so complex that it's hard to manage.

So I can see why people are looking for a seamless arrangement and no distinctions, but the distinctions exist now and it would be certainly a difficult issue, I think, to come up with a feasible, cost-effective arrangement that covered both the aged care sector and the disability sector, but if someone does have an idea about how that could be done, we'd be all ears, wouldn't we, John?

MR WALSH: Yes.

MS SCOTT: All right, Erin and Jeff, any more? You seem to have quite a few pages there, so maybe I should get you to list your points and then we could discuss the ones we need to.

MR CHRISTENSEN: A question of whether an independent assessment is actually required: I think I can see where you're coming from. You want to have a uniform level of assessment and you don't want Dr How Long who gives people what they want whether they should have it or not. But I think generally the - I guess I'm talking about the Tax Office again. We have a network of tax agents and this seems to work fairly well with them. They've got standards they've got to keep to. If you get a particular pattern of results - for example, with taxation if there were a lot of people claiming $299 worth of deductions - - -

MS SCOTT: Work-related things.

MR CHRISTENSEN: - - - because below $300 the Tax Office didn't necessarily check them, and that can be picked up. So I think it would be a lot easier, in my view, to have a larger panel of specialists. I'm saying specialists are fairly rare anyway, and it's very difficult and very time-consuming to get in to one, so I think a larger panel with the appropriate safeguards is better than necessarily a small one, so you can actually get to one. Sure, that increases the chance of non-uniformity and even fraud, but I think that's a risk that has to be taken and mitigated rather than avoided altogether.

MS SCOTT: Your next one?

MS McKENZIE-CHRISTENSEN: This is one thing that's actually happened to me and I find it kind of interesting in a way and I wonder, if there wasn't an NDIS, whether this would maybe solve this problem. You're talking about an independent assessment but I just find it interesting; if somebody already has a physio or occupational therapist or something like that, would they be able to use their own to have an assessment for a wheelchair or something like that instead of having to use somebody in particular? With my wheelchair I've actually got three people that are doing this assessment. I've got my private physio, the person from Domiciliary Care and the person from the Department for Families and Communities wheelchair thing. There are actually three separate people who are doing the same thing. I think it's kind of a bit like a double-up in a way.

MS SCOTT: Yes, it sounds like duplication.

MS McKENZIE-CHRISTENSEN: Yes.

MS SCOTT: What we're suggesting in here is that you would develop a plan, a suggestion of the size of the package you would need and the supports you would require. You wouldn't have to put dollar signs next to it but you'd say something like, "I need 10 hours of attendant care, I need a wheelchair, I need taxi vouchers," or, "I'd like car modification. My therapist suggests that I need so much therapy," and you'd write that down. You'd contact the NDIA, someone would pay you a visit to talk to you about how the scheme works, then there would be an assessment. You'd provide some information to the assessment process - like, for example, some information that you already have at hand on your medical assessments which already exist. I'm sure you've got medical assessments up to your eyeballs, Erin.

Then there could be the short form or the longer form of the assessment process. If it's clear that there aren't many questions about your assessment and you're very clear with what you want then I guess that can be a straightforward process. If it's a case where someone is not too sure what they want - they might have only ever been in a system where services were given to them, no-one ever asked them if they're interested in music or they're interested in working or they're interested in volunteering for something. But if you're very clear in your mind what you need, if you think there is material to support those needs, in the sense that you know exactly the sort of wheelchair you need, then the assessment process would result in an agreement being reached with you about the package.

The NDIA would assign dollars to those needs if they thought they were right. They could always go back and talk to your OT or your physiotherapist just to clarify anything, and dollars would be assigned to those needs, and within some areas you'd have a lot of flexibility, so you might end up saying, "Well, I know I said I wanted 10 hours of attendant care but Jeff and I reckon actually what we all need is attendant care on Mondays to Thursdays and we'll get by on Thursdays, Fridays and Saturdays," or something. You know, you could work out exactly how you want the package to be. You can then make a decision about whether you want to manage the package yourself. Maybe you'd like that challenge. You can hire your own attendant care workers, you can assign where the money goes, or you might prefer to have a broker do that for you, or you might want to say, "I really love the following four or five services and this is how I allocate funds to those four or five services. They'll provide the attendant care, they'll look after my transport, they'll organise my other arrangements."

Now, you can mix and match between those things, but that's what we were envisaging, so it's not anticipated that the allied health professional in our scheme you would see, Erin, would be an expert in wheelchairs, but they may well say to you, "Gee, an $80,000 wheelchair. Now, why would you need that one, Erin?" Do you understand what I mean? There have to be some checks and balances.

MS McKENZIE-CHRISTENSEN: Yes.

MS SCOTT: But it's not the case that the person seeing you is going to be the prescriber. What they are is someone to make sure that there's some equity and some cost control in the arrangement, that you're getting services that you need and that the assessment is forward-looking. So if it is the case that your circumstances change and your needs change then someone has been thinking about that, including you have been thinking about that. So that's what we have outlined in the report.

MS McKENZIE-CHRISTENSEN: Yes, that's amazing if something like that would actually exist. That's like a dream.

MS SCOTT: The point we make is that a number of states have tried individualised funding packages. They seem to be working very well. We received a number of submissions on them. They seem to be working well in other countries and we think they could work very well here and they make a huge difference for people because, rather than services determining what you get, you would have greater control in determining where you get your services from and have more choice.

MS McKENZIE-CHRISTENSEN: I definitely support individualised funding. It sounds very good.

MS SCOTT: Okay.

MR CHRISTENSEN: Is there any indication as to where the caring staff will actually be coming from? It seems at the moment that Dom Care or Disability SA contract out to a lot of minor agencies, smaller agencies, because they don't have their own staff. Is it envisaged that it will increase the number of staff? Obviously it seems that if you go - well, if there is competition then if you have people from lots of agencies they've all got their own administration costs and all their own overheads. That's got to be a cost in itself. So is the NDIS talking about getting its own staff in that way?

MS SCOTT: No, we are not envisaging that the NDIS have attendant care workers themselves, although John is interested in like an emergency sort of an arrangement where if it turns out your attendant care worker doesn't turn up there's some backstop, some emergency arrangement. Certainly we heard in Sydney - John, didn't we - of a scheme that had been operating successfully for 30 years but, again, that doesn't need to be directly employed by the NDIS. We have a whole chapter on workforce issues, Jeff, which is in volume 2 of the report.

In some states they allow for 15 per cent overhead for agencies to NGOs or other agencies to have attendant care workers but we think some people will choose people they know, who they think will look after their needs very well - neighbours and friends, maybe on a part-time basis. We know from surveys of attendant care workers that a lot of them want to work longer hours but just in fact funding blocks them working longer hours. No, we're not envisaging that there will be some grand one scheme employing everyone. We actually think people will probably have more flexibility and more flexible arrangements will emerge.

Just because we've got lots of little retail shops in Adelaide doesn't mean they're necessarily less efficient than David Jones. They actually might be more interested in costs than David Jones.

MR CHRISTENSEN: I see your point. You've heard some ideas about employment and minimum qualifications - indicates a minimum qualification of certificate III. I think that if NDIS were employing people themselves they'd consider a far greater emphasis on training and good attitudes but if they're not employed and it's - I don't think that's really within the scope of the report.

MS McKENZIE-CHRISTENSEN: We only looked at the draft report, just so that you know.

MS SCOTT: That's fine, that's okay.

MS McKENZIE-CHRISTENSEN: I mean the overview.

MS SCOTT: I understand. Everyone is very busy and just don't feel bad about the fact that you haven't got to the 800 pages. Very few people have.

MR WALSH: I don't think many people have read the whole report.

MS SCOTT: Yes. It's okay. You're a rare person if you have, so don't feel embarrassed about that. We might wrap up, though, in 10 minutes, so if you think about any other points you want to make?

MR CHRISTENSEN: No, I think that it's about it.

MS McKENZIE-CHRISTENSEN: No, I think that's just about it. We'll send the written ones.

MS SCOTT: All right. We look forward to getting your submission and Dom is waiting, Jeff, to make sure that we get that act down correctly this time. Thank you very much for coming along today and I know that we dragged you away from work, Jeff, so hopefully the Tax Office won't hold us to account on that. Erin, thank you very much for participating in the process and we look forward to getting your submission.

MR CHRISTENSEN: Okay. Thank you.

MR WALSH: Thank you very much.

MS SCOTT: All right. Well, I think that means therefore that we have drawn our hearings to a close. Thank you very much for participating today. I know that some of you have been here all day, so thank you for your involvement and we look forward to getting your submissions by 30 April so that we can take them into account in writing up our final report. So thanks, John. I'll close the hearing now and we resume our hearings in Perth. Thank you.

MR McDONALD (ADASA):   Before you close, can I thank, on behalf of everybody here - I'm sure everybody would like to thank Dominique for her efficient organisation and efficient ability at resourcing whatever page you wanted to access.

MS SCOTT: Yes. Thank you.

MR McDONALD (ADASA):   And Patricia and John for patiently listening to everybody's submissions and being able to incorporate everybody's passionate ideas. I'm sure on behalf of everybody we'd like to thank you.

MS SCOTT: Thank you very much. I compliment South Australians. I don't think we've ever had that happen before, so it's very nice to have it happen. So thank you very much. Thank you for your time. Goodbye, John.

MR WALSH: Thanks, Patricia.

AT 4.52 PM THE INQUIRY WAS ADJOURNED UNTIL
WEDNESDAY, 20 APRIL 2011