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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

DRAFT REPORT ON DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT SYDNEY ON WEDNESDAY, 13 APRIL 2011, AT 8.59 AM

Continued from 12/4/11 at Brisbane

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MS SCOTT: Good morning, everyone. My name is Patricia Scott. I'm the presiding commissioner for this public inquiry. Welcome to our public hearings today. We are in the process of going around Australia to hear from people. We have been in Hobart, Melbourne and Brisbane, and now Sydney.

You can follow the progress of our hearings by going to our web site pc.gov.au, looking up current inquiries and then looking up Disability Care and Support and there will be transcripts there. Please allow a few days to find today's transcript. Are there any members of the media here today? No. Sometimes there are, and they like to film things and record things. We just need to make sure that we know what they're proposing to do.

There has been considerable demand for people to present to this hearing here in Sydney, so I will be quite firm on the amount of time people have been allocated. John Walsh is the associate commissioner for this inquiry and John will be joining us shortly. If he misses a few minutes of your presentation, please don't be worried, we of course have the transcripts and John can refer back to those.

Under our act you are not required to take an oath, but there is an expectation that you will be truthful in your remarks. Now I welcome to the table the Law Society of New South Wales. We have allocated 30 minutes to your presentation, but please allow some time for questions, John and I might have some. For the purpose of the transcript, could you state your name, please, and then commence with your presentation.

MR WESTGARTH (LSNSW): Thank you, Ms Scott. My name is Stuart Westgarth. I'm the president of the Law Society of New South Wales. I thank you on behalf of the Law Society for enabling us to make this presentation and to make submissions on the draft report on disability care and support. I am accompanied today by key members of the Law Society's injury compensation committee who have a range of personal injury and injury compensation experience.

The committee has reviewed the recommendations in the draft report both from a legal perspective and from a civil rights and social justice perspective. Upon concluding my remarks, I will hand over to my colleague, Brian Moroney, and then to Hugh Macken. Also Geraldine Daley, in the front row, is present. Please note that injury compensation law is not my area of specialty, and if you have any queries throughout our submission I will refer them to one of my colleagues.

We note that those who suffer injury leading to disability are often among the most vulnerable in our community. It is part of the Law Society's mission to work in the interests of the most vulnerable, as is expressed in our motto, which is defending the rights of all. We understand that the Law Council of Australia has already provided written and oral submissions to the Productivity Commission, including submissions on the importance of protecting the common law rights of injured people. The Law Society of New South Wales is the largest member of the Law Council and supports the submissions which the Law Council has made.

What the Law Society can add is a greater understanding of the New South Wales experience and perspective. A crucial element of our submission to you follows from the fact that there are a number of comparisons to make between the recommendations made in the draft report and the existing New South Wales Lifetime Care and Support Scheme. We hope to provide you with insight into the New South Wales scheme and in particular to highlight its shortcomings, so that they can avoided in any proposed national scheme.

The New South Wales Lifetime Care and Support Scheme operates in the context of motor vehicle accident compensation. It is intended to provide treatment, rehabilitation and attendant care services to those who have been catastrophically injured in a motor vehicle accident in New South Wales. The scheme is a no-fault scheme. The Lifetime Care and Support Authority has worked hard to create a system that supports and cares for severely disabled people, and the New South Wales Law Society commends the authority for its efforts. However, the scheme has given rise to a number of concerns and the Law Society has called for reform in three key areas.

First, the legislation under which the scheme operates provides that an application by an insurer for a claimant to participate in the scheme does not require the injured person's consent. This mandatory participation in the scheme reduces the autonomy of the injured person and potentially increases their need for legal advice. When a person is catastrophically injured in a car accident to the point where they require people to provide basic care for them on a regular basis, their autonomy is instantly stripped from them. The injured person may then be forced into entering the Lifetime Care and Support Scheme at the request of the insurer. The New South Wales Law Society supports a person's right to choose. We believe that the autonomy of injured people should not be further eroded.

Secondly, the New South Wales scheme has been set up to limit the involvement of insurers and lawyers. The effect of this is that participants in the scheme have minimal access to legal advice, advocacy and representation. Participation in the scheme is often met with significant decisions and challenges. Participants in the scheme and their families are going through what must be a most traumatic experience in their lives. Injured parties and their families are confronted with complex legal issues. This is often further complicated by various cultural and socio-economic factors. Minimised access to legal representation and advice places the claimant and their family at a further disadvantage.

Finally, the legislation under which the scheme operates allows for limited avenues to appeal decisions made by the scheme authority. The Law Society believes that the legislation should be amended to provide for independent judicial review on the merits. We would therefore propose three broad themes for consideration and inclusion in the development of any national disability scheme. First, that entry into such a scheme should be optional. The autonomy and dignity of people with disabilities should be protected and promoted. Secondly, access to legal advice and advocacy should be freely available and funded by the scheme. Thirdly, all decisions should be subject to judicial review on the merits.

I now wish to introduce my colleagues to you. On my right is Brian Moroney, who is the chair of the New South Wales Law Society subcommittee for this inquiry, who has had extensive experience representing both plaintiffs and defendants in personal injury matters. Brian's specialty lies in the area of WorkCover and workers compensation. Further on my right is Hugh Macken, who is a former Law Society president and is an accredited specialist in personal injury law, having been in private practice for over 20 years. In the front row we have Geraldine Daley, who is an accredited specialist in personal injury law, she is a motor accidents claims and assessment resolution service assessor, and is a former councillor of the Law Society. I am now going to ask Brian Moroney to add to my opening remarks.

MR MORONEY (LSNSW):   Thank you, commissioner. We have considered the brief form of the case management and dispute resolution models which are outlined in section 7.8 of chapter 7 of the draft report. I will essentially be restricting my comments to those two aspects of the scheme, because the broader commentary has already been made by the Law Council of Australia and the Law Society essentially adopts that position. The case management and dispute resolution model bears very close resemblance to a number of injury compensation schemes that already exist in many states and territories.

Consistent with the balance of the initiatives proposed in the draft report, any system of dispute resolution must enhance existing rights and create new rights and not erode entitlements or derogate from the broader objectives of the scheme. It is, in our submission, too easy to assume that these matters can be safeguarded against by employing the right people or having the right guidelines. Arguments to this effect have been proven, particularly in New South Wales, to be flawed. It is important to recognise at the outset that in any scheme disputes will arise, that those disputes will involve arguments addressing issues both of procedural and substantive fairness and law and that all systems of dispute resolution, including that in chapter 7, seek to primarily deal with procedural issues. The challenge is getting the balance right.

It is our position that any proposal must ensure that rights under existing schemes are not diminished or diluted. It is critical therefore that any new care and support scheme has a clear funding stream, which is identified and which ensures there is no risk that existing benefits are eroded. There is, in our submission, no justification for a person to be compelled to participate in a national injury insurance scheme or the National Disability Insurance Scheme and to be prevented from bringing an action for negligence against a party who has caused their injury. These rights should co-exist and there is no cogent reason why they cannot. The concept of double compensation is not a complex one and it is easily avoided by careful drafting.

Much is made in the commission's report in chapters 15 and 16 about the common law and the judicial determination of disputes, and it is suggested that the common law and judicial determination of disputes provides little benefit and has many weaknesses. With respect, we disagree. I am certain that this statement is not new to the commission. It is, however, an important point, and ultimately one upon which the scheme designers and the legal profession will have to disagree.
The common law does provide an excellent mechanism for adapting to change to community behaviours, standards, beliefs and attitudes over time. I said excellent, not perfect. No system I have ever encountered has proven itself to be perfect.

Much has been made and will continue to be made by various respondents to this inquiry about the various failings of the New Zealand no-fault scheme. I think what they're really driving at is that there are inherent weaknesses in all schemes, that over time systematic pressures arise, from which there arise limits to compensation and supports, driven by the need to maintain financial viability. Closer to home I think there are better examples for us to consider. The NSW Wales WorkCover Scheme almost a decade ago embarked upon significant changes that promised that no worker would be worse off, that claims would be dealt with in simpler, fairer and faster way. 10 years later, benefits have remained largely static for many years.

The costs for the provision of services have, likewise, remained static, and in some cases eroded. Dispute numbers have increased, particularly around injury management and costs of service claims. It is now proposed by WorkCover NSW by way of public consultation to implement a model of accreditation of all service providers, all service types and all costs associated with those services; the key driving factor is scheme financial viability. The hope that this scheme will ultimately not be impacted by scheme financial viability problems is a hope, and one that should be approached with extreme caution. Those charged with the responsibility of creating this scheme will not be those charged with the responsibility of managing it into the future.

All disability schemes that I have encountered, including the New South Wales Lifetime Care and Disability Scheme have all suffered pressure over time in terms of access and limitation rules and difficulties caused by the creation of increase in thresholds and caps, and thresholds relating to both procedural and quantum matters, levels of support and compensation are diluted over time. One way to protect this is to legislate for a mandatory increase in benefits and service costs, to keep track with CPI or average weekly earnings, or some such similar measure. The last way that schemes are impacted is the way in which individual cases are managed and the denial of right to proper independent review decisions by scheme agents and their administrators, and it is on this point I will close.

The challenge for any claims management process is that on the one hand it needs to be flexible enough to accommodate the individual circumstances of claims coming before it, and on the other it has to ensure that its decisions are predictable and reasonably consistent. In my experience, this has not been achieved in New South Wales, and the model proposed in chapter 7 is, by and large, a reformulation of models that already exist. I think that what is required in each of the state models is a realignment to their core objectives.

For example, in the work that I do in the New South Wales scheme I am regularly asked to review files following an internal review or following the commencement of proceedings following a review outcome. In the course of that work I am caused to review documented matters of declinature. In the vast majority of those circumstances the declinature requires revision so that the grounds for the declinature accord with either the law or the facts that arise in that particular claim. In other words, the decision-maker and the reviewer got it wrong. And, in my experience, they get it wrong more than they get it right.

You will find a different approach between claims assessors within scheme agents and insurers and you will most definitely find a different approach between insurers themselves. The problem has not been resolved by the creation of rigid determination guidelines enforced by a regulator through inflexible approaches because to do so runs contrary to evidence based decision-making itself. The New South Wales experience suggests that the process of claims management and dispute resolution is by and large more cumbersome now than what it was before the implementation of these schemes. Medical practitioners are called upon to issue binding determinations, not only on impairment ratings but on issues such as the need for services. Some of this has proved highly controversial and unpredictable and rights on appeal from those decisions have limited access of appeal rights compared to rights of appeal from judicial offices.

In terms of case management, decision-makers within the current model are not subject to sufficient rigour and are able to operate with relative freedom and limited repercussion in the event that their original decisions are wrong, even if they're wrong for wholly unmeritorious reasons or, worse, for conduct which is very difficult to explain. A striking example is the New South Wales Court of Appeal's decision in CGU Workers Compensation v Garcia and others include Mateus v Zodune and Gibson v Royal Life Saving Society. I have copies if the commission would like them. These decisions demonstrate the problems associated with inconsistent decision-making practices and outcomes despite a wealth of legislation, regulations, guidelines, operation instructions, review process, training measures. The notable difference in each case is that a just outcome was only obtained for the worker once an independently appointed judicial officer determined that dispute with the assistance of experienced and qualified legal representatives.

Many of the assumptions regarding the failings of courts or tribunals and, for that matter, the common law and what are the stated costs of those claims and the success rate of those claims are, in our opinion, simply incorrect. But none of this means that a dispute resolution model that incorporates the judicial determination of claims in a robust transparent way, cannot be supplemented by proper case management and dispute management processes, modern processes that include evidence based decision-making, front-end loading, the right to an independent review, written reasons for those decisions, the role of arbitration and mediation in those processes and, in our opinion, the need to enforce those decisions and processes by proper representation from suitably qualified and experienced personnel. This is the balance I talked about at the beginning. But that balance will not be achieved by simply adopting the negative aspects of various schemes.

In our respectful submission the commission would be well advised to retain existing common law rights for economic loss, care costs and pain and suffering and that these entitlements can easily co-exist with a no-fault care and support scheme that a person could, upon settlement of the claim, repay and be precluded from payments into the future. This is the essence of the legal doctrine of double compensation and we commend it to you.

Australia is a wealthy country and can probably afford to deliver a first class system. The ideal of ensuring that the very best services and outcomes for disabled people should not be limited by financial considerations alone is a noble one and it attracts broad support, including the support of the Law Society. That ideal, however, should not be derogated from when a dispute requiring resolution is subject to a model that by its very design cannot deliver the best outcome because it is limited by financial considerations. The former High Court justice and Governor-General of Australia, Sir William Deane, was once famously quoted as saying that, "The measure of a society is how it cares for and protects the most vulnerable in it." Quality over cost is therefore critically important. Thank you.

MR WESTGARTH (LSNSW): I now ask Hugh Macken to add to the submissions.

MR MACKEN (LSNSW): Thank you. The commission must be heartily sick of parties which appear before it and saying, "Yes, this is a good system, but". What's probably more constructive is for the commission to hear parties appearing before it saying, "Yes, this is a good system that's proposed and".

MS SCOTT: Hugh, let me just interrupt you there and say I'm not heartily sick of it. I don't know about John, but I'm expecting people to have suggestions and criticisms and, in some cases, a little bit of praise. That is why the government set up the commission with a very clear public hearing process, a very clear public submission process and this is in fact one of the most enjoyable parts of the work, being able to hear back from people and give consideration to their ideas. So I just didn't want you to be under a misapprehension there.

MR MACKEN (LSNSW): I'm very pleased to hear that. Without being too cynical perhaps, it's early days yet.

MS SCOTT: We've now gone through Hobart, Melbourne, Brisbane and Sydney.

MR MACKEN (LSNSW): And Canberra.

MS SCOTT: And I'm truthful when I say that I'm looking forward to each of the days of the hearings. I know you're suggesting otherwise but I'll correct you.

MR MACKEN (LSNSW): I can understand why you would be pleased because clearly this is a wonderful opportunity to introduce a regime which provides much needed support for those catastrophically disabled and their carers. It is with this in mind that I make a number of observations, perhaps more strategic than dealing with the minutiae which Mr Westgarth and Mr Moroney have. There is clearly a need to address the legitimate objections of a number of parties and thereby ensure that when the sharp end of this debate comes into place, that is, the actual negotiations with the states, unions, carer associations, medical and legal professional bodies and the insurance industry that resources are put into finding solutions rather than being put into ensuring that this process grinds to a halt.

It is obviously with some concern and consternation in respect of the draft report that I raise a number of what you might call strategic matters. I will be brief to allow us to finish in time for any questions you might have. Can I suggest that there is a need to work with the existing rights and entitlements rather than do away with them. You can enhance care, without necessarily eroding existing common law rights of parties. It is not proposed to do away with the rights of workers in workers compensation schemes. Those schemes in a number of states maintain common law rights. In Queensland it's a traditional and pure common law scheme. In New South Wales it is a limited rights common law scheme, limited insofar as you do away with your rights to future care and future treatment interestingly enough. Other states have hybrids on that and some states have systems which do not allow anything for common law.

So what this scheme proposes is to work with existing common law rights, albeit only the workers compensation common law rights but conjecture down the track is to do away with the existing rights as they exist in respect to common law claims arising out of motor vehicle accidents, civil liability cases or professional negligence cases. This is not required. There is no need to try to bring things down to the lowest common denominator at the expense of common law rights. If this somewhat combative approach is taken, then combat is where this matter will end.

On a second point, the figures in the scheme need to be pristine. Some concerns have been raised, particularly by the Queensland Law Society and the Law Council of Australia and there has been some publicity in respect to that, that the figures do not seem to add up. Without drilling into the mathematics and pulling out calculators, this scheme will have greater acceptance if the figures are beyond reproach and it might be worthwhile to have another look, particularly in respect to the lifetime care and support scheme and Mr Bowen would clearly be of some passing assistance to you there to try and get accurate figures. But a figure of $12 billion which is quoted in the body of the report is perhaps a figure which is - well, the most polite way of putting it is probably optimistic. If there is honesty, open-mindedness and willingness to engage in true debate in respect of these things, then the scheme is more likely to receive widespread support.

The New Zealand scheme, some attempts have been made to draw the reality of the New Zealand scheme, which is a failing scheme and which simply does not have the financial resources to continue to make a profit or to enhance the benefits available to New Zealanders. If there is a model that is going to be drawn on the New Zealand scheme, then some attention must be paid as to why that scheme is failing and losing lots of money on a regular basis and not a scheme which could in any way, shape, or form be considered a viable scheme. They're the primary pressing points that I thought would be useful for the commission to deal with on a strategic basis. It is hoped that this, as a scheme that's going forward, would have the unanimous support of absolutely everyone, but in order to have unanimous support of absolutely everyone it ought be a scheme which enhances existing rights to its citizens rather than strips the rights off some to enhance the rights of others. That is not a scheme which will gather widespread support. I note there's only four minutes, and if there are any questions?

MS SCOTT: I'm also interested in your expectations that the commission could devise a scheme of any type at any time that will be universally popular. I'm trying to recall a report the commission has made where it hasn't been subject to, at some stage, someone thinking arrangements could've been otherwise. Maybe you can enlighten me if there has been such a report where, in your knowledge, everyone has universally accepted all recommendations.

MR MACKEN (LSNSW): It's difficult to imagine a more socially responsible report such as the one that's being undertaken. No-one has it in their minds that enhancing the care of catastrophically injured people is a bad idea; everyone is supportive of enhancing the care and the systems put in place to manage the care of the catastrophically injured, the most vulnerable in society. Perhaps you will not get absolutely unanimous support for that, but where you will ensure that opposition is muted is where you do not seek to strip the rights of citizens in other areas which currently exist, such as is proposed in chapter 15 of this report.

MR WALSH: Thanks very much for your presentation and a very thorough analysis of the Law Society's views on what should happen in terms of administration, disputes and rights of appeal. I think, extrapolating what you've said, in that no-one's arguing we should enhance the care of catastrophically injured people, you would imply by that we're looking to improve the outcomes of those people as well. I think we'd also agree that the common law and in fact most systems have very poor information on outcomes. One of the things that we've recommended in this scheme is for a review in 2020 which would look at the relative merits of various schemes around Australia. It's very difficult for us to quantitatively analyse the relevant merits of a common law system versus a non-common law-type approach. I'm assuming you would agree that's a worthwhile approach?

MR MACKEN (LSNSW): I think I can go further than just talking about a quantitative assessment. One of the difficulties with the setting of any common law scheme is the qualitative assessment as well, which is where the criticisms come from in public debate. But when you have an individual case with individual circumstances that requires a bespoke outcome to meet that individual person's needs, to then take that outcome and assess it against a broad group of outcomes that arise for many, many different reasons on different facts, it is very hard to get away from it being criticised of comparing apples with oranges. You will always be doing it. It's why lawyers and legal groups around the country will have told you time and time again that the common law is very adaptable and that is one of the best features of it; that it does adapt to the individual circumstances that come before it.

There is some reference in the report to inconsistencies in appellate court approach to trial court outcomes and that is used as some justification for saying this shows an inconsistency in approach in common law. I'd argue that is actually an incorrect analysis of the legal principle arising from those particular decisions. But in any event, what the appellate process is used for is to provide a check and a balance in the event of a miscarriage - and I don't think anyone would say that shouldn't be there - but also to ensure that where the common law needs to adapt, grow, expand, and retract to meet current community standards and needs, it's the appellate function that fulfils that.

MR WALSH: We need to move on. I'm not sure if you had a chance in that context of individual needs and individual outcomes to have a look at chapters 6, 8, and 9, which talk very much about individual planning in a nonadversarial framework, which the commission has put a lot of emphasis on. I'd also just like you to explain to me the recommendation of the Law Society, in terms of how your scheme would work. So you would support access on a needs basis to carer support and those who can establish a negligence action would be able to, effectively, commute those entitlements to a lump sum. Is that right?

MR MACKEN (LSNSW):   I don't see why that would not be possible.

MR WALSH: For those people who extinguish their lump sum before they die, for example, which is likely to happen given the current discount rates in statutory schemes, who would pick up the tab for that after that money had run out?

MR MACKEN (LSNSW):   In claims where rights co-exist in negligence actions, you're talking about?

MR WALSH: Where people had commuted their entitlements into a lump sum and extinguished that lump sum, who would take care of those people after that?

MR MACKEN (LSNSW):   After they die?

MR WALSH: No, after they run out of money.

MR MACKEN (LSNSW):   If they run out of money.

MS SCOTT: Let's say they do.

MR MACKEN (LSNSW):   That risk exists in any scheme where commutation currently is available.

MR WALSH: That's the issue: should commutation be available?

MR MORONEY (LSNSW):   This scheme doesn't seek to cover into old age any way.

MR MACKEN (LSNSW):   If the figure is right, if the commutation figure is calculated right - this is a very basic response, because we could write a book on this - the money shouldn't run out; that's the first point. If it's not calculated right, then the money runs out, what do you do then; good question.

MR WALSH: Maybe you could make a submission on that; no need to answer it now.

MR MACKEN (LSNSW):   I'm happy to look at that.

MR MORONEY (LSNSW): Could I just ask one thing, if this scheme doesn't purport to cover people into their old age in any event. Once you turn 70, 80, 90, 100, this scheme is not going to be meeting the care and needs of those people, so you're talking about people requiring care before the age of 65, aren't you?

MR WALSH: I just want to clarify that. The notion is that entitlement of the person, as before age 65, will carry through into the aged care system; the funding will just go across into the aged care system.

MR MORONEY (LSNSW): Till death?

MR WALSH: Yes, that's right. I also have a bit of homework for you guys to do. You've mentioned and you're aware that about 10 years ago there was a big review of the New South Wales WorkCover system, actually conducted by, in terms of the common law rights, Attorney General Justice Sheahan.

MR MORONEY (LSNSW): Justice Sheahan.

MR WALSH: You said that, since that time, disputes have increased, costs have increased.

MR MORONEY (LSNSW): Yes.

MR WALSH: I wonder if you could provide us with some evidence on that.

MR MORONEY (LSNSW): I'm happy to.

MR WALSH: Comparing the dispute levels pre-2000 and most recently, maybe the legal expenses pre-2000 and recently, and the cost of the total scheme pre-2000 and recently, because I'm not sure what you've said accords with the evidence.

MS SCOTT: Brian, I also wouldn't mind what material can provide in terms of that statement you made that you thought that in the Lifetime Care scheme they got it wrong more than they got it right. I wouldn't mind getting some words around that in your submission.

MR MORONEY (LSNSW): Declinature notices, in terms of where claims - - -

MS SCOTT: Yes, if you could provide some evidence on that, that would be useful.

MR MORONEY (LSNSW): I wasn't talking about the Lifetime Care scheme when I made that comment. I was specifically talking about the way decisions are made within the WorkCover scheme as an analogy of poor decision making practices; that's the point I was making.

MS SCOTT: Thank you. I didn't appreciate it was - thank you. Thank you for attending today.

MR MACKEN (LSNSW): Thank you.

MR MORONEY (LSNSW): Thank you for the opportunity.

MS SCOTT: I look forward to your submission.

MS SCOTT: I now ask AI Media to come forward please. Thank you for coming along today. We have allocated 30 minutes to your presentation. Please allow some time for John and I to ask a few questions. Could you please introduce yourself for the purposes of the transcript and then proceed with your presentation.

MR ABRAHAMS (AIM): Tony Abrahams. I'm CEO of Access Innovation Media or Ai-Media.

MR BALDWIN (AIM): Steve Baldwin, director of business for Ai-Media.

MS JACKSON (AIM): I am Leonie Jackson, head of education access for Ai-Media and this is my interpreter Carolyn.

MR ABRAHAMS (AIM): I've given up a copy of the presentation notes that we intend to speak to today. First I'd like to say that Ai-Media warmly welcomes the Productivity Commission's draft report into disability care and support. We thank the commission for the opportunity to make this presentation, which we note follows a presentation we made on 20 July here and also follows on the written submission that we tendered in August. Founded in 2003, Ai-Media is a social enterprise dedicated to ending the experience of exclusion that people with disability face. Our focus has been on developing solutions for people who are deaf and hearing-impaired.

We regard the greatest priority as being to secure the necessary public and political support to implement the NDIS as soon as possible. Confident that the costs of action are dwarfed by the costs of inaction, we urge the commission to calculate and publish the productivity benefits and cost savings that would accrue as a result of the proposed investments in the NDIS. To that end, we would suggest an approach not dissimilar to that that Access Economics used in their 2006 report Listen Here, where they looked at the costs of excluding people because of deafness alone at being $12 billion a year.

If you look at that in the context of the proposed investments in the NDIS, being an additional $6.3 billion, it seems fairly clear that looking at the cost savings and productivity benefits that would accrue to all people with disability would well exceed that number. As a privately-funded social enterprise, our perspective is perhaps a little different to many of the other groups that you'd see. One of the concerns that we have is securing necessary funding required to drive the innovation that underpins our products. Ai-Media began by providing captioning and subtitling to the subscription television industry and with those revenues, we've invested in new solutions to deliver live captioning in a range of other situations.

Last year we launched a product called Ai-Live, which provides live captioning to deaf and hearing-impaired students in schools and we use that same technology in the workplace to deliver access for people who are deaf and hearing-impaired and in universities and other situations. I'll let Steve and Leonie talk a little bit about our experiences there. We really warmly welcome the innovation fund initiative in particular as a critical component of disability reform that will drive innovation in the sector. It was fantastic to see it in the report and thank you for that. We've provided and are happy to talk to some evidence of our experience, in the absence of an innovation fund, seeking to secure sustainable funding for a technology-enabled solution directed to deaf and hearing-impaired students in mainstream schools.

Some basic comments on the draft report. I think the three key objectives are pretty uncontroversial, but they're so significant that they do deserve clear support, namely ending the rationing in the disability system. We don't ration education, Medicare or aged pension entitlements, so why should we ration disability care and support? A national system. The current mesh of state and territory based non-systems should definitely be replaced with a national system that drives national innovations that can be diffused widely and quickly and give every Australian affected by a disability the same entitlement, regardless of where they live. We agree that the confusopoly must go.

Consumer choice must lie at the heart of the new system. Decision-making must shift to people with disability and their carers. An example of that just within the deafness sector is that, as you can see today, Leonie is getting access to today's proceedings with the use of a sign language interpreter. Many deaf people will choose sign language interpreters in some situations and they will choose live captioning in other situations. It's really important that they be empowered to make that choice, not a government department.

In terms of the innovation fund, creating incentives to deliver innovative approaches that deliver independence to people with a disability must be a central feature of the NDIS. We think that while an innovation fund should not be limited to technology based solutions, it's likely that many novel approaches for cost-effective and scalable solutions to address disability will in some way be technology driven. In the absence of an innovation fund, stretched budgets, scarce management resources, unclear and ambiguous responsibilities between state, territory and federal funding agencies and legacy bureaucracy is frankly not geared towards innovation, combined to leave no formal mechanism to fund and trial innovative approaches to disability, however promising they may seem and however great the potential national benefit.

Competing proposals for an innovation fund should be evaluated, we say, on the link between resourcing and outcomes. The innovation fund should prioritise solutions for those groups most in need, thereby creating a market for innovation. To be successful, the innovation fund need not be large and, consistent with the principles of risk sharing, need not cover 100 per cent of the costs. There should be a competitive semi-annual funding mechanism to reward innovative solutions based on prospective outcomes per dollar or value for money.

Innovative, inclusive solutions are likely to have positive spillover benefits for the entire community and they should be captured in any assessment. In particular we think there is a need for the innovation fund to look to provide support for firstly preliminary pilots and secondly national pilots if and when that preliminary pilot is successful prior to any solution being adopted or approved by the national disability insurance agency.

We further support the long-term actuarial approach to funding, which, as a matter of principle, if economic incentives are to actually drive cost-effective solutions across a whole of life view must be the foundation for the NDIS. We support the national disability insurance agency, but agree that a lot of detail still needs to be fleshed out. It's critical that the NDIA be informed and not a political organisation. We do make a comment on the infrastructure or block funding question. We do believe that sometimes it will be necessary to ensure a service can continue to operate at an acceptable level of business risk, that 100 per cent individual choice can lead to an atomisation of funding. The withdrawal of efficient solutions that require a fixed investment, how that is actually done is going to, I suspect, be one of the more difficult elements of the design of the system. One example perhaps we can draw on is in developing and delivering Ai-Live into schools there's a requirement for fixed infrastructure in the schools to carry the audio out of the classroom, and then our service is delivered by having a remote person who re-speaks that text into speech recognition software that this then streamed back over the Internet to the classroom.

Obviously, the core enablers of that solution are the technology that must be in the classroom to get the audio out, and Internet access to get the captions back into the classroom. We would think that something like that would be funded as part of an infrastructure funding, whereas the recurrent costs of providing the re-speaker to deliver that service could well be done through some kind of individualised funding approach, notwithstanding that education is not strictly included within the remit of the National Disability Insurance Scheme. We do believe that the same consistent principles need to apply to disability funding in education, and we have made a submission to that effect to the National School Funding Review.

We do believe that decisions of the NDIA should be subject to unfettered judicial review. We have had some experience with New Zealand and think that there may be opportunities to collaborate with New Zealand in some of these endeavours as well. In terms of education, we do think it's important that the needs of people with disability in education be included within the whole-of-life-needs calculations that the National Disability Insurance Scheme would need to calculate.

We see a time in the future where it would make sense for all-of-life disability needs to be coordinated in a single national office.

Education reviews into disability should ensure new systems are consistent with the framework in the NDIS and prepared to hand over disability-specific elements of education to the NDIA. The NDIA's education branch should contain a majority of educators, with parent groups, service providers and interested parties all represented. Best practice in education should be available to all Australians, regardless of where they live. We would agree that compulsory no-fault insurance is the most efficient way to fund, we believe it is a matter of human rights, and, furthermore, why penalise someone for life because they made the bad decision of not insuring themselves.

We also think it's a good idea not to recommend a specific levy, because the NDIS should be the core business of government, and we would agree that savings can be made from other less critical areas. However, the case must be made, as we said in the outset, that the costs of inaction are greater than the costs of action. In terms of our experience in delivering Ai-Live for deaf students, the reality is that without the cash flows from a modest broadcasting business and very patient social enterprise investors who have not required a dividend in eight years, Ai-Live could not and would not have been developed.

Ai-Live was piloted successfully at Robert Townson High School in western Sydney from September 2009 with contributory funding from the New South Wales Department of Education and Training, which represented a fraction of the development and implementation costs. By December 2009 it was clear that the solution was effective at enhancing educational outcomes for deaf and hearing-impaired children. Both pilot users experienced significant improvements in school performance, with one student moving from the bottom of the class to come in first in the yearly exam, in less than 10 weeks. The delivery of that whole solution would have cost that student less than $5000. It's the difference between getting the information and not getting the information, it's that simple.

Our experience in seeking to attract funding from within the education sector suggests there is little space in a crowded and confused framework to support promising, innovative solutions and diffuse these benefits nationally. The issues encountered securing funding under the current arrangements are that there is simply no mechanism to evaluate value-for-money investments that improve the educational outcome for disadvantaged students, including students who are deaf or hearing-impaired.

In the absence of an innovation fund, we have encountered the following obstacles in securing funding for this solution. At a state and territory level, budgets are fixed well in advance and there is little scope for assisting new solutions in an expeditious way. Particularly, there is no specific funding available for technology, infrastructure and support costs associated with innovative technology solutions, because they have never been funded in the past. Finally, in the absence of independent research data on the effectiveness of a new solution, no funding can be made available; which we call the catch-22 issue.

At an Australian government level, the response is that education is a state or territory responsibility and that the Australian government is not in a position to fund particular programs outside those agreed in the prior funding round. So we have a system that is entirely looking backwards rather than looking forwards. The Australian government is also not in a position to assess and support particular technologies or support individual businesses over others, and we submit this is exactly what an effective NDIS needs to do.

Perhaps most importantly, education in Australia is controlled and majority-funded by government, and private investors who may support the development of innovative education services need to know there is a proper mechanism and the opportunity to obtain government support if they can prove an invention is worthwhile. Investors are prepared to take that risk, but not in the absence of such a framework. That is the number 1 question we get from investors. Private investors would be willing to share the risk on initiatives that promise to deliver improved outcomes in a financially sustainable way if there was a fair, simple and transparent mechanism to compete for supportive government funding.

MS SCOTT: Thank you.

MR BALDWIN (AIM):   I might just say something about our experience in the workplace, where in a great deal of cases people with a disability - and, in our experience, deaf or hearing-impaired people - face an organisation without the processes or systems to support them properly. What we have been working with is EAF, the Employment Assistance Fund, which is a system whereby someone in the workplace can use services like captioning or a sign-language interpreter and claim that back, the government will fund that up to $6000 a year per person. It's a similar type of system and an example of how an NDIS could work. My experience when I'm out talking to organisations encouraging them to provide services is it's a massive relief to them that they can provide these services without trying to turn around the massive ship of their organisation to provide the service.

MS SCOTT: Thank you. I'm conscious that your business cards have got braille on them as well as normal presentation, and I saw in Melbourne at a hearing a device that enabled text messages to be converted into braille, a device that cost $3000. What is the capacity for your live captioning to be able to be used in conjunction with a similar device which would enable people who are deaf and blind to be able to have live braille?

MR ABRAHAMS (AIM): That's a great question. The core elements of what our Ai-Live solution does is it essentially digitises the analogue information. As soon as that information is converted from speech into text by use of the re-speaker, that text can then be put through any kind of device that could then make that display through braille. So that exact same device could quite easily just plug into to the Ai-Live feed.

MS SCOTT: That's doable now?

MR ABRAHAMS (AIM): We haven't tested it with that particular device, but that's how we designed the system. The system can also be individually tailored, so that an individual user can change the font size and save those settings within a particular device. So for people who have low vision, they can actually increase the font-size settings. It's a simple HTML feed, so you can plug it into screen readers and you can plug it through to the browse devices as well, with ease.

MS SCOTT: I don't know if this is a question for you, Tony - or Stephen. We'll have to see how we go. Tony, you mentioned on the way through that while there had been very substantial development costs in terms of putting live captioning into the Robert Townson High School, you thought the incremental cost was $5000. $5000 per student, or $5000 for the two students?

MR ABRAHAMS (AIM): That was the cost for that student for that term, to deliver that result. But the total cost would not exceed $20,000 a year per student. The key there is that there will be efficiencies within the system that will drive better financial performance; namely, there is a cost for captioning a classroom, there is not a cost for providing the service to a student. So the more students you have in the classroom, the lower the cost per student. So we could see and we do see within the schooling system that there are hub or feeder schools for an area, so you get hearing support units within particular schools that support 15 or 17 deaf students. Robert Townson High School in Raby in western Sydney is the school where we trialed that, where they do actually I think have 17 deaf students.

MS JACKSON (AIM): Yes, that's right.

MR ABRAHAMS (AIM): Leonie can perhaps talk a little more about why deaf students benefit from being in an environment together, but that includes obviously being able to meet each other's communication needs and have a peer group and so on. So the cost of providing the re-speaker is going to be in the order of, say, $60,000 a year. When you have a look at the fact that not every class needs to be captioned, so that there's not a huge demand for captioning PE or maths, but there is a huge demand for English, for geography for the sciences, we have found. In fact, some kind of mechanism to allow the schools to choose how to deploy that single re-speaker resource across the curriculum is the easiest way, we have found, to actually embed this solution within the existing framework, because schools are used to doing that with their other resources.

MS SCOTT: That's right. So effectively it becomes another part of the timetabling.

MR WALSH: Tony, just on that, suppose you did have a school where there were 10 or 20 children with hearing impairment, have you got the numbers, what the total annual cost to that school set-up would be?

MR ABRAHAMS (AIM): Yes, we benefited from the government's digital education revolution.

MR WALSH: Just gross cost.

MR ABRAHAMS (AIM): So the infrastructure now has been provided, largely. But then in terms of re-speaker, as I said, the labour costs of the re-speaker would be about $60,000, then there'd be about another $20,000 on top of that for the infrastructure and support charges. So we are talking about $80,000 per head effectively for providing that. Then it depends on how many re-speakers you need for a particular school. I'd say if you had a school of, say, 20 deaf kids you'd look at probably having two re-speakers.

MR WALSH: Is that $20,000 per classroom?

MR ABRAHAMS (AIM): No, it's 20,000 per re-speaker. That's assuming the classrooms are already wired up, to get the audio out and deliver the captioning back.

MS SCOTT: Can I just check on that? You mentioned the digital revolution. Let's imagine we're at the end of the roll-out period. That should mean that all students, I understand, in years 10, 11 and 12 would have a computer on their desk, and most classrooms over time will be effectively online and will have some online facilities. I don't want to go into things that are commercial-in-confidence, but would it be possible for you to provide at another time, and maybe in your submission, if that infrastructure is in place what additional infrastructure does your system require. That's what I'm getting a little confused about.

I imagine it's the case that what you're saying in response to John's question is that your re-speakers and the students in, say, a high school are in different classes, but that has effectively enabled all those students with timetabling to have their needs met by two re-speakers. It's effectively labour costs for the two re-speakers and the X infrastructure costs, about which I'm a little unclear.

MR ABRAHAMS (AIM): Look, it's not commercial-in-confidence; I don't mind sharing that. The costs are in relation to the support for the re-speaker. So that involves the software, the hardware support, the technical support for making sure the system is in place, as well as the training, accreditation and quality assurance process, to ensure that that re-speaker is delivering the service that is required for that student.

MR WALSH: If you could just put it in writing for that, that would be useful.

MR ABRAHAMS (AIM): Yes.

MR WALSH: I just have one more question. If I understand it correctly, you have suggested here that over time in NDIS and NDIA would assume responsibility for all services that are required by people with a disability, including education and so on. We have, I think, tried to take a different approach and tried to encourage people to use mainstream services wherever possible. It sounds to me like putting NDIS at the centre of everything it sort of segregates disability to some extent. So could you just talk a bit about that?

MR ABRAHAMS (AIM): Firstly, I would agree, I would encourage people to use mainstream services where those services are available. But, say, for example, in relation to deafness, people will have fairly similar needs whether they are in education or in the workplace, which are to provide essentially a means to get audio based information visually, and those solutions, particularly the way we have designed our solution, have meant that the solution will work in education, it will work in schools, but it is also going to be portable to the workplace, to a health care environment, to the courts, parliament, meetings with your solicitor, etcetera. The only thing that really changes is the degree of support needs that you would require.

So those support needs are likely to be higher in different phases of life: probably starting off relatively modest at primary school, going up towards senior school and obviously higher education; and then in the workplace what we have actually found is, say, for the EAF, while $6000 a year is probably not enough, it's certainly not going to be as high as $20,000 a year that might be required for an education-type setting. So, rather than leave it up to different education bureaucracies to make an evaluation of the same evidence again and again, it would be good to have some kind of national whole-of-life repository of what the best available solutions are from which people with a disability could choose with confidence, knowing that they have gone to the one place. That's really the point there. Steve, did you want to add anything, or Leonie?

MS JACKSON (AIM): Yes, I just wanted to add something about that. I'm also a parent of a deaf child and I'm very heavily involved with a parents group for deaf children, so we all share the same frustrations. When we actually try to get access to services in different areas of our child's life, it's very, very difficult, because we have to go to one department to ask them for funding to provide transport so the kids can actually get to a special program, then we have to go to the education group for assessments, then we have to go to the health sector for hearing aids et cetera.

So there's a lot of time on the parents' part spent trying to provide everything that they need for their deaf child in order to be able to access their everyday life. So we all share the same frustrations and we're trying to make sure that our child actually gets through every part of their life. I've also been talking with people who have other disabilities and they have said the exact same thing; it's very, very frustrating and time-consuming going to different government departments, trying to get bits of information just so they can get through their everyday lives.

MS SCOTT: Thank you very much for coming along today. Thank you, Carolyn, as well.

MR ABRAHAMS (AIM): Thank you.

MS SCOTT: I now invite the Attendant Care Industry Association to come forward, please. We'll take a morning tea break after this next presentation, in case you're wondering. Good morning, how are you? Could you identify yourselves for the purposes of the transcript, please, and commence your presentation.

MR BENNETT (ACIA): Good morning Commissioner Scott and Commissioner Walsh. My name is Craig Bennett. I'm the executive director of the Attendant Care Industry Association of New South Wales; what we will refer to as ACIA here today. To my immediate right is the president of ACIA, Danielle Bennett. Danielle is also an industry representative as she owns a small provider. To my far right we have Barbara Merran, who is also from ACIA on the ACIA Committee of Management, essentially our board. Barbara is also, essentially, the founder of ACIA, a former president, once against representing industry as the owner of a provider. Barbara is also a representative of the Lifetime Care and Support scheme council and also Enable New South Wales, New South Wales Health.

MS SCOTT: Thank you.

MR BENNETT (ACIA): I'd like to begin by, just firstly, congratulating the commission on its very comprehensive report and also thank the commissioners for having us here today to present our submission. I'll just commence with some contextual information that forms the background to our comments, a little bit about the organisation and then framing where we're coming from with our comments on the report, and then I'll then handover to Danielle to look at the key issue of quality and also, given Barbara's wealth of experience in the area, she's also here to take your questions as well.

Just a little bit of background, attendant care, which is in many instances also referred to as community care, refers to any paid care or support services delivered at a person's home or in the community to assist them to remain living in the community. It targets people of all ages with ill health or disability. Attendant care therefore aims to maintain or improve a person's independence, allow them to participate in their community and reduce his or her risk of admission to a facility or hospital. This is achieved by providing assistance based on each person's individual needs. It may include nursing care and assistance with all activities of daily living, including personal assistance, domestic services, community access, vocational support, educational support, childcare services, gardening, home maintenance, respite, palliative care, social support, therapy program support. So all those services that are delivered within the person's community. It therefore supports Commonwealth and state government policies of allowing people to actively participate in society and remain in their homes and therefore avoid unnecessary admission or inappropriate admission to residential care.

A little bit about ACIA, then: it's the peak body that represents private and not-for-profit attendant care service providers. The organisations that we represent employ more than 15000 workers in all states throughout Australia, and I also note that the organisation is currently in the process of becoming a national body. ACIA's vision is that the attendant care industry is known and respected as a provider of quality services which enhance outcomes for service users. In terms of the commission's report, ACIA members are keenly interested in all components of the inquiry. As our membership is concerned with the actual delivery of those attendant care services - those community care services - our comments relate to those issues that impact on the effective delivery of such care and support. I would also note that our comments are shaped by our focus, our experience, and that of our members, of working with the scheme with a similar focus, the New South Wales Lifetime Care and Support scheme.

To the report, ACIA strongly supports the Productivity Commission's recommendation that Australia move to establishing two new schemes that will ensure all people with severe or profound congenital or acquired disability are provided with an entitlement to essential care and support. As the commission's report highlighted, the current disability system is underfunded, unfair, fragmented, inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports; it is not a system. ACIA members frequently encounter situations where people with disabilities are in need of additional and/or more flexible care and support services to enable them to remain at home and to participate in the community. The need to move to an entitlement based system is not only the right thing to do, but it makes sense economically. Ensuring access to support for all individuals to participate in the life of their communities, while freeing up a large and hidden informal workforce, the unpaid carer, will have untold productivity benefits for everyone involved.

Moving on then with respect to the establishment of the two schemes, the National Disability Insurance scheme, the NDIS, and the National Injury Insurance scheme, the NIIS, ACIA would like to offer additional comment on two issues that we believe must be at the forefront of consideration in the establishment and effective implementation of both these schemes. These issues are quality of service delivery, and that relates also to one of the commission's recommendations of the establishment of a nationally consistent quality standard; and the second issue we'll touch on is maintaining an appropriately skilled workforce. I'd now invite the president of ACIA to talk about that force key issue in the importance of quality in service delivery.

MS SCOTT: Thank you.

MS BENNETT (ACIA): Good morning and thank you for this opportunity today to speak to you both. The issue of quality is well canvassed throughout the commission's draft report. Chapter 8 discusses the factors to be considered in safeguarding quality of care delivered in the community, including the need to approve specialist providers, develop a single set of national standards and an associated accreditation process, provide consumer or service users with information about the quality and performance of service providers on a national Internet database of service providers. ACIA commends these suggestions and fully endorses the need for an appropriate level of oversight to ensure the delivery of high-quality care and support that is focused on individual need. The commissioners' draft report also gives great emphasis on the role of consumer choice in ensuring quality service delivery, that is, as power is transferred to the individual to exercise choice about the services they would like to purchase to meet their unique needs. Providers of those services will respond to market forces by offering high quality services that appeal to their customers or the service user.

ACIA supports all policy directions that align with the United Nations Convention on the Rights of Persons with Disabilities including the principle of respect for freedom to make one's own choice. ACIA therefore concerns that individuals requiring support services must be given choice in selecting a service provider on an entitlement basis and as the result of assessed need. The key to implementing this in practice is ensuring that service users are able to make an informed choice. All individuals need to know that the service providers they are considering purchasing services from is well managed, has a competent workforce, can provide effective care and will uphold their individual right in accordance with relevant legislation.

Many individuals requiring supporting services are very vulnerable and require assistance to make informed choices. Service users and their carers are overwhelmed by the complexity of the system and find it difficult to locate services and aids that meet their needs. Furthermore the types of care and services being delivered in the community will become increasingly complex as the population continues to age. This will inevitably expose service users to increased risks that need to be managed by service providers. It is widely acknowledged that the community care industry is still largely unregulated and there is a lack of consistency of service delivery. The industry is also relatively new, fast growing and in demand. ACIA and funding bodies regularly receive feedback that the quality of care and service provided in the community is inconsistent between providers and sometimes does not meet expected standards of professionalism.

Furthermore, their recent report following the inquiry into disability services provided or funded by the New South Wales government, the New South Wales legislative council standing committee on social issues - the committee - found that:

> Services are also sometimes not provided in accordance with either the disability standards of the relevant state or the United Nations

> Convention on the Right of Persons with Disabilities. The poor monitoring of service compliance with this policy and legislation is one of the most significant issues identified through the inquiry.

They also note a significant gap exists between the theoretical standards, the New South Wales Disability Service Standards, the practical implementation of the standard and the compliance monitoring of this. The Disability Council of New South Wales, as the official advisory body to the New South Wales state government on disability matters, also note during the inquiry:

> To have moved over the last five years to increasingly fund non-government organisations to deliver services to people is absolutely the right one so long as there is a clear control and clear monitoring, which should be independent and across the board, of course.

These findings and statements are further evidence of the need for a robust system to ensure approved community care providers are delivering high-quality services at low risk to the service user and their carers. It is in this context that ACIA believes that the lessons of implementing the lifetime care and support scheme in New South Wales which covers people on a needs basis who are catastrophically injured on New South Wales roads can be applied to the approval and monitoring process for providers of care and services under the NDIS and NIIS.

The lifetime care scheme ensures services users are able to make an informed choice on who will provide their care and services by maintaining a list of approved service providers who have been selected for the quality of their service so that service users know which provider are likely to be able to best meet their needs. The panel is split into three groups based on each organisational experience. As of 2011 ACIA notes that approved providers are required to achieve and maintain ACIA endorsed certification to the Attendant Care Industry Management System Standard which I will refer to as ACIMSS.

The ACIMSS certification is primarily focused on achieving demonstrable quality outcomes for service users and requires that service providers can demonstrate that they are: delivering high quality, low risk services; have appropriate corporate and clinical governance structures; have appropriately experienced management and qualified staff; have the essential financial capacity and viability; are committed to achieving continuous poverty improvement; are fully aware of and can demonstrate that they are meeting all legislative requirements specific to the types of services that they are delivering; understanding their duty of care and have developed and implemented risk management strategies.

The ACIMSS focus is on key issues required to deliver high quality individualised care within the community. It is suitable for any type of individual requiring support to live in the community and it is not limited by scope to any one particular government department or funder. ACIMSS addresses the organisational management and the quality and appropriateness of care and service delivery to people with disability, the frail aged, people with acquired brain injury and people with a physical injury. Given the ACIMSS program has already been developed as a complete national consistent standard that can and is being applied to a range of funded specialist service providers and disability support organisation across Australia ACIA would welcome the opportunity to be involved in the implementation of the commissioners' draft recommendation 8.3 which calls for the National Disability Insurance Agency to develop and implement a quality framework for disability providers. I'll now hand back to my colleague Craig Bennett who will talk a little bit about the workforce.

MR BENNETT (ACIA) : Thank you, Danielle. Just one last issue that we'd like to touch on and this relates largely to chapter 13 of the commission's report which deals with workforce issues. The commission highlights there is mixed evidence about the current severity of shortages in support workers but acknowledges that any shortfall could be much greater under this scheme. The commission notes that the degree of expansion required in the sector, along with other structural factors, population growth, competition from other growing industries with similar labour markets means labour constraints could potentially actually undermine the core objectives of the proposed scheme.

In line with the comments that Danielle just made in reference to quality, ACIA remains concerned about the lack of consistency in the quality of service delivery. This obviously has key implications for workforce issues. So therefore with an expanding sector which is going to be called upon to provide increasingly complex and diverse levels of care and services, how we locate and maintain that sufficient qualified pool of workers is only going to become more challenging. ACIA notes the commission also calls for the maintenance of low barriers to working in the sector where appropriate.

Now, this approach is obviously necessary to limit unnecessary barriers to entering the care workforce. But ACIA would argue that a quality framework, as referred to in Danielle's comments for approved disability providers under an NDIS and NIIS must include the following elements of human resource management to ensure that appropriately qualified pool of workers. So such a quality framework would need to include a system to monitor the proficiency of careworkers; identification of the scope, limitations of services provided by workers; ongoing training that ensures attainment of required careworker skill sets; systems of supervision and support appropriate to the role of the worker and the complexity of risk associated with the services provided; an organisational framework that identifies the responsibilities, accountabilities, interrelationships of each position within the organisation; position descriptions that outlines the outcomes, responsibilities, authority, accountability and the function to be achieved in each position; systems of recruitment and retention which facilitate care workers to feel supported, part of a team, valued, confident and competent; orientation and induction processes which are completed by all workers prior to commencement of duties; system of feedback to care workers about performance and clear OH and S consultation system, including mechanisms to report hazards, incidents and injuries.

Just finally one last comment. It is difficult to consider how a great increase in workforce demand could be met within the current system. ACIA believes that this position will not change unless considerable changes to pay and conditions are supported. ACIA does know that this issue is the subject of the current case being headed by Fair Work Australia under the issue of gender equity and calls on funders and price regulators of the NDIS and NIIS to support service providers to pay wages that are sufficient to attract committed workers into the sector and a pay level that is commensurate with the value of the work delivered in the community. Thank you.

MR WALSH: I've got a couple of questions. Thanks, everyone. My first question relates to the ACIMSS, the standards.

MS BENNETT (ACIA): ACIMSS, yes.

MR WALSH: Can you talk a little bit about the relationship between that and the national disability standards and what you add to the national disability standards?

MS BENNETT (ACIA): Sure. I might ask Barbara Merran to discuss.

MS MERRAN (ACIA): The ACIMSS standards have been mapped against all disability standards throughout Australia, so each state and national standard, including specific standards set by other government funders. So anywhere that there is service delivery that relates to a legislation or act, ACIMSS has been mapped against those. It also has a scope to build specific areas. For example, if you are looking at people who are ventilator dependent, then there is the scope for that area specifically to be addressed, and that's how the lifetime care scheme divided their panel relevant to the level of skill required.

MR WALSH: Thanks, Barbara. Intellectual disability, that covers?

MS MERRAN (ACIA): Absolutely.

MR WALSH: Just one more, Patricia. You talk a lot here about qualifications and the elements of human resource management. I'd like you to talk a bit about how you reconcile that with evidence we've heard around Australia that people with a disability feel that they are very comfortable having support workers that - the qualifications that we've heard time and again are attitude and aptitude, so someone that they can talk to. So I'd like your response to that.

MS MERRAN (ACIA): I acknowledge that that is a fundamental area of service delivery and the most important thing that is a part of the ACIMSS process is the acknowledgment that, first of all, the ultimate end user, the service user, has choice of provider, secondly that they then actually meet with every worker before they are taken on to determine whether they're compatible. It's also not a locked in situation. They remain, as they should, with the power of choice to say, "I thought I was going to get along with this person, but it isn't working." That is where you need a structure of providers who can then perhaps, rather than removing them from the workforce, they're shifted into another program where a relationship may be better.

One of the problems that has happened for so long where services are being bought - and I use the example of the Law Society where insurers have been buying services - it actually hasn't been about service delivery or the service user. It's a, "Let's get the cheapest product on the ground. Don't worry if they don't have professional indemnity. Just let it happen," no consideration to the service user having any involvement in the choice. ACIMSS addresses that clearly and it's a fundamental philosophical belief of ACIA that that should always happen.

MS SCOTT: I've got just a few quick questions. In your written presentation, you refer to a sufficiently qualified pool of workers and then in response to John's question, your answer, Barbara, was about the need for people to have the right attitude and aptitude and for the right fit between the customer and the provider, not the care attendant. What is your organisation's view about what is the minimum? What constitutes your sufficiently-qualified pool? Is it sufficient to have induction or it has to be a particular TAFE certificate? What is your view about what constitutes sufficiently qualified for what I'm going to call - I'm not talking about nursing care.

MS MERRAN (ACIA): No. Attendant care.

MS SCOTT: Thank you.

MS MERRAN (ACIA): That's pretty easy to answer. What I can tell you is the way the federal and most state governments have worked in the past is on what is called certification. So it might be certificate III in community care or disability care or aged care and the reality of a service provider like my own organisation - and we have 1000 people working for us - is they come with their certificate but actually don't know how to do anything. What happens in the real world and in the modern world of caring for people with disabilities is that you recruit based on the need of the individual service user.

Someone may actually come with no skills but has the right philosophy, so they would require the mandatory training of a provider that is built into the ACIMSS system which covers the basic OH and S, infection control, professional boundaries, the rights of the service user, the rights of the worker and then training modules are built dependent on the person's needs. More often than not, the person with the disability or their unpaid carer or a family member or friend may wish to be involved in that training so that the service remains consistent with how they've done it. There isn't a right or wrong and there is not one way to do one task in community care. The training has to be built around the needs of the person.

MR BENNETT (ACIA): If I could just add one point on that. When we're talking about, as you refer to, that sufficiently-qualified pool, ACIA doesn't have this idea, as Barbara was just saying, that everyone needs to have that certificate III or whatever it may be. It's about having a quality framework that is exactly what Barbara was just saying. It's matching the needs of the end user to what the organisation believe that can be delivered under some quality management framework, like how it is being achieved under the standard that we're talking about, ACIMSS. It's not about having off-the-shelf ready workers that have been trained to some specific level through the TAFE system.

MS SCOTT: Barbara, I'm interested in your views about the quality of the certificate III providers anyway. Would you like to make a few comments. I'd certainly welcome comments on that in your submission. So that is my first one and I've got one more after that.

MS MERRAN (ACIA): I have some fairly strong feelings about this and although I believe I am reflecting the belief of the industry, I have to talk about my own organisation.

MS SCOTT: Sure.

MS MERRAN (ACIA): I'll give you a very sound example, and it's an area that's been neglected. We do quite a lot of work with indigenous communities in Far North Queensland. I find it interesting that we have an indigenous workforce who have certificate III who actually can't read, don't know how to fill out a time sheet so they can actually get paid, but do know something about you've got to go to work on time. They've studied for a year at TAFE. Our answer around that is it doesn't work. It just does not work, so we have taken on a local indigenous liaison coordinator to work with that team.

It's the same as aged care. In every state and nationally there's about 50 different certificates and none of them have anything to do with the actual reality of delivering services. You don't learn how to do a PEG feed for somebody. You don't learn how if someone has a trachy, what the risks are. You don't learn any really serious issues about crisis management in the community or emergency evacuation.

With these days of floods and all the disasters we've been having of late, there is a lot of management around that. You can't rely on someone with a certificate to understand any of that. I'm passionate about it, so I could talk to you for about an hour.

MS SCOTT: I would welcome your views and, in case it's not possible within the 30 April deadline, if it's not possible for your organisation to have a consensus view on that, Barbara, I would welcome your submission just in its own right. I'm also interested in the quality of providers. We had one suggestion to us - and I don't know whether it's relevant here in New South Wales and I would welcome any comments you can provide on that in writing - that there's almost fly-by-night operations: "Attend this course, fill in this form, and at the end of the weekend you've got a certificate." I don't know if that's true, but if you have any views, a quick comment now?

MS MERRAN (ACIA): Yes. On behalf of the industry, this is very clear. The Attendant Care Industry Association I'm speaking on behalf of, not just my own organisation: anyone, you don't even have to have a certificate, can start to be an attendant care provider tomorrow and can deliver services, often through government-funded programs in all states and nationally through federal government funding without any insurances, without any requests for true management viability, which is the most important thing. It's no good in being warm and fuzzy, it is no longer a cottage industry. If you are not sustainable, you are no good to the people in the community who need the services. That person will get referrals, because they've got a nice smile or because you like the colour of their cardigan.

MS SCOTT: I'm interested in the issue of the quality of providers, don't get me wrong, but I was also interested in the quality of providers of training for these certificate IIIs, so I'm interested in both aspects. But thank you very much for your attendance today.

MR WALSH: Just one more thing, Patricia. ACIA, could you describe the representation around the country? You're represented in all states equally?

MS BENNETT (ACIA): Yes.

MS MERRAN (ACIA): Yes. Most providers these days deliver more than in one state and that's the issue; they may be New South Wales based or Queensland based or Victorian. Whilst we've talked about the Lifetime Care scheme, that's not the only funder who is using the ACIMSS system.

MR WALSH: I think it would be useful, when you send in your written submission, just if you could list the members of ACIA.

MR BENNETT (ACIA): Sure.

MS SCOTT: Thank you very much for your attendance today.

MS BENNETT (ACIA): Thank you.

MS MERRAN (ACIA): Thank you very much.

MR BENNETT (ACIA): Thanks for having us.

MS SCOTT: We're now going to have a morning tea break and, because we're just a little behind schedule, we need to resume at 10.50, 10 to 11. There are bathrooms off the side at the back and the bathroom with disability access is on the 1st floor. Inica and Peter can assist you if you need any directions. Thank you very much. 10.50 and we'll be returning with the Independent Rehab Suppliers Association.

MS SCOTT: Good morning, welcome to the hearing, and thank you for attending today. We have allocated 30 minutes for your presentation and I know you've been in the audience for a while. Feel free to start when you're ready.

MR GALLAGHER (IRSA): Thank you, commissioner. I'm Terry Gallagher, president of the Independent Rehabilitation Suppliers Association. With me is Chris Sparks, and I'll introduce Chris more a little later. From a personal perspective I should also acknowledge that I have a son with a disability that doesn't require assistive technology, just for disclosure purposes. We welcome the Productivity Commission's review as it provides the first real opportunity to discuss assistive technology with an influential group that's examining the perspective of disability support in its entirety, including the cost and provision of assistive technology and the benefits to the consumer, funding bodies, the workforce, and society in general. We thank you for giving us this opportunity to present, we see it as an exciting opportunity to work with the commission to formulate and implement best-practice provision of assistive technology in practical and cost-effective ways that ensures best possible outcomes for Australians with a disability.

We're a national representative body and our membership comprises more than 50 companies, mainly local distributors and local technical support businesses as well as national and international manufacturers. As such we provide an efficient point of contact for the commission and we hope we'll be an important ally in implementing the practical considerations of any policy program. IRSA, this month, is changing its name to the Assistive Technology Suppliers of Australasia or ATSA. This is to bring us in line with internationally accepted nomenclature for products for people with a disability. So if I slip between IRSA and ATSA, we're right in the middle of change. We've provided a detailed submission prior to today through the process, so today we would just like to highlight a few key points for about 10 minutes and then we would like plenty of questions and discussion.

MS SCOTT: Okay.

MR GALLAGHER (IRSA): I'd like to introduce Chris Sparks, executive officer of our association, a long-term wheelchair user with extensive experience with the provision of assistive technology at all levels.

MR SPARKS (IRSA): Thanks, Terry. Commissioners, we'd like to talk about timely access to appropriate assistive technology being a primary enabler for people with disabilities. I'll talk more about that a little bit later. We believe it's often critical for health and wellbeing, it increases independence, improves workforce participation, reduces caregiver workloads, and certainly provides for more rewarding life experiences. Where I think our organisation stands apart is that our membership is working day in, day out with occupational therapists and people with disabilities, implementing solutions, making assessments. We're at the forefront of cutting-edge technologies and it means we bring practical knowledge to the fore from lots of different sources. Much of the skill and knowledge base for the efficient prescribing and fitting of assistive technology resides predominantly with suppliers and manufacturers, and some specialist therapists working at specific centres of excellence, such as spinal units, for example, or cerebral palsy associations.

Our membership, we believe, assumes a much broader role than normally performed in a standard industry environment. Some examples are that we work with government and bureaucracies to ensure practical considerations are considered a priority in policy development; we work closely with therapists in their professional associations to deliver training to improve outcomes for assistive technology users; we work with funding groups to develop effective new policies; we're working to maintain standards through regulatory compliance with things like the Therapeutic Goods Administration and compliance with our own mandatory internal code of practice; we provide a point of information for flow to our clients, therapists, and also businesses; and we work directly with end users to ensure the appropriate prescribing and fitting of assistive technology and with local distributors who often develop great empathy with end users through a lifetime of service and contact.

We believe it's critical that an industry group is involved in the process of developing an effective assistive technology funding platform within the NDIS. There's evidence to suggest that assistive technology provisioning systems that have been developed without supplier input can be some of the least efficient, the costliest and provide people with disabilities poorer outcomes. When I mentioned the phrase before "primary enabler", from a personal perspective, all the access to training, education, job opportunities, respite care, et cetera, frankly for me is useless if I don't have my wheelchair and my cushion. I can't get out of bed, I can't exploit all those other opportunities without the primary enabler being my piece of assistive technology. We know that it's sometimes very complex, but in the vast majority of cases, our members deliver this service efficiently and effectively, often despite unwieldy funding systems.

Just touching on the current systems. There have been some significant improvements in state based systems in recent years, but I've got to say it's disappointing to advise that currently in Australia we believe there is no program that we would recommend wholeheartedly to the commissioners. We see that most schemes act as gatekeepers and limiters, rather than working towards optimal outcomes. We're optimistic that there's significant efficiencies and savings to be gained through a national system.

An example that the commissioners may wish to investigation is the Danish system and some of the philosophies that underpin their provision of equipment and assistive technologies. We're happy to provide further detail on that. We also know that the question of what should be funded is often quite vexed and as you look around Australia today, what is funded in one state jurisdiction may or may not be in another. The extents of funding vary greatly, as I'm sure you're aware.

We would like to refer the commissioners to ISO 9999, the assistive products for persons with a disability. On page 1 the scope clearly states what should be excluded. We believe that this will help to ensure that the new scheme does not cover products covered under other programs, such as medicines or implantable devices. It also has the benefit of aligning Australia's scheme with international schemes. It's often difficult for those outside the assistive technology network to grasp the inefficiencies and failures endemic in existing systems and the associated costs and wastes.

I note that one of the commissioners is a spectacle-wearer, as am I. I doubt that you would go to an optometrist, take time out of your day, spend your own money or the government's money to get your eyes tested, receive a prescription for new spectacles, go home and then order them one to two years later and discover you need a retest. That's what goes on every day with the provision of assistive technology. There is huge waste in the system and the person with the disability suffers. Could you imagine going to your doctor and you get him or her to prescribe a medicine. The doctor then rings around a few pharmacies to see what price he can get. He then contacts the funding body to see how much they'll pay and when he sees a shortfall, he'll call three or four charities to help you get your medicine. Again, that's what happens with assistive technology.

Purely from the perspective of the supplier, imagine if you're running a small business that sells whitegoods, sells something specific like a refrigerator, which is about the same price as a good custom manual wheelchair, as a supplier you'll get a call to say, "We need a fridge. Please bring three or four different models out for us to have a look at. We then expect you to leave the one we prefer most with us for a week or two. Please come and install it and if you need to do something to the kitchen, it will be to your expense. After we've tried your fridge for a while, we might get another one or two suppliers to do the same and after some months or years when we get the funding, we'll go and buy one. You will probably need to bring your fridge out again to check that it still meets our requirements. If the kitchen has changed, we'd like you to rework it at your expense. We'll tell you exactly what configuration of fridge we want and your factory will make it specifically. Please deliver it and then sometime over the next few months we'll try to pay for it. We may need a co-payment from our flatmate, so I hope you're reasonable in collecting that payment as well."

I don't mean to be glib about this, but these are the realities of the schemes that we deal with today and it's one of the reasons we're buoyed and we're so optimistic that as you move forward, we can help to build a far better and more effective scheme that will deliver better outcomes for people with disabilities. Terry?

MR GALLAGHER (IRSA): The draft review stated that disability support is under-funded, unfair, fragmented and inefficient. Our association is keen to participate in the process to address these issues and ensure better outcomes for people with disabilities from the national scheme.

MR WALSH: Thank you. I've got a couple of questions. The first one is on the definition of "assistive technology", you imply that it covers other than medical and implantable devices. Is that a fair summary of where it begins and ends, do you think?

MR GALLAGHER (IRSA): If we refer to ISO 9999, it basically says "used by a person with a disability, but the following items are specifically excluded," and it excludes medicines and implantable devices, and that's to differentiate between an artificial limb - - -

MR WALSH: A pacemaker is not included.

MR GALLAGHER (IRSA): A pacemaker would not be included as an implantable device and that's the way the international standards are going, because it is a vexed question, but they're more medical requirements, rather than - - -

MR WALSH: Is that a reasonable definition for us to use in what we call aids and appliances equipment?

MR GALLAGHER (IRSA): We suggest that in the development of any schemes in Australia, the closest we can get to international standards will be more efficient and save time and cost down the track.

MR WALSH: I understand all the delay stuff and predominantly that's, you think, funding and inefficient systems and regulations and so on. With respect to the efficiency of the industry, I'm interested in any views you've got on the extent to which the industry will change under a different and more effective funding model and in particular I'm aware that a lot of overseas countries, for example, have aids and appliances that are not as expensive as they are in Australia, so the extent to which there are efficiencies to be gained in a larger scale of operation and the international market.

MR SPARKS (IRSA): I think it's important to understand what I talk about, the assistive technology pyramid. Down the bottom you've got fairly simple aids and equipment, generally higher volume, lower cost. Simple things, standard wheelchairs, rollators, crutches and canes, et cetera. As you come up through that, the complexity increases, generally the cost increases and the volume decreases. That's how the market is. I think you need to consider systems for the differing levels of equipment. For example, there's a PBS-style system for low-cost simple aids and equipment in the most efficient way where a therapist can give somebody a simple script and any authorised or accredited provider, they can take that and they can get their aid, know that it will be fitted appropriately and the job is done. It's quick, clean and efficient.

As you climb up through that and the complexity increases, necessarily the complexity of the provision process has to increase, trialing becomes necessary. You need to take all of the quasi-medical considerations into account, such as pressure care, long-term positioning, long-term wear and tear on a person with a disability's body to maintain them for as long as possible. Our biggest inefficiency we see there is the assessment and re-assessment process, and it impacts on everyone, including the person with the disability. We hear commonly occupational therapists with case loads where you can't get to see them for six or eight weeks, yet we then get them to do a full-blown assessment, which is a very involved process for someone at the complex end.

We then park that while we sit back and we wait for funding. There are so many gatekeepers and steps to go through that it can be, in some state jurisdictions, six to 18 months before that funding is approved. Then we redo the whole process. It costs tens, if not hundreds, of millions of dollars annually and I'm sure the business is passing part of that cost on to funding schemes. We've finally got the New South Wales organisation, EnableNSW, to come and sit at the table and see if there's a better way to handle the process, no more funds required, but to get rid of those inefficiencies, and it will save them.

MR GALLAGHER (IRSA): Commissioner, just on that as well, we have had brought to our attention by people at various times saying they can buy a wheelchair over the Internet for X, and people can do that, but on every occasion that we have investigated it doesn't include the seating systems that have been previously quoted, so it's a standard wheelchair without the support and all the extra accessories generally required to appropriately support a person with a disability. There has been a number of those brought to our attention, and in those cases it has proven that you do compare apples with apples.

MS SCOTT: Gentlemen, I have got a few questions and a few requests, in terms of what might be in your submission. You would have seen from our draft report that we find illustrative examples quite powerful, people can relate to that where they can't relate to generalisation, and we're looking for evidence of problems. So I'm interested in any material you can provide us where something would have been clearly needed by an individual with a disability and yet your service providers had to wait till they raised money through charities. I mean, I have heard of Rotary clubs and Lions clubs providing wheelchairs for, clearly, children who needed them. But I'd like to have some examples, and if you can actually give me real-life examples that would be useful. I'd be also interested in any views you have about the efficiency loss as a result of having a federation arrangement for disability services in Australia when it comes to what might be gained by moving to a national approach, as we have suggested here.

MR SPARKS (IRSA): It's interesting that both New South Wales and Victoria have looked to centralise their funding schemes, the A and EP in Victoria and the PADP in New South Wales, and there's swings and roundabouts. We are seeing a lot more equity and fairness than ever before. Our industry knew that where you lived dictated what you had access to and how quickly you could get it. From a purely commercial perspective, the administration is light years ahead. You're dealing with one administration, instead of 16 or 17 doing it all their own way. So we're starting to see greater efficiencies.

There has also been a loss of knowledge on the ground close by, and where we see that most evident is in the area of repairs and maintenance Both schemes have stumbled in this regard and have had to address their early moves. In days gone by, the local area health coordinator knew that if you needed this type of repair so-and-so did it very well and very affordably; they knew if you had to go up to a complex repair, like a powered wheelchair for a ventilator-dependent quadriplegic, you called a different company, they understood all of that.

When it was centralised New South Wales went to a process of quoting. So you'd ask some fellow who has got a business on the northern beaches to drive to Kurnell to quote in the repair of a man's powered wheelchair. That person is used to the repairer turning up and fixing the chair. But not today. He turns up, does a quote and leaves. The irate end-user has steam coming out of his head, and everybody loses. So that was an example of a strategy that was embarked upon through the centralisation process, no negotiation with industry, and it was flawed, it drove costs up, and we had to take a step back. In terms of the general provision of aids and equipment, the centralisation processes are very good and I think the Department of Veterans' Affairs has some lessons to be learned in that regard.

MS SCOTT: That's a good suggestion, for us to talk to them. If you would chance your arm at services, not so much centralisation of services, but centralisation of accreditation or the list of aids of appliances and so on, that would be useful, and then what services you think should be ideally at the region and what discretion you think individual case managers or the regional officers should have, I'd welcome that, because you have seen various schemes. In relation to the ISO 9999, we will have a look at that. But just as a quick remark, I wonder whether it ends up including things like stand-up wheelchairs, and things like that, that in fact it's so broad that committing to that standard could mean that you would inevitably have then enormous cost pressures on the scheme because effectively the list is so large and so encompassing.

MR SPARKS (IRSA): We can make comment on what is on the list. Our comment to that is that if a stand-up wheelchair took a person back to their original occupation and the average cost of that stand-up wheelchair over their lifetime would be a maximum differential of maybe four to five thousand dollars a year, if the person went back to their original occupation, surely that benefits the system.

MS SCOTT: Good point. I'll think about that one. You made an observation about there being no state scheme that you can point us to that you think we should try and replicate. All states have particular strengths in some areas, and I guess weaknesses in others. Some states are more forthcoming in accepting that there are weaknesses in their systems than others. Could you make some observations about where you see, from your national perspective, particular strengths in the provision of aids and appliances, and why you see those jurisdictions as particularly good, and then maybe contrast that to a state, where you think arrangements are particularly disadvantageous for consumers and what that is disadvantageous. I'm interested in the scorecard, basically.

MR SPARKS: We would be happy to. One of the other facets - and we constantly raise this with the state jurisdictions - is a transparent streamlined and efficient way to adopt new technologies, because the old government purchasing regime of, "Let's go to contract and lock it in for the next two or three years and we'll get the great price," frankly, is totally flawed. We are constantly seeing new products coming out that are cheaper, have longer warranties, more facilities, more benefits to the end-users, and there needs to be a method to adopt them rapidly.

A case in point, I was talking to a parent of a disabled child who needs communication devices, and she said, "Isn't it great we have got the iPad? I'm finding apps that can help my child communicate. So for less than $1000 I can achieve pretty much what a $6000 aid used to cost me." She said, "I wonder how the funders are dealing with that." It's that inability to rapidly adopt new technology that disadvantages people with disabilities and adds cost.

MR GALLAGHER (IRSA): Speaking specifically to your question, Queensland, for instance, does do more timely provision of assistive technology to their clients, but they have a ceiling cap and so there is often a co-payment required. New South Wales will fund the total expense of the powered wheelchair or the lifting aid or whatever is required, but you may actually have to wait 18 months for that. We could put the best things together and highlight on an individual state basis what we see works and does not work.

MR WALSH: That would be useful. While you're doing that - and you mentioned the PBS before and the PBAC - if you have a think in terms of how it would work. So we know that industry and manufacturers will build bigger and bigger and better and better, as long as it is paid for, but there's clearly a limit on what should be paid for. I mean, a stand-up wheelchair might be a good example. If everyone went back to work using a stand-up wheelchair, that would be a good cost benefit; but if only one in 50 do, it's probably not a good cost benefit. So any things you can think about. Okay, let's suppose a scheme where you get the script for a wheelchair, say, that might allow you to buy a manual wheelchair worth two or three or whatever thousand dollars, but not a $10,000 one. Any advice you have got on those sorts of ideas would be useful.

MR GALLAGHER (IRSA): We have been investigating different schemes around the world, because we anticipated questions like this, and, as we say, we'll provide information on it. But our preliminary investigations show that they have been answered, saying the Danish scheme or other such scheme, so we will be able to provide that.

MR WALSH: Any data you have got on the market size would be useful as well.

MR GALLAGHER (IRSA): It would be useful for us too, commissioner.

MS SCOTT: We actually have an opportunity as a commission to meet with disability ministers soon, and so while the deadline for your submission is 30 April, if we could get information within days on your scorecard of state arrangements, strengths and weaknesses, that would be very much appreciated. We would hate to have that information after our conversations with disability ministers.

MR SPARKS (IRSA): We'll see what we can do.

MS SCOTT: Just one thing. I guess when I first heard you say that you wanted to be involved in the process, effectively of design in some way, of the scheme, I was a little bit worried about conflict of interest. But, if I understand you correctly, the idea of keeping you at arm's length from the design of individual schemes has sometimes been at a loss of efficiency for the taxpayer, because the process doesn't work for your members or people are ignoring opportunities and so on. But how would address the concern that, quite reasonably, you have got commercial interests involved and your members' commercial interests? How do you reconcile your involvement in an area where normally you try and keep potential providers at arm's length from the design of a system?

MR SPARKS (IRSA): I understand that sensitivity, and we encounter it everywhere we go. The fact of the matter is in the provision of equipment there are generally four key stakeholder groups. It starts with the potential consumer and their immediate family and caregivers; you have then often got an independent therapist advising; you have got the funding bodies; and you have got the suppliers. To me, unless you galvanise the knowledge of those four groups, you will end up with an inferior scheme. What our organisation offers is - our organisation doesn't sell anything, we have no transactions or anything, we simply have knowledge to bring. So depending on how you fashion the scheme does not benefit our organisation.

Our members, some will have wins and some will probably have losses, like out of any new scheme. But I firmly believe our organisation as an independent group has no conflict of interest, because we are not peddling any wares to you, we are simply offering advice. It has been shown to be a failure in previous schemes where they haven't consulted the industry to ensure that the scheme will work for those four groups.

MS SCOTT: In relation to chapter 17, about implementation, you may want to have a look at where you think your involvement would best occur. We are not getting down to nitty-gritty details of guidelines and the transition arrangements, but you might have a look at that chapter and see in particular where you think your engagement would be appropriate. Thank you for coming along today. We look forward to your early advice in the next few days, and then your submission before the end of the month. Thank you.

MR GALLAGHER (IRSA): I'd say you're looking at by the end of this week.

MR WALSH: Thank you very much.

MR SPARKS (IRSA): Thank you very much.

MS SCOTT: Good morning, Adam. We have allocated 30 minutes for your presentation today. So we're going to go right through to 12 o'clock, and then it is going to be lunchtime. So you might take that into account in keeping to your 30 minutes, please. Would you like to commence? Just say your name, just to see if it's coming through clearly.

MR JOHNSTON: Adam Johnston.

MS SCOTT: Great. Please commence.

MR JOHNSTON: My name is Adam Johnston. I appear here in a private capacity. I have appeared here previously about this matter and I have consulted your draft report and the overview of the draft report. I have read what I can of the full report online. I must say I still have some concerns that I'd like to outline to you, the first of which is really the viability of the funding scheme. This is a scheme as you design it which is pretty much run by government, or government agents. It is run in the context of an ageing population and a reducing tax base overall.

You do indicate that there may be an element of raising certain taxes, but, as I have said in my second submission, the prospect of raising taxes is always a difficult political manoeuvre, particularly when you also suggest that governments may have to re-order priorities at the same time. Now, the political difficulty there is of course, how do you tell the people who suddenly don't have the same priority that their priorities have been re-ordered. So I think you're asking government to do two almost impossible things, and it really concerns me that that may be the end of all reform, because I see that there are important opportunities for reforming this process.

I would draw your attention, because I know at least one of the commissioners was on a prior inquiry which was called the Disability Investment Group, and the thing I noticed about that report which I'd like to emphasise when talking about this is that you did set out in that report international savings plan models, and that was on pages 26 and 27, and that did involve not only government but a high degree of private savings and private sector involvement. From what I have seen overall, it is a concern that the schemes you're proposing in this context are, largely, government based schemes, because I think there is an opportunity for greater private sector involvement and that greater private sector involvement actually increases choice for individuals and families.

I would also draw to your attention the difficulties with publicly providing anything, noticeably Medicare. Medicare is a wonderful idea in principle, but over the 20 or so years of its inception we are still having long hospital queues. We could still end up with a system in disability where you get long queues, particularly at the high needs end, unless you put in very stringent management schemes around tiers 1 and 2. One of the recommendations which I have outlined in my submission at this stage is that you give serious consideration to not having tiers 1 and 2, because advice portals and people producing papers and brochures, and awareness, that's sort of a honey pot for spin doctors and advertisers, and it's not actually core services.

So I would think very closely about whether tiers 1 and 2 are sustainable and whether they can be capped because in the Medicare example and I drew your attention to a recent paper by Dr Jeremy Sammut of the Centre for Independent Studies, he has analysed Medicare and worked out that the PBS and the medical benefits scheme at the front end of medicine is the real cost. But what that means is governments have then capped hospital and complex care to stop the budgets getting out of control. He has again recently released a paper on the economics and the problems in that and I recently attended a speech where he presented that paper and I parallelled that to the potential here.

MS SCOTT: Adam, are you comfortable if we maybe pause at various stages just to clarify things or ask questions? Is that all right?

MR JOHNSTON: Yes, certainly.

MS SCOTT: I just want to check on your understanding of what we've written. So when you say you'd favour greater opportunity for private sector involvement, that's actually in the administration of the scheme. So could you talk a little bit more about that because, as we've tried to make it clear in the report, the actual provision of services, the actual provision of attendant care or aids and appliances or so on, that would be left to the market. Some people could choose to use non-government organisations or they could choose to buy an iPad if that was their best communication device and so on. So I'm just interested in whether - - -

MR JOHNSTON: Yes. Look, I understand that, let's make that clear. But let's unpack what that actually means. If you're having an NDIS when that is set up where will that look to refer people? It will refer people by and large, I assume, to the already established bodies and agencies. So for all the arguments that this will result in some form of change, I see it as almost reinforcing the status quo and I also think in terms of the claim about the private sector being involved, with a lot of the NGOs - and, I mean, I've had contact with some of them and I have been involved with a few of them which I openly declare - they are heavily reliant at times on government grants. So in many respects they're not fully private, they're actually a semi-government organisation.

What I have said to you in my submission is actually what I'd like to see the body do - if we indeed do need to have an actual body - is for it to encourage the selection of other agencies or smaller agencies and even to the point of people being able to select staff out of whatever agency they choose and hire them directly.

MS SCOTT: I suspect, Adam, when you get a chance to read more of the report you might find that you see more of your ideas reflected in the report than you may think just from your preliminary reading, and I refer you to page 32 of the overview and chapter 8 of the main report because it's clearly our intention, and maybe we need to be clearer about this, that individuals will choose who their service providers are and some people will be able to actually get funded packages that they are able then to manage and spend, within reasonable constraints, on the services they want. I think the diagram on page 32 does seek to represent the system as we see it operating. I just wanted to clarify that as I think there is not a complete understanding on your part about what we're proposing in terms of the role of the market in the operation of the system.

MR JOHNSTON: I concede at this early stage that I'm happy to review that point. What I would say though is that there is still a key role for people called case officers, advisers, therapists and things like that. I would just like to flag with you, as I have in the submission, that one of the problems you often find as someone with a disability is that to get anything done you have to run a gauntlet of people whose agendas may be somewhat unclear, whose sometimes professional judgment you may doubt but they seem always to be gatekeepers - and not necessarily the best gatekeepers, I might add - to a whole range of goods and services.

Now, I acknowledge that in some respects people do take a degree of comfort in these professional reports but I state on record that there are some professionals who, in my experience - you know, I and many other people would know far more about our conditions, both medically and practically, than some of the professionals - and these will be may of the same people that we have to deal with and negotiate with to get through the system that we have now - know about us or our needs. They can also, if they hold the power of approval or disapproval of a proposal, exercise that power very negatively towards the person concerned and their family. I refer you back to my first two submissions, particularly the first one where I outline experience exactly with an attendant care body.

Now, I would still assert that many of the difficulties, many of the elements that are, shall we say, negative about the current system are retained and I think we really do need a greater level of scrutiny and accountability around these advisers and these therapists and I have gone to some length again in my submission to suggest that people also be able to challenge the therapist's opinion and potentially move their fund from one service provider to another so that there is a counterbalance in an approval process so that the end of an argument will not be, "Oh, you have to wait for the assessment," because that line shuts down every part of a debate. It has for me in the past and to overcome it you have to get to the point of writing to managers, directors and making ministerial inquiries. This problem potentially remains and is potentially enlarged by a national system.

MS SCOTT: Again, we've sought to address the concerns we heard in the first set of submissions, including your own, to look at providing people with greater choice and more confidence about complaints mechanisms and the greatest capacity for people to exercise choice is the strongest discipline on providers that they know they may lose customers because they may go elsewhere is a powerful thing.

MR JOHNSTON: Look, I accept that but can I also add that really a significant element would be that they could also lose staff because - a real benefit would be if the client could take staff with them.

MS SCOTT: I just want to check, Adam: that's the idea that you might find the individual attendant carer quite good but the organisation that they work for hopeless.

MR JOHNSTON: The management hopeless, yes; so the ability then to take the staff.

MS SCOTT: We do suggest that people, if they have got an individualised funding package, if they wanted to go down that route, subject to certain controls, that they could actually hire staff in their own right or make an arrangement through a third party. I think we may have addressed your concerns on that but we welcome of course your further submission once you get a chance to get on top of the detail.

MR JOHNSTON: Again, I guess my major worry would be the level of potential control that a body would still have over families and individuals. I again put on record that people can be intimidating, even in the alleged caring sector. Still, this is a government-centric model from what I can gather. The insurance scheme is an under-statute of the government. That inherently means something about how it might plan and how it might be centrally planned. Can I also then raise - there are articles on the failure of central planning, even from Soviet areas, which I'm more than happy to provide you with, but that makes the point that the more something is centrally planned, the more the central planner loses touch with individual needs and assumes that everybody fits neatly into boxes. That is the problem we have now and again, my fear is it might be continued in some way.

I also wanted to raise just one concern about the model of hypothecation of the tax system. Now, I note from your report that is not actually the model that is supported by Treasury because it's earmarking, so my immediate concern with that is if it's not the accepted framework for doing things, would government seriously look at the model if it involved a form of taxation which is not approved of. Again, I also acknowledge that earmarking is a very controversial subject in the US, part of the budgetary problems, that to get things through, moneys are earmarked, budgets are not followed.

There's a very interesting paper on economic incentives and tax hypothecation by Alan Duncan and Andrew Jones from the University of York which says while it's useful at times, it does raise certain dangers. It's not always guaranteed to grow and the part of the budget that is not earmarked, potentially the government can pull back on other related services to try and make it balance. So there could be unintended consequences of earmarking certain moneys.

MS SCOTT: Okay. On that one, I wouldn't mind having a little bit of engagement on that. I'm going to let the concern about Soviet central planning go through to the keeper.

MR JOHNSTON: I just use that as an example because in my own life - and I state this quite honestly - sometimes I have felt that it has got to that point. I'm not trying to be melodramatic, I am simply trying to state that the entourage, OTs, physiotherapists, reports, papers, appeals, it really does begin to grate against you, and I do raise that advisedly.

MS SCOTT: In chapter 12, we do have a discussion of the benefits and the pitfalls of hypothecation earmarking and I'd welcome your comments, once you've had a look at that chapter, whether there's another argument against earmarking that we need to include, but we have I think drawn on many areas of study to highlight that there are some pitfalls with hypothecation. But in some cases, as alluded to in your reference paper, it can actually be an appropriate arrangement. So I think you and I would agree that we need to go into this very carefully.

MR JOHNSTON: Yes.

MS SCOTT: One of the comments you made was that of course if a particular form of tax is hypothecated and that tax doesn't prove to be sufficient and then you have an issue, that's why we have suggested in part in the draft report that the earmarking occurs through a formula on general revenue rather than on a particular tax, in part because of that risk but also because we envisage that there will be, over time, tax reform and more efficient taxes will emerge or be used and it would be disadvantageous to suggest the government locks in on a particular form of tax. So I just wanted to address that particular point you had. I also suggest that if you look at the Henry tax review, there's a section in there about earmarking taxes in relation to Medicare, I think it's page 326, where it does say that while Treasury specifically doesn't support earmarking, it then goes on to suggest that it would be better to have things expressed as shares of general revenue, rather than to have particular earmarked taxes per se. So you might find that your disquiet at having a hypothecated arrangement suggested in the Productivity Commission report is allayed a little bit with those two sets of discussions that I referred you to.

MR JOHNSTON: I accept all of that and I take it on notice. I will continue to, in a detailed fashion, examine the report and watch the debate as it develops here. Again, I will concede I am not at heart an economist but the paper I referred you to, some parts of which I have here and I'm happy to provide to you, it's available online, did seem to indicate that there could be significant changes with only minor amendments to a particular flow line or a particular quantity along certain theories and baselines and quotients that econometrics people use. That was something that sort of flagged with me that there still could be a great degree of variability.

MS SCOTT: I think you will see that chapter 12 addresses the concerns about variability. I won't labour the point. Please proceed.

MR JOHNSTON: That covers most of the issues that I wanted to address to you. The only other issue that I really do want to raise is I know from the report you seem fairly committed to moving forward the idea of insurance for disability. My concern with that is that one of my other clear interests is the advancement of medical research. I would just put to you that within the next 10 to 20 years, we could be looking at a very different world and hopefully you and I won't be in these things any more, these wheelchairs, and I think that's a real possibility. There is real scientific research going on about the regeneration of nerves, cells, the regrowth of body parts, things like that, both here and overseas. I also note that scientists in Australia are currently debating quite forcefully and in public the merits of withdrawing or holding certain research funds. Now, there is a certain degree of choice between insuring for something and deciding that disability is going to continue or also deciding that there is a real possibility for cure or amelioration of disease and a question of priorities.

I know that you have indicated that you're looking for new funding of a couple of billion dollars, I think the figure was $6 billion, and particularly with current events, I just wonder what that $6 billion could do in the scientific field, because again over the past several years, my thinking on disability has changed in terms of not seeing it as permanent but seeing it as temporary. Look, I'd prefer to see it as temporary and therefore I have a bias towards the sciences, I have a bias to see them continue. I hope that they give some ground in relation to the Patent Act, so that people have more ready access to the outcomes of science and it's less costly. I would ask you to consider that in making public expenditure for an insurance scheme that there may be an opportunity cost in other areas, particularly science advancement, cures and amelioration of diseases that we're insuring for.

MR WALSH: Thanks, Adam. I think you make some really good points. I think as Patricia has pointed out, I think that the report does find ways of meeting most of your concerns. We have recommended in the report an enhancement or research funding in disability. It's been poorly funded in the past. I think the basic research you're talking about in terms of nerve regeneration and so on is covered pretty well in most medical research. The NH and MRC funds somewhere around eight or nine hundred million dollars a year in terms of basic research, so I think that's well covered in the medical area.

MR JOHNSTON: I can say that that is what I'm talking about. Look, while I appreciate that these are in most ways separate issues, I simply want to flag with you that there is an opportunity cost and that there are always competing interests when it comes to government expenditures. Look, I'll be quite open: I will take scientific research with the potential ahead of a guaranteed insurance program for the simple reason that from what I read, the science is really moving ahead and it literally could produce a lot of positive outcomes fairly soon. Now, I know that this scheme has certain benefits to it, but again I guess you've just ultimately got to make a choice in the end about I guess quality of care now or the potential in the near future of not needing anywhere near the same level of care that you might have, because that which afflicts you will likely be eliminated for one reason or another.

MS SCOTT: All right. Thank you very much. I take it that you've wrapped up now?

MR JOHNSTON: If you have any further questions - - -

MS SCOTT: No. Adam, thank you very much for coming along today and for your earlier submissions and we look forward to getting your further submission. Thank you. We can now break for lunch and we will be resuming at 1 o'clock with People with Disability Australia. Thank you.

(Luncheon adjournment)

MS SCOTT: Good afternoon again and welcome back to our hearings. I now invite People with Disability Australia to come forward to the table, please.

MS DAISLEY (PWDA): I'm Jan Daisley. I have prepared (indistinct) thank you for having us here.

MR CASSAR (PWDA): Firstly, can I congratulate the Productivity Commission on a comprehensive interim report into the issues that pose challenges for people with disability in receiving the support they need and in providing recommendations to address these challenges. We welcome the significant reform the interim report is calling for. With the review of lifetime care and support for people with disability Australia has the opportunity to provide significant positive change for people with disability. It holds the promise of creating a support system that is genuinely in the control of people with disability and not the service system.

For too long the service system has dictated when we will receive a service, how we will receive a service and what kind of service is best for us. In my own case the service system detained me in an institution for 30 years in order to receive the supports I needed. Myself and fellow residents had to fight the service system to be able to live where we wanted in the community, in an ordinary street in an ordinary suburb. I was told I wouldn't last a week, but I have been living in the community for the past 17 years. I know what is best for me, what I need and how I want to live, and I want the service system to support this, not the other way around.

Significant positive change for people with disability can only occur if it is based on the principles and rights outlined in the CRDP, United Nations Convention of the Rights of Persons with Disabilities. CRPD should be the guiding framework for a new system, and the aim of a new system should be to achieve human rights outcomes. There is very little reference to the CRPD in the interim report, and that is of concern to us. It will be very important that the final recommendations from the Productivity Commission are in line with the CRPD. In this regard PWD is working with other disability representatives and advocacy organisations to undertake a human rights audit of the recommendations from the interim report, and we will submit the audit to you once completed.

We would also suggest that the Productivity Commission seek advice from the Australian Human Rights Commission about your final recommendations and CRPD compliance. People With Disabilities Australia will be providing a comprehensive response to the interim report of the Productivity Commission and will be seeking to address all of the outstanding issues that you are seeking further information on. Today I wanted to highlight some key points that I believe are critical if people with disability are to achieve human rights outcomes.

These key issues are, firstly, self-assessment by people with disability. The next system must allow people with disability to have control over the assessment process. Self-assessment tools can be based on independent objective criteria and contain an assessment of the barriers people with disability face in achieving inclusion in all areas of community life. The international classification of functioning, disability and health, ICF, is a potential framework for the development of a self-assessment tool. PWD is currently working with Sydney University to test such a self-assessment tool with our members and with other people with disability, and we will be providing the Productivity Commission with our results.

Secondly, governance by people with disability. The interim report recommends the establishment of a disability advocacy group rather than have people with disability on the governance body of the new National Disability Insurance Agency. While the governing body may require expertise to meet financial insurance and management expertise, as stated in the interim report, this does not mean that people with disability do not have this expertise; nor does it mean that expertise about the delivery of supports for people with disability is not required. We argue that this expertise is essential and the inclusion of people with disability is critical to obtaining this expertise.

Thirdly, people with psychosocial disability and chronic health conditions, such as those with HIV, must be included in a lifetime care and support scheme and not be confined to support only from the health system. There must be a clear distinction between those supports which are provided under and NDIS disability and nonhealth-related supports and those provided as part of ongoing health and medical care. This reflects the social model of disability that underpins CRPD and recognises that medical and health-related needs and only a part of the support needs for people with disability. Thank you for the opportunity to appear before you today, and I am happy to answer any of your questions.

MS SCOTT: Thank you, Jan. Thank you, Peter.

MR WALSH: Thanks, Jan. Thanks, Peter. Yes, I do have some questions, not specifically about your presentation, just to get some advice really. We say a lot in the report about the change that's needed both for people with disability and for service providers, and basically we're suggesting flipping the scheme upside down so that people with the disability, the support users, are able to frame and request the supports that they need. If you have got any thoughts on what needs to be done to make that change, I'd appreciate it. Given that you have been living with a very significant disability in the community for so long, any lessons we can learn from that experience?

MS DAISLEY (PWDA): Lots of people like myself know what it's like to live (indistinct) they don't what it's like to live with a severe disability. I have a very severe disability, as you can see. I have never let it stop me doing anything I wanted to do, but living under a service provider I find it very hard to have my needs met as an individual. I have to (indistinct) to other people's needs. To me it is wrong. I have a life and I want to live my life my way and do what I wish to do, where other people just take it for granted. Years ago I decided that I wanted to go to university and my supervisor told me I had to find special aid, couldn't afford it.   So I did that. I have two degrees. But it's always a fight, it's always over money, can't afford it, and therefore when they assess you they can't afford to let people have a life and do what they want to do.

MR WALSH: Thank you.

MS SCOTT: Do you have any idea when the work of your organisation with Sydney University will be available in terms of self-assessment?

MS DAISLEY: I'm not quite sure. I can find out and let you know by 30 April. I will ask for sure.

MS SCOTT: Thank you very much. Jan and Peter, thank you very much for presentation today.

MS SCOTT: I now invite to the table Trevor Robinson, please.

MR ROBINSON: Good afternoon.

MS SCOTT: Trevor, we have allocated you 30 minutes.

MR ROBINSON: Goodness gracious. Well, I'll try not to take up too much of that time. Unfortunately, I have been unable to make all of these committee hearings, simply because the gods have been conspiring against me. But anyway, if I can go from my prepared notes?

MS SCOTT: Please do.

MR ROBINSON: Firstly, allow me to thank you for providing me the opportunity to comment on the disability, care and support review by the Productivity Commission. Due to a myriad of competing tasks I was unable to attend the various consultations the Productivity Commission had on the subject. Therefore, to be here greatly satisfies my democratic drive. I'm from Canberra and you had yours in Canberra last Friday.

Before I detail the crux of my argument against - and I'm not for the NDIS model - let me outline my credentials for providing evidence at this inquiry. Hopefully my experience and expertise qualifies my rationale of reasoning to my evidence. First and foremost it demonstrates my family's first-hand experience of a dysfunctional disability system and our genuine and, importantly, pragmatic desire to get things right for the betterment of people with a disability. Secondly, my evidence has a high degree of academic credential and validity towards and from a social and disability perspective. We have no funding master to please, no political agenda to push or personal aspirations to be recognised or accredited. We just seek an egalitarian Australian where everyone is valued and no-one is singled out.

Trent, the eldest of my four sons - and that was my youngest that provided water - was born 26 years ago with a severe developmental delay resulting in significant brain damage and epilepsy. Consequently, Trent has a cognitive age of a three to five-year-old with very challenging behaviours that require 24-hour supervision and attendance. Despite Trent's severe disability, we have lived and worked in many different locations, from the highlands of Papua New Guinea to the goldfields of Western Australia, and because we have lived in various locations, we have first-hand experience of disability service in New South Wales, Western Australia and the ACT. We currently live in Canberra.

Due to Trent's challenging behaviour and recent changes in family dynamics Trent lives in emergency supported accommodation in ACT supported accommodation. Trent has been in this emergency accommodation for almost seven years.

MS SCOTT: Trevor, because you have half an hour, is there any chance you could just slow down a little bit.

MR ROBINSON: Sorry.

MS SCOTT: I'm taking down a few key notes.

MR ROBINSON: I get told that a lot. During these seven years we have hear promise after promise of permanent accommodation with the only surety of the next glossy government report stating that everything in disability is rosy. As for myself, I was involved in a motor vehicle accident in 2008 which left me a complete T5 paraplegic. Neither my wife nor I sat on our hands during the 26 years since Trent's birth waiting for someone to help us with Trent. We became very proactive and vigilant on disability issues. My wife and I have been heavily involved in disability issues service members of various committees, groups and panels. Until February of this year I was chair of the ACT government's disability advisory council, a position I held for three years. I was also a member of the ACT accessible transport group, the taxi panel review, the ACT strategic governance group and a working group looking at reviewing the ACT Disability Services Act.

We had to be proactive on Trent's behalf and lobby, threaten or plea. Trent would have floundered if we had waited for services to come to him. From an academic perspective, I have a masters of applied anthropology and participatory development, a masters in marketing and communication and I'm tinkering with a masters of social research. Most of my research has concentrated on social attitudes of people with disabilities, specifically family and focus on spinal cord injury as well as the attitude of others towards people with disabilities.

The introduction is done. Now, let me state that I'm here as an individual representing only my family's interests and opinions. Furthermore, may I state categorically that should anyone attend these hearings claiming to represent a united and informed opinion of the disability community, they are making false and misleading statements. Opinions within the disability community that question the scant detail of the NDIS model have either been ignored, labelled as anti-disabled, anti-change or anti-progress or considered as the vocal minority. What confounds me is how those lobbying for the NDIS model, those influencing, advising and committing the disability community to accepting the NDIS carte blanche can do so on virtually no detail or economic and social modelling. The NDIS is not going to be the panacea of disability of shortcomings either now or in the future. If anything the potential of more money has a real potential to perpetuate the problems, not solve them.

Few, if any of the disability organisations, have informed their members of the NDIS in an unbiased, informed, balanced manner. I should know. My family is a member of numerous disability organisations and have not been questioned once for our opinion. Much of the information circulated by these organisations on the NDIS is vague, idealistic and overtly positive. This accounts for nothing more than spin or PR. Exacerbating the issue is a lack of consultation with the grass roots, ie, the people who this proposal affects. Elitism is alive and well in the disability community. Like William Easterly's paper titled the Cartel of Good Intentions which discusses the problems of bureaucracy and foreign aid and the disconnect between recipients and aid providers, the disability community shares similar traits with many committees and policymakers disconnected from the wider disability community. I'm saying this as a chair, so I was part of the problem as well.

My fundamental opposition to any social insurance scheme specifically aimed at funding disability services for those with severe to profound disabilities is that it is subtly labels this group as a burden on taxpayers, necessitating the need for an additional levy, fee or premium. While I have no objection in significantly increasing welfare funding to this disability group and advocate strongly for it, I do object to the fundamental need to institute an additional payment on top of existing general tax revenues. Singling out disability as a cost burden only services to stigmatise and devalue people with a disability to the wider Australian population.

According to Treasury figures - and these are recent, 2010, I think - the welfare cost for the aged is more than the disability sector, yet a new tax is never contemplated. Again, according to Treasury figures the welfare cost for the indigenous program is similar to that of the cost of disability programs, yet a new tax is not considered. It costs several hundred million dollars in pensions, benefits and entitlements to what is a small number of retired politicians, yet no tax is mooted. It costs between four to six billion dollars for the national broadband network - what's a couple of billion dollars between friends - but no new tax is pondered. The government spends billions to stave off the effects of global financial crisis, but not a cent is channelled towards alleviating the crisis in disability accommodation and care. The government spends billions going to war on spurious, erroneous, misleading intelligence, yet seems keen to institute a new tax to pay for the civilised care of what is its most vulnerable citizens. So much for the Christian adage of the meek shall inherit the earth. God, it seems, was an economist.

However, my objection to the NDIS has also historic and legal foundation. The Social Services Contribution Assessment Act of 1945 placed a social insurance levy on taxpayers for elements such as social protection and care of children, the unemployed, widows, the disabled and the disadvantaged. Although this act was repealed in 1965, not surprisingly the levy was not removed with contributions rolled into general PAYE income tax collection.

MS SCOTT: Trevor, would it be okay if we asked you a couple of questions of clarification along the way?

MR ROBINSON: Yes, certainly.

MS SCOTT: I think you effectively have moved onto this new topic. Is that all right?

MR ROBINSON: Yes.

MS SCOTT: I want to return to your concern about the new tax proposal and you've expressed your concern about that. I just wanted to clarify that in fact the commission is not recommending in the draft report a new tax.

MR ROBINSON: A social security insurance scheme?

MS SCOTT: Well, it's not recommending a new tax and I just thought I should say that for the - - -

MR ROBINSON: Certainly.

MS SCOTT: In part because of the reasons you're actually advocating so I just wondered whether we should just clarify that for you. I wonder whether you want to distinguish between the report that the commission has been asked to prepare in your discussion and what had gone earlier in terms of the public debate. So, for example, I think it's important that people don't confuse the two. So recommendation 12.2, the draft recommendation, is that the Australian government should direct payments from consolidated revenue. In other words, like the aged pension, in that you would not - anyway, I just think some of the arguments you are putting very forcefully are effectively in the report as they are.

MR ROBINSON: From my perspective there are a number of areas - and, as you would realise in my paper there's many different aspects, lack of consultation with grass roots with regard to aspects of disability. Much of the disability community - and I can say this from the circles that I mingle in - has been the NDIS is going to be the panacea, it's going to be a great big bunch of money, it's going to fix up the disability - and I'm not seeing any of the discussion with regards to what the Productivity Commission is asking that has divorced the NDIS from improved disability support and care. So I'm a little bit concerned when I see NDIS mentioned and I'm fundamentally not for that model why I keeps getting mentioned.

MS SCOTT: I just wonder whether you're objecting to a model that is not the model that we've got in our report, that's my concern. But could you just go back a little bit. I was so distracted by your vehemency against the tax we haven't recommended - you went on to a second point and you might have to go back a little bit.

MR ROBINSON: Yes.

MS SCOTT: What is your next point after the - you didn't want a tax. What is the next key point after that?

MR ROBINSON: This is consultation? I'm just trying to - - -

MS SCOTT: Your concern is that the public inquiry process we have is insufficient. Is that the point?

MR ROBINSON: Yes.

MS SCOTT: I've got that. Thank you.

MR ROBINSON: I don't want to necessarily stigmatise any - and I won't name any organisations but out of a number of organisations that my family and I are a member of, either with intellectual disability, general disability or spinal cord disability, none of the organisations have asked us as grass roots - have asked the question, "Guys, what do you think about the inquiry?" So when they come to these fora and say, "Well, our members think" - I'm just wondering how they know that. I think that - probably not so much the Productivity Commission, having worked in the Commonwealth government - they have their protocols for consulting with community but some of those that come to the Productivity Commission representing organisations have probably got flawed consultative arrangements within their organisations. Does that make sense?

MS SCOTT: I think I've got your point.

MR WALSH: I'm just wondering, Trevor, we've had over 600 submissions, it was advertised in the newspaper to anyone to look at it and write submissions. Have you been through those to look have at the responses? Probably half of the submissions are from individuals and families and the message is pretty overwhelming. They're unsolicited, it's open.

MR ROBINSON: I think there is always a thing that the basis of what are they basing their submissions on, you know, whether they be a large, voluminous one, how much research have they done? The information they have been provided, has it been balanced from their organisations or from their peer supports? I've not seen anything - once again, I continue, that everything I have seen with regards to the Productivity Commission has never had NDIS divorced from it.

MS SCOTT: Talking about research and the importance of research, I would recommend you have a look at the personal submissions which were a response to an issues paper, and all of that is available on the web. But let's not distract you from your presentation. We've got the bit about consultation. Would you like to proceed now.

MR ROBINSON: Now, I've got to work out what page I was on. Another case of the validity of truthfulness of bureaucratic reporting. In the three Australian jurisdictions that my family has experienced WA, New South Wales and the ACT, I have never once seen a report that genuinely outlines the level of unmet need in accommodation, respite care, equipment or health services. Many of these reports outline the start of new services but are generally silent on the closure of existing programs. Until a level of honesty and rigour exists in bureaucratic reporting, the level of unmet need will continue to be masked and poor performance of programs hidden and perpetuated. Again, in the time that my 26-year-old has been in various programs, never once have we been asked whether it has been successful or whether there was any benefit. It was as though they asked everyone else but us.

It is not just the level of unmet need that is at critical levels. The standard and quality of services is extremely variable. This is acutely evident in the ACT where respite and accommodation services are audited on a shameful six-year cycle further emphasising how poorly people with disabilities are held. ACT prisons are visited regularly by the human rights commissioner, yet people with disabilities in respite are never once inspected by human rights or independent agencies.

I would like to return to my previous point for a moment that succinctly demonstrates disability's downward slide in the mind of the Australian government. According to the Productivity Commission's report 2006 titled Employment of People with Disability in the APS it states, "At June 2005 people with disability represent 3.8 per cent of ongoing APS employees down from 6.6 per cent in 1986." The report goes to say, "Fewer people with disabilities are being recruited into the APS and existing staff with disability are leaving at a faster rate than they have been recruited."

While government scratch their collective heads and postulate how extremely complex the problem is and commissioning expensive consultants, the Occam's razor principle is generally what should be applied. For those not familiar with Occam's razor, I'll provide a quick definition. Developed by William of Ockham in the 14th century, Occam's razor principle determines that the fewest possible assumptions generally explain - or in this case solve - the most complex of problems. Employment of people with disabilities in the Australian Public Service declined after the removal of employment quotas, reinstitute quotas and employment will follow. Simple. Should people with disabilities be more imbued within the

Australian Public Service, it would be easier for those in power to see that people with disabilities are not an economic burden but an asset to be treasured and valued.

One disturbing element of the social insurance model, NDIS model, is that it builds up a level of expectation by recipients and administrators alike, unlike the existing system of needs analysis whereby recipients are assessed, hopefully in a negotiated manner, on their physical, social and environmental needs. Social insurance models such as the NDIS are less actuarial. They are either excessively restrained by anorexic budgets or spend excessively due to overestimated demand and impending end-of-year accounting.

MS SCOTT: Trevor, can I just ask you to pause a little bit. Can I just check that I've understood your point. What you're saying is, if I've got it right, that while you have a lot of concerns about the current arrangements and pinpointed figures of unmet need and all sorts of problems with the system, not enough feedback information and so on, that current arrangements are needs based - have I got that right - - -

MR ROBINSON: Yes.

MS SCOTT: - - - and that your concern about the proposal from the Productivity Commission is that it's not needs based. Is that the gist of it?

MR ROBINSON: Essentially the way it works is that - well, there's not enough funding - I don't think anyone would question that - and it tends to centre more on perhaps the carers than looking at perhaps the person. For example, how does it pay for or does it pay for gratis care - there is so much family care that's given around - how that's going to - it's all focused to one organisation that would provide the funding, instead of if you can get a hybrid of organisations that provide funding for, say, someone with a severe or profound intellectual - or any disability.

MS SCOTT: Okay. Just for the record, I think it's worthwhile saying that the commission in the draft report is not advocating a social insurance type model along the lines you're suggesting and that it is advocating one based one assessed need, so just in case somebody is reading the transcript and becomes confused.

MR ROBINSON: Yes.

MS SCOTT: Okay, please proceed.

MR ROBINSON: Should the latter occur, what happens to the new surplus? You get the next political promise of an upgraded highway, a new football stadium or another Oprah show occurs. In my time as chair of the Disability Advisory Council, I saw several expensive disability government programs that provided negligible short, medium or long-term benefit to the disability community. What worries me greatly with the increased revenue - and you've mentioned the NDIS model - is it provides government, as the amount of money wasted on ineffectual and ineffective programs and projects will only increase, with scant independent oversight review or genuine recipient feedback.

In closing, my short and somewhat tempered response only demonstrates there is not enough being done to rectify unmet need in disability via funding from existing tax revenues. Realistically the Commonwealth government is awash with revenue. The evidence of this is everywhere. The Department of Defence recently discovered they had a spare billion or so, so they chewed up this cash and bought a couple of big aeroplanes. If the Commonwealth can increase funding to private schools, build overpriced school halls, spend billions laying Internet cables and go to war on a hunch all out of existing tax revenues, then why should the most vulnerable, the most marginalised and the less able to talk for themselves be labelled as a burden, requiring a new special tax or levy. Are they not Australians valued as everyone else?

MS SCOTT: Thank you very much.

MR WALSH: I think you've made your point fairly clearly. I think in fact what you're advocating is very consistent with what we're recommending in the report.

MR ROBINSON: If I can say that the stuff that I've seen coming out of many organisations, particularly in the ACT, did integrate an NDIS model and my concern was that whether I was the only voice or a lone voice, I don't care, I wanted to contribute to it. I still want to be positive that people with disabilities - my son has been emergency care for seven years, you know, seven years that he's been not provided for and gone pillar to post. I don't think that's right and something needs to be done, but I don't think we need a new tax should it not be there. Thank you.

MR WALSH: Thank you.

MS SCOTT: I now invite Alexandra Rivers to provide her presentation, please. Welcome.

MS RIVERS: Good afternoon, commissioners, and everybody else.

MS SCOTT: Alexandra, we've got 30 minutes for you as well. Just start and we might ask a few questions.

MS RIVERS: I'm a parent of a person with a severe mental illness who has had that illness for 26 years. Unfortunately he was one of the persons, like many, who got it in their late years of school, so never has experienced any proper developmental milestones in adulthood, including getting a job or having relationships with other people or developing sporting activities and so on. I've been a long-term vice-president of the Schizophrenia Fellowship of New South Wales, but this is not a presentation on their behalf. They and the national body, the Mental Illness Fellowship of Australia, will be making formal presentations, but I thought it important that an individual who's experiencing the daily realities of mental illness receive some input to the commission.

MS SCOTT: Okay.

MS RIVERS: The other reason I think it's very important is that there's a lot of dissension, confusion and discussion about whether a psychiatric disability falls under Disability or Department of Health. This seems to confuse funding and lines of responsibility and dissension in parent groups, carer groups, consumer groups as well. I think it's really important that people recognise that a psychiatric disability is a very real and incapacitating disability and in extreme cases, a comparison being made that a severe psychiatric disability is the equivalent of paraplegia and in some cases quadriplegia. It's a functional disability, not a bodily disability, but it impairs people to that degree.

I also thought it important because a lot of the legislation and regulations and opportunities for assistance that exist, limited though they may be for people with other disabilities, are not available to people with psychiatric disabilities and I think that people need to take care when they're drafting legislation to make recognition of people with psychiatric disabilities so they're not precluded. For example, often these regulations of whether or not a person can feed themselves, whether they can go to a toilet independently, things like that which are often not necessarily applicable to people with a mental health problem but sometimes are, or they take effect in that the person might need prompting or monitoring rather than being able to actually do them themselves.

Psychiatric disabilities, as people probably know, are functional disabilities, and though every disability is different, these have some unique differences too and, as I said, require adaptation of general disability regulations and guidelines to ensure non-discriminatory treatment of those with a psychiatric disability. While all people with a psychiatric disability can progress along the road to recovery, for a considerable number, this progress is not to their pre-impairment capabilities and for many it's not very far at all.

Currently there is no cure for many psychiatric problems. The conditions can be ameliorated but not cured and so must be lived with. Differences involve the variability of the nature of impairment, the degree of impairment, the variability of response to medication, the variability of community supports, the episodic variation of the impairment, the chronicity of the impairment and very especially in psychiatric conditions, the community stigma attached to psychiatric conditions. Unfortunately, this even exists within the psychiatric workforce as well as out in the general community and among employers and other people who might be involved.

These factors require some formal departmental means of individualisation of the application of general disability regulations and guidelines for people with a psychiatric impairment. First of all I want to talk about some of the special needs of consumers from the experience with my son and with the numerous other consumers with whom I've come in contact. Employment is a big issue. There is a lot of research that shows that, as with other disabilities, people with a psychiatric impairment benefit greatly form full-time or part-time employment and there's a lot of research that establishes that this is so.

Of Australian people receiving a disability support income over half a million have a psychiatric impairment, but of these only 9 per cent earn any money other than income support. This is a very poor situation in relation to other OECD countries. For example, in Sweden 50 per cent of those with a psychiatric disability earn other income. There is a lot of gold standard research regarding the types of support necessary to enable successful employment with psychiatric conditions. Those listed in the US are the clubhouse model and the support employment model, both of which are advocated for and implemented here by Schizophrenia New South Wales and the Mental Illness Fellowship of Australia. However, many of the government provided current entry to work schemes don't use either of these models and are doomed to fail therefore with people with a psychiatric disability.

This is especially worrying with the new moves by the federal government to try and eliminate people from receiving income support and transit to full employment or part-time employment in the workforce by either cutting the amount of benefit that people might be able to receive or using more sticks rather than carrots. There also needs to be specialised employment services for those with a psychiatric condition, apart from the general disability employment providers and these people need to be experienced and informed service personnel with training in psychiatric support, not generic disability employment providers. Workplace training and support of employees and colleagues must be included in the service. This is because of the issues of chronicity, people can be well one day and not well the next day, the incredible variability of a diagnosis, such as schizophrenia and the range of symptoms a person might experience and the difference with which they might respond to medication and the degree of impairment that they have, their age and so on.

Currently Australian disability regulations act as a disincentive to all those with a disability attempting to transition from disability support to open employment. They find themselves having to exist on a reduced income while beginning work and required to attempt to comply with complicated paperwork and financial computations as they attempt to establish themselves in employment. This especially affects those with a psychiatric disability as their condition may be episodic and fluctuating and exacerbated by the stress of their new routines and demands interrupting their former assessed ability to work. If their symptoms re-emerge, they can be left with no income until they qualify again for income support.

Persons also need to be able to keep their health and travel cards. Psychiatric medication is very expensive, it has to be taken regularly. If they use income and their travel cards and support cards, they can't either access medication and public transport, as we know, is now so expensive, they can't afford that either. So there are built in incentives in the current transition to work systems that don't encourage people with disabilities to work and especially people with psychiatric disabilities. There are no schemes that supply subsidies for taxi or private travel for people with mental illnesses, including - some people get accompaniment travel for aeroplanes - nothing like that happens for people with a psychiatric disability.

Many people with a psychiatric disability are chronically and severely functionally disabled. They require help with finding and maintaining accommodation, in-home support with tasks of daily living, access to medical support, shopping, financial management, companionship and rehabilitation and activity programs. Very few of these are provided and currently many providers of in-home supports to people with disabilities generally don't provides these supports, specifically don't, to people with a psychiatric disability. They don't like to enter the homes of people with a psychiatric disability and the stigma extends to them.

Many health funds and providers of other types of insurance discriminate against those with a psychiatric disability also, so it's difficult for people to protect themselves against incidents of psychiatric health problems. There are some excellent community support services for people with psychiatric conditions but they are insufficient to service both the number and the range of needs of people with such conditions. For example, there is a housing and support initiative, a government based scheme. It's only servicing a fraction of people and people with high-support needs don't qualify for it. There are also unique difficulties such as people have to sign their consent for a lot of these services. Many people with a psychiatric condition won't sign. They're frightened of signing something because they think it indicates that they're ill or that it will be used against them or that that is what has caused their illness that they signed a piece of paper or whatever. So there is a lot of difficulties put in place for people's protection that actually prevent people with severe disabilities from getting assistance.

If people can't be assisted by these particular supports, there are no higher-level accommodation supports available. So that is why we see a lot of people on the street or in very, very poor conditions in private boarding houses. There needs to be a really large range of accommodation options available, as with people with general disabilities, that range from motel-type accommodations in the city with communal halls and cleaning and meal arrangements to farm-type settings where can people can live in those types of settings, to independent settings with high-level supports in the home, to group homes. It's hard for a person without a disability to live with another person with a psychiatric disability. Sometimes putting three or four people together in one house is the very worst thing you can do and yet that is the only model that people seem to be providing for at the moment with group homes. No wonder we have a lot of aggression incidents between people.

People with a psychiatric disability generally have poor physical health. There is Australian research leading the world that shows that the physical health of people with schizophrenia particularly but also other severe mental illness is the worst of any group in society. The lost years and early death is even worse than that of people in outback Aboriginal communities. A lot of the difficulties come from side effects of the medication but also side effects of the lifestyle with which people have to live which leave them unmotivated, not getting out of bed, not getting out, no friends, no wherewithal to organise themselves into activities, no motivations for continued exercise and so on. So they're very prone to metabolic syndrome which is metabolic difficulties that result in diabetes, high cholesterol and so on. So people are dying from heart disease and diabetes. If the government doesn't intervene early, they end up with enormous expense trying to care for people in hospitals with these chronic conditions which could be head off early with early intervention and more coordinated support.

With regard to electoral support, most people with a psychiatric condition, including many in prison, are eligible to vote. There's no initiatives to assist people to vote or to assist them to be on electoral roles, and I think this needs to be addressed. The absence of national laws and regulations impact on those with a psychiatric disability. This includes guardianship and financial management and Mental Health Tribunal rulings, all of whose authority does not cross state boundaries. People with a psychiatric condition are very mobile and they don't have an intellectual disability, though they have a cognitive impairment.

I have had numbers of people who have suddenly found their child has got on an aeroplane and ended up in Darwin. How do you get them back? They leave the state when they have a community treatment order, which means that if they don't take the medication they will be put back in hospital. If they go and live in ACT, Victoria, Queensland, that community treatment order will not apply. Many people get given community treatment orders by a mental health tribunal in any state and there are no persons anywhere who monitor those community treatment orders or ensure that they are complied with. Even in New South Wales, that is so.

There is not enough money in the health budget spent on mental health, and I don't know about the state of disability funding being allocated to people with mental health problems, but when they are in the community it is a grey area as to whether it's a disability problem or a mental health problem, and there certainly needs to be much closer interdepartmental cooperation to ensure that this particular group of people gets the assistance needed.

Guardianship authorities avoid addressing guardianship and often financial management issues for people with a psychiatric disability. So even if families or the person themselves goes for assistance, they can be avoided. There is a problem with consent and compliance to guardianship orders, because people with a psychiatric disability are capable of independent decisions and actions, even though at times these may be very bad decision or they may be from their being exploited by other people, or they may be ineffectually carried out. People can say things, but not carry them out. There seems to be a need for those tribunals which exist for the protection of people with disabilities to do a lot more work regarding psychiatric disabilities, and particularly the nature of consent and ability to consent.

A significant proportion of those in prison have a psychiatric disability. The restricted availability of community support services, lack of early interventions, lack of court support services and lack of diversionary options available to magistrates lead to this expensive and unjust response to incidences involving those with psychiatric conditions. Again, it needs to be interdepartmental responses between health departments, disability services and justice departments, in order to help prevent the occurrence of these illnesses by early supports and interventions. As I have said, issues relating to capacity and consent need addressing.

There needs to be greater representation of those with psychiatric conditions on consumer disability forums and committees. There are a lot of separate psychiatric consumer forums and committees, but their voices are often not heard at the general level when regulations for disability and laws and arrangements are being made. There needs to be greater recognition by authorities and service providers of the effects of anosognosia and psychiatric symptoms on decision-making and executive planning and formal accommodation made for those impairments. Anosognosia is the inability of a person, because of the brain damage from the mental illness, to recognise that they have disability, that they need to take medication, that they're not reasoning soundly. Often the logic is very good, but the premise under which a person is operating can be very flawed.

I know, for example, with my son at the moment, he had five kettles. The reason he has five brand new kettles is he keeps turning one of the fuses off at the power box, which means that his kettle doesn't go, so he has to go and buy another kettle; then he'll try that kettle, and then there's be two kettles plugged in, then he'll end up plugging a kettle in another room. It's not that he doesn't understand that kettles go in that way, it's just that he is, for some reason, getting a fear of the wires in the box or the electricity from the box, so he turns it off.

That will apply to answering the phone. For example, you can get a free phone from Telstra which enables you to ring emergency controls. A family member can't ring such a person up, because they don't answer the phone often, so they have to be able to ring you. But if course if you do that that costs you $39 at least per month in order to have the service for free phone calls. Mobile phones can't work because people lose them, smash them or forget to turn them on, or whatever it is like that.

I agreed with what the commission has stated in regard to money support for people with psychiatric conditions and disability, thinking it much preferable to a national insurance scheme. But, if there is any National Disability Insurance Scheme implemented, I would hope that people with psychiatric disabilities be recognised and included in that scheme. E-Health legislation is another difficulty for people. It shows a lot of promise, but because of the sensitivity and stigma surrounding psychiatric disabilities, it is a big problem for many people if the control of that e-health record is not with the individual consumer or carer. With carers, the current eligibility guidelines for carer benefits and carer support payments precludes many of those who care for persons with a psychiatric condition from receiving assistance. I have cared for my son for 26 years. I have never been able to access any form of carer benefit or carer support payment.

MS SCOTT: Why is that?

MS RIVERS: Because of filling in the form, the way it has to be filled in. Even though I have had it signed by a psychiatrist and the mobile assertive treatment team, the people who have assessed it at Centrelink haven't done it. I know many people have been able to receive it, but I think it depends on the Centrelink officers where it goes in, I'm not sure.

MS SCOTT: Okay, but they haven't given you a reason why your - - -

MS RIVERS: They have just said that I'm not eligible.

MS SCOTT: They haven't said why you're not eligible?

MS RIVERS: No. No, that I don't meet the criteria. Access should be available to all disability carer supports that are available for general disability and respite programs. This has been made more available recently by the federal government and it has made a big difference, in terms of respite particularly. Specialised psychiatric carer support programs though still need to exist and be delivered by experienced and informed providers and personnel, not by generalised disability service providers or religious organisations without experience in the field.

Carers of people with psychiatric disabilities need to be represented on disability committees and government carer bodies, and all legislation applying to carers of those with a disability should be applicable to them. Some form of specialised and informed assistance with estate planning and provision should be available to carers of those with a psychiatric disability, including options for management for the person with the disability after the carer ceases care or dies. This is a general problem for all people, but it can be especially difficult for people with a psychiatric problem, because of the limited range of accommodation and other options. The impact of caring for persons with a psychiatric disability on carers' health is well researched, particularly in Australia. Carers should be eligible for a government health card, if requested.

MS SCOTT: Alexandria, thank you. I wonder whether you'd like to move to your last couple of points.

MS RIVERS: My last couple of points, okay. Now that much mental hospital care is not available in a carer's local community, support for travel by carers to distant hospitals, mental health hospitals, needs to be addressed. The current impact of privacy, confidentiality and informed consent legislation needs to be investigated. The last one I had is there's a lot of financial liabilities on carers of people with a disability. Frequently they throw all the goods in the house out. They smash all the things in the house. They incur court cases for various things. Court support for carers is not available, though there is limited support for some people with a psychiatric condition. That whole interface of psychiatric disability with the legal system and supports for carers needs to be improved. That's basically all, but I've included there for you A Mother's Prayer for Mental Illness which summarises a lot of these things in a nice way and ends by addressing the need for who's going to care for these people when their parents die.

MS SCOTT: Okay.

MR WALSH: Thanks very much, Alexandra. This is clearly a difficult issue for us, the intersection between the support needs of someone with a mental illness and the support needs of people with a disability, given that mental health falls within the health system, so it's one that we're giving particular consideration to in the lead-up to the final report.

MS RIVERS: I know it's difficult because once a person is discharged from the hospital, they're not in the health system, so with disability and with chronic illnesses, if it's not recognised as a functional disability, then a significant proportion of people are disabled. One in five people have a mental illness; it's not that many who are chronically disabled though.

MS SCOTT: That's right. So drawing the distinction between those with mental illness and those with chronic - - -

MS RIVERS: Functional - - -

MS SCOTT: - - - functional psychotic illness - I noted earlier that you appeared in your presentation to be making a distinction between the two. If you can assist us in how you make that distinction, that would be very useful. I know we had discussion yesterday with Queensland Health officials and they were explaining that in the Queensland system, people with significant psychotic disability are within the disability system but that's the system in Queensland, it's not the system more generally. So anything you can assist us with in terms of making that distinction, that would be most welcome.

MS RIVERS: Would you like something in writing?

MS SCOTT: Yes, that would be good. It doesn't need to be long.

MS RIVERS: Right. It's very difficult, especially since a lot of consumers feel that if you say that people have a chronic disability, it's a further stigmatisation and reflection and it means that people are abandoning hope to get better. Also, you can't always limit it to psychotic illnesses because some people with less than a psychotic illness - cannot leave a house, for example, or have great difficulties with other functional impairments in the home, so it's not even as simple as a psychotic versus what used to be called a neurotic type of disability.

MS SCOTT: Okay. Thank you for coming today.

MS RIVERS: Thank you very much.

MS SCOTT: Good afternoon, Rob. I understand you've asked for 20 minutes. After Rob's presentation, we will then have a break for afternoon tea. So, Rob, over to you. I understand you're representing the Muscular Degeneration Foundation. Is that correct?

MR CUMMINS (MDF): No, it's actually the Macular Degeneration Foundation. We've had some other issues with the commission in the past saying it, but it's Macular Degeneration Foundation.

MS SCOTT: Yes, I can see that. Thank you.

MR CUMMINS (MDF): Thank you very much. Firstly, I'd like to express our thanks to the commission for the opportunity to present today. I'd also like to give the apologies of our CEO, Julie Heraghty, who currently is attending a board meeting of our international federation. She's unable to be here, so I'm taking her place.

Firstly, if I could just take a couple of minutes to indicate some of the issues regarding macular degeneration - not muscular - because they are relevant to some of the points I would like to make. The Macular Degeneration Foundation is a not-for-profit organisation. We're the peak organisation for Australians with macular degeneration. Macular degeneration, which I'll now call MD for obvious reasons, is the main cause of legal blindness and serious vision impairment in Australians. It does not produce total or black blindness but robs you of your critical, central vision. So every time you write, every time you read, right now when you're looking at me, you're using your macula.

There are several forms of MD and it can affect people of any age. However, the most common form is known as age-related macular degeneration. The early signs of the age-related form often commence in one's 50s, although serious vision impairment is most common in your mid-60s or later. It's critical to recognise that while this is considered an age-related condition, it is not a natural or inevitable consequence of getting older. In other words, ageing is not a cause of the disease, it's simply a risk factor, along with genetics, smoking and also various dietary issues can also increase one's chance of getting this disease.

It's a disease that can produce significant disability. Just to give you an example - and I'd invite all of you to participate here - if you clench your fists together like this, fingernails together and then put your fist over your face with the thumbs against the bridge of your nose and if you focus directly into your fist, that is kind of what MD looks like. Focus into your fist; you will still be able to see things around the outside in a very vague way but you won't actually be able to read anything or to see anything with any clarity or any detail. So that's kind of a simulation of what the later stage of the disease is like.

It's in this context that we'd like to make a number of important observations about not only the draft report for disabilities but also that of the Caring for Older Australians draft report. We've also made a submission to that report. Our concern is that there appears to be a clear gap emerging between the two draft recommendations, and this gap appears for those over the pension age who have a significant disability with vision loss. At the moment, today, regardless of your age, if you have severe vision loss, your service needs are provided by organisations, mostly not-for-profits, working within the disability sector. There is currently very little or no service provision for the blind or vision impaired within the aged care sector.

Under the proposed framework, if you have a significant vision loss at, say, 50 or 60, your needs will be covered hopefully under the NDIS as an entitlement. If you sustain this loss over the retirement age, the current recommendation is that your needs will be covered under the aged care framework using a co-contribution mechanism. However, as mentioned, the framework for low-vision care simply doesn't exist at the moment in the aged care sector. So if older people with serious vision loss are to be helped within the aged care sector, then there will need to be huge duplication of existing services at substantial cost. Most importantly, there is currently an acute shortage of trained qualified people in the area of low-vision services resulting in quite acceptable delays for the management of people with vision loss and this would be exacerbated if a new duplicated structure were to be created.

It is our view that regardless of one's age, appropriate support based on needs should be made available in an efficient, timely and cost-effective manner, pretty obvious. Currently, while far from being perfect, this support is managed through the disability sector, as I mentioned, much of it being through not-for-profits. We simply can't see why the government would want to duplicate and further complicate this by creating a whole new system within the aged care sector for those people over the pension age. We believe that ideally the highly-specialised services that are needed should continue to be provided through the disability sector, rather than recreating a new system in the aged care area. The issue about funding and whether the funding comes to that from the aged care is a whole different story, and we could spend hours on that. But I guess the key point is that we believe that it would be, we think, inappropriate and highly wasteful to have to recreate a whole new mechanism for vision care within the aged sector.

A good example of this is in the area of low vision aids and equipment, ranging from things like this very simple magnifier and also little mini telescopes through to electronic magnifiers that allow people with low vision to read tiny food labels or tablet labels on their medications, all the way through to quite complicated desktop magnifiers and electronic scanners that allow people to have text read back to them in a very, very simple and manageable way.

For three years now, the MD Foundation has been working to ensure accessibility and affordability of low vision aids and technologies for people with vision impairment. At the moment, if you're vision impaired, how well you read is dictated by where you live, by your postcode, because there are different arrangements from state to state. Different private health funds also have different and, I might add, usually grossly inadequate funding of such aids. The Department of Vet Affairs also provides some aids to people with vision impairment, which is terrific.

Thousands of people with vision impairment have communicated with their local MPs to have this issue addressed. There is a clear outline in the disabilities draft report relating to aids and appliances under the NDIS. But unfortunately we can see no provision for this in the aged care framework. So in February of this year, the Honourable Tony Windsor, minister for New England, received a reply from the Honourable Senator Jan McLucas, minister for disabilities and carers, in response to a query from a constituent. Senator McLucas indicated that support for disability aids and technology would be considered by the Productivity Commission, including possible provision through the NDIS, and yet that is not what is being proposed if you are over the pension age.

We also believe that the proposed arbitrary cut-off whereby one can get a disability service as an entitlement if you're under the pension age, but you may have to provide a co-payment if you're over the pension age, may in fact be a breach of our obligations under the UN charter for the rights of the disabled. Macular degeneration and other causes of blindness do not cease being a disability simply because one turns 65 or 67 or whatever.

We understand that a basic tenet of the proposed changes is that no-one should be worse off under the new arrangements, however people over the pension age would be potentially liable to significant co-payments and services, much of which is actually provided for free at the moment through not for profits. Of course the elderly with vision impairment also commonly have other comorbidities, which may be managed through the aged care sector. This again highlights the need for very, very close links between the two systems. Again, that's very obvious.

Regardless of whether low vision services remain within the disability sector for everyone or a split based on age, we believe that the proposed generic disability assessment tools are likely to be inappropriate for people with low vision. The generic assessment tools are largely focused on long-term care. However, people with low vision typically access services on a short-term episodic basis, such as when they experience a sudden drop in vision or when a partner dies or if they change address and need new things done around the house and things like that.

Moreover, it would appear that the generic assessment tools are quite inadequate to measure function for people with low vision. Low vision assessment requires specialised tests performed by low vision specialists measuring functions under things such as different lighting conditions, different contrasts, different colours and so on, none of which are normally relevant for other disabilities of course.

As a general comment, we also believe it's critical that referral pathways, including assessments are significantly shortened and not complicated for people with vision loss. People with sudden or rapidly advancing vision loss are at a substantially greater risk of falls and hip fracture, serious burns and depression. All of this is in the immediate time straight after they've had this sudden vision loss. It's crucial that low vision services are available quickly to minimise the chances of these and other problems occurring. As such, we think it would be counter-productive and unnecessarily expensive for someone with established vision problems to have to wait for repeated assessments and re-assessments each time they needed to access some short-term assistance.

We're delighted that the commission acknowledges the important role of early intervention in improving outcomes, and we think this is really, really important. Early intervention of course can mean a whole range of different things, but in one critical area in macular degeneration, it's that of educating people in their 50s or 60s firstly to get their eyes checked regularly and obviously to state they don't have a disability, but also later on if they do start to exhibit the early signs of the disease, they need to be encouraged to make simple changes to their diet and lifestyles, stopping smoking and things like this, all of which have been proven to slow down the progression of the disease.

We would encourage the commission to consider such activities as part of your overall funding requirements for early intervention. We would also urge you to consider the importance of funding a specialist information provision and advocacy. Informed choice requires good quality information and in the case of people with vision impairment, this means making this information available in different formats, including audio or large print size and also computer files that can be read back on computer software.

It also means making information available in different languages, and, as an example, we actually provide our material in something like six different languages and we have audio equipment and things like that. It's really, really important for people to make informed decisions, but of course it all costs money. As a final point, we would like to encourage the commission to really strongly advocate for minimum standards and accreditation for low vision providers. At the moment with the current providers there's a huge variation in the scope and the quality of service offered around the country and improvements are definitely needed. There's also a dearth of services available in many regional areas, and obviously there are huge implications in that in terms of costs of getting to services and so on.

With more money in the system hopefully but without accreditation, we're very concerned about the potential for new, fly-by-night, profit-driven organisations with big marketing budgets entering the scene, only to disappear soon after, having ripped off vulnerable elderly and vision-impaired people. I guess a good analogy of this would be with the education sector recently where we've seen a lot of foreign students ripped off by these fly-by-night companies with big marketing budgets and so on.

MS SCOTT: Rob, can I hold you up just a little bit. Could you talk about who the service providers are. What are we talking about? If you live in Wagga, for someone with MD, where would they be getting these services from?

MR CUMMINS (MDF): Depending on the level of the disability they have, in the early stages, often it's just information they're requiring and that's actually where they come to the foundation. We're primarily an information provider. We're not a service provider. As their disease progresses and they get increasing vision loss, then they may need to access services from organisations such as Guide Dogs, who do a lot more than providing dogs of course. They provide a lot of accessibility for mobility training and things like that Also organisations like Vision Australia. There's the Royal Society for the Blind in Adelaide, who do an extraordinary job and probably have - - -

MS SCOTT: But these are not the fly-by-nighters.

MR CUMMINS (MDF): No.

MS SCOTT: So who are the service providers - - -

MR CUMMINS (MDF): No, at the moment the providers are mostly not for profits in providing this service, although there is a lot of variation around the country in terms of the quality of the service they provide. What we're concerned about though is in the future if there is significantly more funding made available, that there will be conditions ripe for fly-by-nighters to start up that are there on a for profit basis and that are not necessarily going to have qualified, trained people to provider these services, but can spend a lot of money on marketing. We think that the provision of standards and accreditation will go a long way to improving not only that, but also to improve the overall quality of care at the moment as well.

MR WALSH: Can you talk a little bit about what the support needs for someone with macular degeneration might look like?

MR CUMMINS (MDF): Certainly.

MR WALSH: You've talked a bit about the aids and enhanced vision - - -

MR CUMMINS (MDF): Generally speaking, assuming of course the person with MD or indeed many other vision impairments, assuming they don't have other diseases as well, generally speaking they want to maintain independence, they're wanting to stay in their own home, and mostly they can. They can usually still get around reasonably well with this peripheral vision, but they have great difficulty with reading, with doing things like looking at the labels of cans and bottles in the shops, and reading the labels on their pill bottles and things like that. So most of the support they're needing is actually do with reading and also very often with mobility. Really just getting access to things like low-vision aids to help them read, maybe services such as either magnifiers or special computer software that actually reads back text to you; also there are electronic scanners that can actually, with text placed under the scanner, take a snapshot of it and it will read it back to you; there's also little handheld reading books, like little mp3 players that are specially designed.

MR WALSH: In terms of practical supports, getting through a day, it sounds like it's a personal support person who could go along and help read the labels on things. Is that right?

MR CUMMINS (MDF): Depending on their level of impairment and whether they're able to use equipment such as this, it may be.

MR WALSH: If someone had all the equipment that you've described.

MR CUMMINS (MDF): Again, depending on the level of impairment; sometimes you can have varying degrees of blindness. But it may be they need assistance for, certainly for shopping, for getting around to see the doctor, for filling in forms; these sorts of things can certainly be a major imposition for someone when you just can't see in front of you.

MR WALSH: But it would be episodic support?

MR CUMMINS (MDF): That's right. So it's generally not long-term, continuous, 24-hour support. These people, generally speaking, want to maintain their independence, in fact they fight for it ferociously. We certainly really encourage that. Mostly they can do that. It's more the aids and equipment, depending on what you need, which can cost up to three or four thousand dollars, usually lasting many, many years; this is not an annual cost, these last a long time. The actual costs involved, they're not necessarily all that large.

There are of course other things that can come into it. In terms of transportation, if someone has lost their licence because they are legally blind. In fact you don't even need to be legally blind to lose your licence, it's much lower than that. Transportation can be an issue of course, they can need assistance there; getting to doctors' appointments, things like that. But generally speaking they want to maintain independence. Does that answer your question?

MR WALSH: It does.

MS SCOTT: Can I just ask, I've got a couple of follow-up questions.

MR CUMMINS (MDF): Yes.

MS SCOTT: Don't be anxious about the time; it's all right.

MR CUMMINS (MDF): Sure.

MS SCOTT: Going back to one of your earlier statements about your concern that the draft report on Disability Care and Support has funding after - the suggestion actually, there's two options within the report, as you know, about the link between the aged care system and the disability system.

MR CUMMINS (MDF): Yes.

MS SCOTT: Quite reasonably you've drawn our attention to this issue. I just want to explore that a bit further. If it is the case that for many people in post-pensioner-aged age groups that what they're after is assistance with equipment, assistance with mobility, assistance with some basic aids, why would that necessarily be problematic if the funding for that came from the aged care sector rather than a disability sector? Given that you've talked about the longevity of the items; the fact that the assessments, generally speaking, take place, I suppose, with specialist allied health professional or doctors; I'm trying to work out why, without a great deal of effort, those services couldn't be available if funded by the aged care sector.

MR CUMMINS (MDF): I think funding through the aged care sector is absolutely fine; where the funding comes from is really immaterial. We have a system at the moment which is not perfect, as I said, but it is certainly functional and can be improved, but to duplicate that within the aged care sector seems to be crazy.

MS SCOTT: I just want to explore this. You wouldn't actually need to duplicate it, would you? Why would you need to duplicate the arrangement if the only thing that a person may require is assistance with mobility - well, the aged care sector currently provides that for some people; certainly a better funded one would - and if they needed assistance with aids and appliances. I was very taken with your argument about wholesale duplication until you actually explained the services.

MR CUMMINS (MDF): I understand your point. Certainly the training that's required for mobility is often quite different to that which is through the general mobility training.

MS SCOTT: No, I understand. Let's see if I've got this right: leaving aside the potential fly-by-nighters that could come in the future. Have I got that right, you're not suggesting - - -

MR CUMMINS (MDF): No.

MS SCOTT: The organisations that people are largely using now are non-government organisations that currently provide these services.

MR CUMMINS (MDF): Yes.

MS SCOTT: If the funding came out of an aged bucket rather than a disability bucket, you wouldn't need to replicate your organisation twice, would you?

MR CUMMINS (MDF): No, certainly not.

MS SCOTT: And you wouldn't need to replicate Vision Australia twice or Guide Dogs Australia. So effectively the only duplication is that the funding - actually there's no duplication at all, if I've got it right, because effectively the funding source could be different.

MR CUMMINS (MDF): No. In fact that's exactly the point we're trying to make; that if the funding can be made available from the aged care sector to allow what is currently in place, that would be ideal, we think.

MS SCOTT: All right.

MR CUMMINS (MDF): Providing that again there is this good communication between the two areas to make sure that it does happen then.

MS SCOTT: Yes, I understand that. The concern that future fly-by-nighters, there's a recommendation in the report, 8.3:

> The NDIA should develop and implement a quality framework for disability providers, which would include: the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should

> monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors - - -

Some of this is not appropriate for every service provider.

MR CUMMINS (MDF): Yes.

MS SCOTT: "- - - senior practitioners, independent consumer surveys, complaints," and so on. It goes on for some time and there's quite a chapter on quality control. Did you take any comfort from that? I'm just trying to work out whether that met your concern about addressing the fly-by-nighters. One of the things you made reference to was the education sector and I think I would describe that as either a light touch or no touch. This doesn't sound like light touch or no touch. Does any of that provide some comfort for your concerns?

MR CUMMINS (MDF): I had actually missed that particular part. What was the reference for that again?

MS SCOTT: Recommendation 8.3.

MR CUMMINS (MDF): 8.3, I'll look at that more closely.

MS SCOTT: All right, thanks.

MR CUMMINS (MDF): No, that's great. Certainly if there are requirements in there, that's fantastic. Because, as I said, the current providers by and large do a very good, honest, caring job. It certainly can be improved and, as I said, better consistency across the country is needed, and particularly better access in the more regional areas certainly is needed. Okay. Thank you very much.

MS SCOTT: Thank you. Is that it?

MR CUMMINS (MDF): That is pretty much it, yes.

MR WALSH: Any numbers you've got on the number of people will macular degeneration of various levels, that would help us.

MR CUMMINS (MDF): Yes, certainly.

MR WALSH: I know they'll be rough.

MR CUMMINS (MDF): Taking it from the bottom up: there's something like one million Australians that have the very early stages of the disease that are totally asymptomatic; one in seven people over 50 have early signs of it, but in most cases that won't develop into anything at all; through to about 250,000 people that have significant disease that may lead to more permanent problems - and they may have some vision impairment, but not necessarily what we would regard as a disability, but certainly some impairment; through to 38,000 people that are legally blind from MD. It represents half the people that have legal blindness in Australia, actually have MD.

MR WALSH: How many of those 38,000 would be under 65?

MR CUMMINS (MDF): Actually about 97 per cent will be 65 or over, but have legal blindness. There are also certain cases of younger forms of the disease, typically genetically-linked diseases - things like Stargardt disease, Best disease, Sorsby's macular dystrophy - that can also lead to significant vision impairment and legal blindness in very young people, even as early as 20s and 30s. But certainly the vast majority of legal blindness is in the elderly.

MS SCOTT: All right. Thank you for coming along; thank you for your presentation.

MR WALSH: Thank you.

MR CUMMINS (MDF): Thank you very much.

MS SCOTT: Is Carol Birks here? Great. Look, Carol, I wondered if Peter has mentioned to you, you might be on earlier than you were originally scheduled, because someone has unfortunately had to pull out. I'm aware that some people have been sitting in the audience for some time and they may feel they want to make a comment at some stage, even though they're not formally on our list of presenters. If you do wish to make a comment, you could come forward at the end of our scheduled presenters and make a few remarks. They would go on the record and you would need to identify yourself, but we would give you this opportunity if you kept your remarks brief. Is there anyone who would like to take advantage of that opportunity, could you indicate that now, just so we can think about when we will be able to finish? There you are, John, Sydneysiders are much more reticent - you'll be the sole Sydneysider? All right, turns out there is one. You might think about what you'd like to say and maybe jot down a few ideas. If you could keep your remarks to five minutes, that would be appreciated. All right, now we're going to have a 20-minute break, so we'll resume at 3 o'clock, Bronwyn, and then we'll have Bronwyn, Carol, and then our special presenter. Thank you.

MS SCOTT: Good afternoon. I now invite Dr Bronwyn Morkham to the table, please.

DR MORKHAM (YPINH): Bronwyn Morkham from the Young People in Nursing Homes Alliance. I hope you don't mind, I'm going to read from this. First of all, I wanted to thank you both for the opportunity to appear today and to discuss some of the issues the alliance has identified in the move to a national disability insurance scheme. I'd also like to congratulate the commissioners on the draft report. I think it's a terrific piece of work, what an insurance based funding stream for disability services might look like, how that funding might operate and who it would support. It really is a major piece of work. I'm mindful of the last time such a significant effort was undertaken, I think 1974 by Sir Owen Woodhouse, so congratulations.

I may be putting my foot in it a little here, but I attended the Melbourne hearings and I have to say I was a little disappointed by the sector response and I'm mentioning this only to say that I think, as a general comment, the sector is going to struggle to get its head around some of the more high-level policy stuff here; that's just for me to say. When the draft report comes out, it is made public and I hope it will be as uncomplicated as possible so we can get our heads around it.

We are particularly pleased to see the commission recommend two schemes, one for catastrophic injury and another for those with severe and profound disability. Establishing a separate scheme for the catastrophically injured will not only require our existing mix of fault and no-fault injury schemes to be better aligned under and NIIS but will offer an NDIS, tailored to the long-term needs of those with differently acquired disabilities, a real chance. Each scheme has different realities and imperatives such as income replacement in common law in the NIIS, so having two schemes is a much more pragmatic option than a single mega scheme.

We are also pleased that the Young People in Nursing Homes group has been identified as a priority group in any new scheme and that early interventions will apply to these young people. There is substantial evidence already around that this really is the best approach to take for this group. As many studies have also found, their complex and profound needs are well beyond the capacity of any one arm of the service system to support. Responding to the suite of clinical and other support needs Young People in Nursing Homes present with as a group requires an integrated service response that draws on a variety of disability, health and housing programs. We believe the schemes proposed will deliver certainty of response and hopefully the quantum of funding required to support the lifetime care needs of this group.

We are also pleased that the commission has identified interfaces between the various arms of the service system, such as those between disability and health, as areas that need to be managed carefully. We agree, but would also make the point that partnerships in collaboration with health, with disability and perhaps even with aged care programs are essential to develop and deliver the suite of services the YPINH group require.

One concern we do have though is that it appears that rehabilitation hasn't been identified as a benefit type in the NDIS. We note that therapy services are listed as a service type but it's not clear at this point whether rehabilitation and in particular slow-stream rehab is going to be covered in the scheme. While this is something that an NIIS would deliver, it must also we believe be part of the services an NDIS delivers for individuals requiring habilitation or slow-stream rehabilitation services to maintain life skills and/or slow disease progression.

The lack of rehabilitation has been identified as a key cause of admission to aged care and of increased disability in the YPINH group. This is especially the case for those with progressive neurological diseases as well as those young individuals acquiring hypoxic brain injuries from near drownings, stroke, hyperglycaemic coma in diabetes and so on and who may not be eligible for an NIIS. Slow-stream rehabilitation currently is a major service gap and is something that would be beneficial for the NDIS to be able to purchase for its clients as part of their ongoing support program.

We also have concerns with the draft report's apparent concentration on funding as a driver of reform and development of appropriate service responses. The alliance believes this expectation is a little misplaced as it will take much more than market mechanisms to create the support environment needed and that making financial arrangements the key relationship between the service user and a service provider puts the end user at real risk of commodification under such an arrangement. The report does acknowledge the need for reform in a number of areas but doesn't propose the framework, and this is perhaps beyond the scope of the inquiry but is really fundamental to the successful introduction of either scheme, we think.

Last week, the alliance convened a national round table on lifetime care and support. Representatives from the disability, health and aged care sectors attended, as well as members of peak organisations, advocacy groups, providers, no-fault motor vehicle scheme delegates and government representatives. We will be including results of that round table in our submission and response to the draft report.

I just wanted to briefly mention the outcomes the round table participants agreed on, and these are just a few. One of the fundamental things they wanted to make clear was that an individual is more than just one person but is surrounded by family, friends, work colleagues, neighbours and clinicians, as just a few. A lifetime care scheme has to enable input and contribution from all of these support sources. Participants were also very clear that funding alone will not deliver the outcomes we need and in that, I was going to mention the Younger People in Residential Aged Care initiative which has delivered a decent quantum of funding to disability services but it hasn't actually resulted in any reform imperatives at all. That's for a range of reasons but it has been a business-as-usual approach by disability there.

A long-term care scheme must include transparent and flexible engagement with those who directly and indirectly impact the individual's life. Another comment that was made was that lifetime care - and this is an obvious comment - is inherently dynamic, and the schemes we're talking about have to be flexible enough to respond to important life transitions, whether it's into or out of rehabilitation, work, school, living arrangements, even palliation. I note that that's been mentioned that something that health would deal with but I think for our group, end-of-life care is sometimes not just something that health has to manage on its own.

MS SCOTT: Bronwyn, would you mind slowing down a bit.

DR MORKHAM (YPINH): I'm sorry, Patricia. I'll slow to a gallop. Just quickly, some of the other things, the comments that were made including formal or informal partnerships or collaborations that are at the heart of developing and delivering the suite of responses a properly responsive lifetime care scheme would manage, these would involve - - -

MS SCOTT: Bronwyn, can I implore that you slow down.

DR MORKHAM (YPINH): I'm sorry, am I doing it again?

MS SCOTT: Yes. I'm just trying to follow your argument and I just can't think as fast as you're able to read.

DR MORKHAM (YPINH): Sorry, Patricia. These are just obvious collaborations.

MS SCOTT: Yes, all right.

DR MORKHAM (YPINH): I guess the other comment - - -

MS SCOTT: Can I get you to go back. After the round table, funding alone will not achieve the reforms.

DR MORKHAM (YPINH): Yes.

MS SCOTT: Can you go back to that, and then maybe even if you've got to paraphrase a couple of points - that's where I lost you.

MR WALSH: Bronwyn, I was going to ask a question about that. You made the example of young people in residential aged care had enough funding, had a lot of funding, but didn't achieve any effective reform. How might that have worked different?

DR MORKHAM (YPINH): I think one of the biggest problems was that the initiative didn't actually demand a different response from the state disability services systems so it was very much a business as usual approach that was delivered. The disability services did what it did.

MS SCOTT: Wasn't it about getting younger people out of nursing homes?

DR MORKHAM (YPINH): It was and it was also about providing support to those who couldn't move out, as well as preventing further admissions in.

MS SCOTT: Well, did anyone leave a nursing home as a result of the package?

DR MORKHAM (YPINH): Certainly did, yes.

MS SCOTT: So you're more concerned about the people who didn't leave nursing home as a result of the paper?

DR MORKHAM (YPINH): No, both. The people who did move out have largely moved out to group home supported accommodation services. The providers that have been required to develop those services though have largely been those without expertise with this group. So we've now got situations where people with high clinical needs are living in services without any clinical overlay and are really very much at risk.

MS SCOTT: Okay.

DR MORKHAM (YPINH): So I guess the need to understand the complexity of needs and how that's delivered wasn't enabled by that funding alone. There's got to be some other mechanism that come into play. I guess the other point to that comment is that we really - we have a small coterie of case coordinators, if you like, tertiary case coordinators that we use to run some innovative programs. The Continuous Care pilot is one example and I think we've provided that. Using that approach which involved proactive risk management over the short, medium and long-term worked really well for this group. I think at the moment most disability services see accommodation as the issue and the answer.

For us accommodation is the last thing we need to consider. It's the service response that involves clinical input very particularly for this group that is desperately needed but so often missing. If you are going to develop a new service, you've got to look at what level of support you're going to be supporting, what you're staffing levels are going to be around that, therefore, what is the cost of running the service and a range of other things before you eventually get to the accommodation that should wrap around and be designed according to those particular needs.

MR WALSH: So in the context of both of the schemes we're proposing, the NIS and the NDIS, I think what you're saying is - and I don't mean to paraphrase, correct me if I'm wrong - that the service sector and probably also the people with disability themselves need to think a lot more about what the support model looks like.

DR MORKHAM (YPINH): Exactly right. I mean, I think for many people with disability, as well as providers, they don't know what they don't know effectively. So one of the big challenges the scheme is going to have is how to bring a level of expertise together around particularly this group that does understand their very different needs and can provide the supports they require.

MS SCOTT: So you're suggesting that really some of the organisations that have particular affiliations with certain forms of disability would be best thinking about what they'd like to see designed - the model they'd like to see wrapped around certain arrangements, not just focus on location, accommodation but the array of services they would like to have available.

DR MORKHAM (YPINH): That need to come, yes, most definitely.

MS SCOTT: Okay.

DR MORKHAM (YPINH): There are obviously some organisations that have done this and are better at it than others at the moment, not to say that others can't learn to do it. But at the moment predominantly service providers out there, because of the historic development of disability services, is really focused much more on providing individuals with support. There is a predominant focus on those with congenital disability. So, for example, the Young People in Nursing Homes group are people who have obviously had an enabled body life but are often parents of young families. So we need to think how do we support that and enable that.

One of the other fundamental points to make was that I think the report has talked about the scheme as being an entitlement. We would rather see this as, instead of entitlements - which I think can bring a lot of expectation and high expectation that may not be able to be met - we would rather talk about rights because we think rights come with responsibilities and in the way of everybody getting their heads around what is going to be fair and reasonable in this, we need to have a sense of responsibility from both sides of the equation. I won't go on - we'll provide all of these. I'm just conscious that time is going on.

MR WALSH: Time is fine, Bronwyn.

DR MORKHAM (YPINH): Are you sure?

MS SCOTT: You've got 10 minutes.

DR MORKHAM (YPINH): The important point I wanted to make - well, there are two: the report mentions the disability support organisations, we think that is a terrific idea. We would like to see though a clear divide between providers. We don't think providers can be disability support organisations and carry out the range of functions that were described. To me it's a bit like giving Dracula control of the blood.

MS SCOTT: No, we agree.

DR MORKHAM (YPINH): Yes, good.

MR WALSH: Bronwyn, just on that where do you see advocacy fitting in?

DR MORKHAM (YPINH): That's a very good question, John. I think the disability support organisations can deliver that. We don't have decent advocacy services at all at the moment, I don't think. I think the advocacy that would be needed within these schemes is substantially different to what is out there now which is often a very adversarial, you know, "Why haven't we got what we need," approach. To me advocacy here is much more aligned with information, education and helping people get their heads around what is reasonable and what can be reasonably expected from the scheme. So I think the disability support organisations could do that as well.

The other thing I notice that the report recommended that the DSOs should - the funding or the payment for their services should come from the individual support package. I actually think that is going to be a bit difficult. We prefer to see maybe block funding, maybe FaHCSIA could be involved in that as a transition arrangement. But to provide the quantum of funding for support needs we would rather see that separated, I think, there.

MS SCOTT: Can we talk about that a little bit.

DR MORKHAM (YPINH): Yes, sure.

MS SCOTT: Although it was John's original idea, I'm happy to take ownership as well. But I saw the person acting always in your corner, and whilst it's true they'd have an advocacy role, they would also be assisting you to exercise your rights, to exercising your purchasing power, act as a broker if necessary. Now, if you have block funding of DSOs, why would they be concerned with one individual Patricia or one individual John when already they're assured of the funding for this year or this three years or this five years? Whereas if funding was coming out of my package and I really found the person irritating or disinterested in advancing my arguments for a better package or better services or a more clever arrangement of services, I could basically say, "Well, goodbye, you've lost my income from me and I'm moving elsewhere."

I appreciate there might be some need for advocacy; I think the argument put to me yesterday was the need for generic advocacy services being block funded. But I'm looking for something - and maybe it's not DSO, maybe you want direct by thinking in a new area - or someone to look after my interests when I'm maybe very experienced in exercising my rights as a consumer and my rights as an individual. Could you talk about that. If it's not the DSOs, what would you like it to be?

DR MORKHAM (YPINH): I've been assuming that this notion of case coordination that we've talked about quite a bit, is wrapped up in that. If you have a case coordinator with significant expertise, when I look at the case coordination role in the continuous care pilot it did advocacy, it did that, it provided information, it helped people come to terms with various transition points they were dealing with, it interceded with the funding mechanism - it did everything. So I guess I'm prefacing my comment, Patricia, from that point of view.

MS SCOTT: Okay.

DR MORKHAM (YPINH): Just one other comment is that advocacy, as it is now, is premised on LAC. I'm assuming that the quantum of funding somebody should need will be available, therefore, the role of advocacy would be quite different in how do you work with whatever it is that's being delivered, I guess, if that makes sense.

MS SCOTT: Yes. I thought it could be more about, "Well, you've got this package now, but you've expressed an interest in kayaking so - - -"

DR MORKHAM (YPINH): So arguing back with the scheme saying - - -

MS SCOTT: Either arguing back with the scheme or saying to the person, "Right, so you're interested in kayaking, let's see if there is a kayaking club around here that will be interested in making their services available to you."

DR MORKHAM (YPINH): Yes.

MS SCOTT: All right. Here is a challenge: given that you've got a slightly different view about how things should be modelled, not only am I interested in seeing your text on that, we have a number of commissioners that think in diagrams, so I would welcome you trying your hand on diagrams. You will see in the overview that we tried to explain the role of the DSO separate from service providers and maybe you would like to take that diagram and move the blocks around and add some other blocks.

DR MORKHAM (YPINH): I'd be very happy to do that.

MR WALSH: I think the other character in the diagram, Bronwyn, is the local coordinator, local case manager, whatever it is, because the way you described DSO a minute ago, it sounded like it was doing some of the roles that we thought the NDIA local rep would be doing, so if you could have a think about how all that hangs together.

DR MORKHAM (YPINH): Yes, I agree. We had seen the disability service organisations - that's where the case coordinators would live. They would be carrying out the roles under that umbrella.

MR WALSH: So it's almost as an agency of the NDIA.

DR MORKHAM (YPINH): But not its factotum either. We've talked a little about some of these. I guess the DSO model, as we defined it in our submission, we believe provides a unique way of safeguarding the role of the NDIA and managing that inherent tension between expectations of the scheme and what the scheme can reasonably provide. We think that's a very important point. Basically if we get the front end right, and the case coordinator should be the eyes and ears of the scheme, they should be able to identify where there's areas of lack; maybe there's need for innovation, an innovative response and so on. If we can get the front end right and make that work, then obviously the back end will be hopefully less in terms of complaint and dissatisfaction.

I guess the other part of that is that case coordinators we envisage travelling the journey, that they don't just come in and do whatever and leave. They may not be active all the time but they're there. The other couple of things: the report mentioned workforce issues, it wasn't keen on having any sort of qualifications - that's not the right word - - -

MS SCOTT: Minimum - - -

DR MORKHAM (YPINH): Yes. For our group, that's of concern because of the clinical nature of their support needs some time, so we would like to see some sort of qualification in there, some very clearly identified training. If you've got somebody with a tracheostomy who is requiring support in the community, you can't expect a disability support worker who hasn't had that training to come along. I don't think that's what you meant.

MS SCOTT: No, it's not.

DR MORKHAM (YPINH):   No, but there's got to be some way of - how do we know that people who are coming in to provide what are really life-changing things - how can we be sure they have the right qualities and skills, I guess. Two other points: one is about trialing this in a region. I understand the imperative and I understand the need to take this slowly perhaps but I'm not quite sure about trialing it in a region. I think I would rather see the trialing done with one of the early intervention groups or the early intervention group or whatever because you will have them going right through. You will start off maybe with children, maybe the Young People in Nursing Homes group which are a complicated group to deal with. If you can get that right, other things should fall into place a lot more easily, I would think. That's just a comment. I honestly don't know the answer there.

The other one - and I'll make this my final comment - is really around the age of 65. I really do have an issue with this. I think 65 was chosen as a line in the sand in 1907. The aged care system is there. I understand we've got a two-tiered system at the moment. I believe both schemes should have a mandate to actually question that and try and find a way where we don't continue to determine need according to how old you are. I think to offer people the option of either staying with the NDIS or moving over to aged care at age 65, you won't get many people going to aged care as it currently stands. Part of my thinking there is that the Young People in Nursing Homes group are still relatively new to the service system. They haven't had a chance yet to age into that aged care, so-called, bracket yet. If they were to age into aged care now and be put there, aged care would not be able to manage their needs. So I think perhaps that interface - there is a need for some genuine partnership between disability so-called and aged care to manage that. But I really do think that one of the scheme's imperatives should be to try and think through: how do we get away from this two-tiered system we have at the moment? Maybe that's pie in the sky but it does worry me that we are still relying on age as a definition of support-needs delivery, I guess. I might stop there, thank you.

MR WALSH: The aged care, it's an issue of partly pragmatism, I suppose. There are many reasons why we've gone for the age transfer. There's the pragmatic reason of cost. The scheme is already an expensive scheme and providing ongoing support for the whole of life would have greatly increase the cost of the scheme. The aged care review, the Productivity Commission's review, has very similar philosophies in terms of individual packaging and so I think the pragmatic response we took was that the person's entitlement under the national disability insurance scheme, when they reach that transfer point, would stay with them. They could choose to continue with that, continue with their existing provider and arrangements in place, it's just that the funding would flip over into the aged care funding bucket.

We do have an alternative model in there which is quite complicated in which effectively the aged care system would fund the proportion of care that was attributable to ageing. That's going to be a difficult thing to do but there is a bit in the report about how it would work if that's the way it was adopted.

DR MORKHAM (YPINH): I think that's an interesting point because we've been sort of pushing a little bit down that line with the ACFI review and so forth too. Maybe I haven't moved my thinking from where we are now to where we could be, but at the moment, I mean, turning 65 doesn't take away your disability and at the moment when you turn 65, you lose your continence stuff and what have you and there was a comment in the report from memory about people who need residential aged care placement should go there, and I guess if you marry that with what you've just said, John, it's not an issue, but I read it as a bit of a stand-alone comment that if you needed to be in aged care, aged care should do what it does. So I was a little concerned that that wouldn't be as comprehensive as it might need to be. It's a vexed area.

MR WALSH: The way in which it rolls out will be an area for further work, I think.

DR MORKHAM (YPINH): Yes, thank you.

MS SCOTT: I thought maybe we should clarify the point about trialing in the region. While I concede there would be attractions for going with an early intervention group because it could have some longitudinal experience which would be very good to have, the fact that there's paucity of data means that you really would like to trial it out on a whole population group, and the whole population group of Australia is just too significant. So the actuarial view is that a region makes sense because it gives you whole population characteristics in a small area and you can learn by the experience and so on.

DR MORKHAM (YPINH): Right.

MR WALSH: Yes, what we don't have at the moment is a population on which to base any costings, and a whole-of-population sort of subgroup would give us a lot more information than we have at the moment in terms of dynamics, numbers, data. We'd have a few hundred people who have probably come from a nursing home, a few hundred people with spinal cord injuries, a few hundred people with intellectual disabilities, et cetera, so we get a whole range of support needs that would allow us to - and also to have a look at the way the systems would operate. So I think it's not just about getting started, it's about understanding a little bit more about what the whole stream would look like when it was fully operational.

DR MORKHAM (YPINH): That makes more sense, I think, and I guess part of my concern was that every region is so different, would you be able to draw down standardised data. I guess you do. That's part of the job, isn't it? So it's a bit of a shakedown exercise in a way.

MR WALSH: Yes. I think you could choose a region that had a broad range of characteristics in terms of socioeconomic - - -

DR MORKHAM (YPINH): That are representative, yes.

MR WALSH: As far as it could be possible.

DR MORKHAM (YPINH): I believe some states are already lobbying to be first cab.

MR WALSH: Yes.

MS SCOTT: It's like signing on early. You get to - - -

DR MORKHAM (YPINH): Yes, you get additional benefits.

MS SCOTT: You get the trial there. Thank you very much

DR MORKHAM (YPINH): Thank you both.

MS SCOTT: Thank you for coming along.

MS SCOTT: Carol please.

MS BIRKS (MNDA): Carol Birks, national executive director, Motor Neurone Disease Australia.

MS SCOTT: Thank you.

MS BIRKS (MNDA): Firstly, thank you for the opportunity to speak today. Also, we'd like to congratulate the Productivity Commission on the breadth and depth of this draft report. We believe the proposed framework for a national disability insurance scheme will go a long way in providing an appropriate support structure for people in need of urgent and complex support services, following a diagnosis with a rapidly neurodegenerative diseases, such as motor neurone disease. The draft report has included many of the key characteristics that we outlined in our original submission, and that is certainly welcomed.

People living with motor neurone disease and their carers are at great risk of falling through the gaps of service provision. The recognition in the report of the need for early intervention for people with progressive neurodegenerative disease, an assessment process that will anticipate change and effective protocols for timely and smooth referrals to and from the different sectors is integral in minimising this risk. We're very pleased that this has been recognised within the draft report.

The crucial issue in the report that must be addressed is this access to services based on need, not on age. So we come back to that again. The report states that the needs of those who acquire a disability after age 65 would be best spent by the aged care system. This is not the case. MND is not a disease related to ageing, but many people are diagnosed when they are over age 65. People diagnosed with MND aged over the pension age will need services from both systems to address their changing and complex needs and to ensure their quality of life.

As just discussed, the draft report does suggest that those who acquire the disability before age 65 can elect to stay with the NDIS or transition to aged care services. This will mean that people diagnosed with motor neurone diseases before age 65 will have access obviously to all the services, those diagnosed aged 66 would only be able to access services through aged care, and this is a real concern for us. We have read the draft report from the aged care - the Productivity Commission report and it does not seem to include within that draft any access to aids and equipment for people aged over 65 and so we are concerned about where aids and equipment will come from for those people.

The existing aged care system certainly doesn't provide enough hours or support for people with motor neurone disease to live at home assisted by their family. So that is a great concern for us. I guess the other concern is that we have no idea what a future aged care system is going to look like, so we need to be mindful of that, I think. We believe that to achieve lifetime care and support in their chosen setting, people need to be able to access services based on needs related to their disability and their age.

This is obviously an approach to funding that the Productivity Commission is suggesting, but we believe that there needs to be a bridge of continuity of support services and this is imperative. They need to be able to access services from both sectors. There are different experiences in different states at the moment and in Victoria, the Disability Act makes no exclusion of people based on age, so they can continue to access services from both sectors, whereas conversely in New South Wales at the moment, the experience of people with motor neurone disease over 65 is that they can't access aged care services until they're 70, so we have this variation at the moment which must be addressed within the Productivity Commission's reviews at the moment.

I guess one thought that we had when reading the report is that there is a proposal that the NIIS would fully fund people's support needs attributable to the injury and that the aged care system would then fund support needs attributable to their age, and we were wondering whether a better approach would be a similar approach for the NDIA as well. So that was a suggestion that we hope will be considered.

Another aspect within the report is early intervention, and that has been addressed by the draft report. Early intervention is vital. People diagnosed with motor neurone disease and progressive neurological disease need access to information and counselling from diagnosis. This provides a solid base upon which the needs of people diagnosed can be addressed through appropriate levels of support.

We believe this is integral to avoiding crises and obviously also integral to saving costs as well across all sectors. The scheme targets people with severe and profound disability. So for people with progressive diseases such as motor neurone disease, I guess there is that concern that access to services in the early stages of the disease may be an issue, and we would like to see a scheme whereby people have that early intervention.

MR WALSH: I think we can just clarify that Carol, and it goes to Bronwyn's point earlier. Bronwyn was taking the point about rehabilitation and habilitation. There is a category of people in tier 3 in which degenerating neurological conditions are specifically mentioned. That would come under the early intervention entry point. So we do think that that covers off the point. We haven't anywhere actually used "severe and profound disability" as an entry point to the scheme.

MS SCOTT: Maybe when you're providing your written commentary, you might look at p.13 of the overview and look at the eligibility criteria. I know people think we have said "severe and profound", but we actually haven't. So if you could have a look at that and if you wish changes to the eligibility criteria, actually look at what we've suggested and then make adjustments to that. That would be helpful.

MS BIRKS (MNDA): Thank you. That's good to hear. We were very pleased that within the report, you have actually highlighted the continuous care pilot in Victoria, which MND was a part of, and certainly that is a very good model to highlight the interface between the different sectors as well. Another area of concern is for people with terminal disease. For motor neurone disease, it is a terminal illness, but palliative care is not going to be able to provide all the supports for people to enable them to stay at home, so there needs to again be that interface between palliative care, disability and health which is mentioned in the report, and that is certainly welcome.

MS SCOTT: Carol, can I just pause there. John and I heard some testimony in the last couple of days about palliative care arrangements in Queensland. I wondered whether - and if you can do it briefly now, that would be great, but maybe in your submission, if you could talk about the range of services that a person would receive in the palliative care system, that would be helpful, because we had thought the palliative care system in some states provided more than it appears to do in reality.

MS BIRKS (MNDA): That is the issue, I think, that palliative care services vary so considerably, not only between states but also between localities. In Victoria, there is a pre-eligibility for people with motor neurone disease into palliative care so they are able to be involved right from the beginning and then come in and out as the person needs. They may not be needed for a couple of years, but they make that contact right at the beginning. Whereas there's been experiences in WA, in particular, whereby people with motor neurone disease can only access palliative care in the last six weeks of life; how you measure the last six weeks of life for someone with motor neurone disease is very difficult. Then there are other services that don't take people with motor neurone disease, so that's very difficult.

MR WALSH: If you could give us a little bit more information on - you've mentioned the Victorian system, presumably that's a diagnosis based entry point. If there are other diseases that might be in the same category, if there's any information on how that works in Victoria, that would be useful.

MS BIRKS (MNDA): Certainly I can include that in the report.

MS SCOTT: That would be great, thank you.

MS BIRKS (MNDA): Another big issue for people with motor neurone disease is obviously aids and equipment and access to that. We really welcome the report focusing on the need for that early intervention and a national approach to the provision of aids and equipment is long overdue and will be very welcome, I think. Also welcome was the inclusion of PEG feeds. I think that's been an issue for a long time for people with MND and it's just, again, the differences between states with regard to that.

An area of concern, however, is access to non-invasive ventilation machines and masks; very expensive intervention for people with MND, but an intervention that evidence now really confirms makes a difference to length and quality of life. So that doesn't really sit anywhere at the moment and, again, varies very much within the states.

MS SCOTT: I'm sorry, I didn't catch what it was?

MS BIRKS (MNDA): Non-invasive ventilation machines, to assist with breathing.

MR WALSH: Is that oxygen?

MS BIRKS (MNDA): No, it's not oxygen. It's a bit like a CPAP machine for people with sleep apnoea, but it's a bi-level respiratory support.

MR WALSH: So what are we looking at in terms of cost for those sorts of machines?

MS BIRKS (MNDA): The masks cost about $300 and the machines themselves probably around $4000 or something like that. They can be rented and often that's the preferred option for people whose life expectancy isn't very long, but that cost is prohibitive for many people with motor neurone disease. It impacts on people being able to access that intervention. There's no cure for MND, but we do know now that there are interventions such as PEG and non-invasive ventilation that improve quality of life and that's what we need to focus on.

The focus on respite is welcome too and we were very pleased to see that a wide range of respite options have been suggested. It's imperative that respite is flexible and is what the person feels is respite to them and their family; I think that's really important. It is as a highlight that I've just received, just yesterday, an email from somebody who received funding through FlexiRest, which is a NSW initiative for neurodegenerative diseases. He got $1000 towards petrol so that he could go off across the Nullarbor while he could still move. He actually can't move very much at all, but while he's still able to do that. So it's that flexible approach that is actually vital to quality of life and to enable people to achieve that is important as well.

The assessment process and the case management role within the NDIS, we just talked a little bit about that with Bronwyn. What we are hoping is that the expertise of existing assessors and case managers who understand pretty rare diseases, like motor neurone disease, is not lost. It's a little bit unclear as to how these assessors and case managers will be employed; whether they will be existing services or a whole new level. I think we need to be mindful of that and mindful of the existing expertise that is out there.

MS SCOTT: Will you indicate your position or the position of your organisation in your response on those issues?

MS BIRKS (MNDA): Yes, we can do. Disease-specific organisations have played a vital role over the years in educating case managers, care coordinators, about those diseases and how the needs of those people, so we don't want that to be lost. The DSOs, again I'm not quite clear from the report as to, is it the intention that the disability support organisations are existing disease-specific organisations like Motor Neurone Disease or MS Society.

MR WALSH: Could be.

MS SCOTT: All existing organisations would have to contemplate where they see themselves if governments accept the final report; did they want to stay as service providers, do they want to stay as advocacy organisations, do they see themselves having the role as a DSO. I think it will be quite interesting; where do they consider their best fit in the new world order would be. In some cases we're suggesting that you couldn't be all things to all people, because of the inherent conflicts of interest.

MS BIRKS (MNDA): Yes, and I agree with Bronwyn that I think it's important that service providers and the DSOs are kept separate. I guess the issue is what constitutes a service provider: is the provision of information and support a service provider or is it actually hands-on care. I think that needs to be clarified properly.

MR WALSH: I think the conflict arises where, if you assume the DSO is in a position of trust, in terms of helping an individual understand who might be the best to provide their support need, there's a clear conflict if that advice says, "The best person to support you is my friend here who happens to work at the same organisation as me." I think it's pretty clear there what is service provision and what's not.

MS BIRKS (MNDA): Right. Just minimising that conflict of interest is important. Similarly Bronwyn, there is a concern around the person-driven approach to funding, rather than block funding. I think that could be a problem for some DSOs, as to whether enough funding would come in that way to maintain their existence. I think that's something that probably needs to be considered as well. We welcome the development of a shared electronic record; I think that's really important and imperative for these clients. It's going to help with the maze of service provision, which hopefully will be minimised anyway, but it certainly will help with that interface between disability, health, palliative care, and mental health. The issues related to integrating that electronic record with personal e-health records are acknowledged. However, I hope there will be some way they can talk to each other, because I think it's important that the health and disability are integrated at some point. I think that's most of our points and concerns that we have.

MR WALSH: That was good. Thanks for that.

MS SCOTT: Thank you very much, Carol.

MS BIRKS (MNDA):   Thank you.

MS SMAIL (CSL): Thank you very much for the opportunity to speak. My name is Carol Smail. I am the CEO of Chatswood Supported Living. We are an government-funded NGO supporting adults with mild to moderate intellectual disabilities on the north shore of Sydney. My particular interest in the Productivity Commission, when I read the interim report, was regarding chapter 8:

> The Commission seeks further feedback on the effectiveness of monitoring instruments and any other others that could potentially be used to assist oversight of the disability sector.

In fact, our organisation had been thinking about this for some time, and bearing in mind that there's been huge advances in technology, we decided to do something about it. Because what was happening, and I suspect it's been happens with a lot of organisations, is you're required to report, you're required to have incident reports, progress notes, individual program plans. So we were producing large amounts of paper and we thought there must be a way to do this better. So what we did was, in 2007 we developed what was model 1 of our intranet, where we started capturing in-house and in our group homes, intersecting with our database and our office all the information electronically and as we learnt a bit more about it we moved out into our drop-in support sector, so that now our staff are able to report on their mobiles because everybody has a smartphone. The group homes have computers, all of it can be accessed remotely. So you can be anywhere in the world and you can see what's happening in your service.

One of the really good things about it is that what it's actually done - and as a side issue it's made us much more accountable which I am really very pleased to say. Another thing it has done which I really didn't expected it would do, has really captured the staff in that they feel they have a lot more ownership of the process because it is a monitoring tool for our clients, it's a monitoring tool for our staff, it's a way that we can record, we can produce reports, we can graph - do all the things that you can generally do. But the data isn't just static data as it was before so we can show progress, we can look at the interaction of staff with clients, we can see where there is a problem, we can see what's working and what isn't working but the staff can see it as well. So there isn't a disconnect between the admin and the support staff and it has been hugely beneficial. Our staff retention rate now sits at something like six years which I think in the disability sector as a support worker is quite unusual, but we generally speaking have very happy staff.

The next stage of this - because we see this as an ongoing project, not something, "Well, we've done this so that's all we're doing" - is actually bringing the families into the process, families and clients who are using computers. So that they will all have their own log on and they will be able to see the progress and perhaps even be able to make comments, particularly clients regarding staff, because we're very concerned with matching clients with staff so that there isn't, "Well, this is your support work and that's bad luck if you don't like them." One of the things that I have certainly noticed over the years is family say, "Nobody tells me what's happening. You are funded as an organisation but nobody tells me - I know that you do this with my son or daughter but I don't actually know what it is you do. What is it you do?" We thought long and hard about how we would be able to address that because I think there is a real disconnect. A lot of people get incorrect information and you have a hostile family member ringing and saying, "I believe that this has happened," when in fact it hasn't, and if you have the living data there and they can perhaps access it, I think that may be a way around it.

The level of accountability is an extraordinary thing because from time to time you get audited and there is nothing like having, "At 7.30 on 4 April this happened," when in fact you've been told, "I believe something else happens." It's a bit like the policeman's notebook except it's electronic. I think that if we move forward with this, all these suggestions and the individual funding that will come out of this hopefully, that there needs to be something like this because we cannot just have services who are funded or clients who are funded and then presume that all is going to be well. I think there has to be a monitoring tool and we think that something along the lines of what we have is a possible way because there is so much technology available and I think really we all should be using it.

The other thing I would say about the NDIS, as much as people may say it's not a perfect system, one of the things that has really heartened me is how disability has been brought into the mainstream. I remember not that long ago when you had to search through the newspaper and maybe find an opinion piece about disability, now it's on the front page and I think that is a remarkable thing. It wasn't that long ago that certainly people with intellectual disabilities were locked away in institutions. Certainly when I was growing up that was the case and I think that we have all moved on. I think it is a brave new world and I think that we all have a responsibility to do our very best and in our small way I think our organisation is making a contribution. Thank you.

MS SCOTT: Carol, I think it's fantastic that you came forward because I don't think many people have commented on chapter 8, so that is great. The fact that you have an example that you might like to share with us in writing would be very, very useful. A fiscal impact of this scheme would be significant. People quite rightly would want to have confidence that there would be good accountability and that there would be an improvement in the quality of outcomes and the wellbeing of individuals with disabilities that are in the individualised funding packages. So if you are comfortable with sharing those reports with us, it would be great.

I don't even have an idea of what you might reporting progress on, so just even knowing that would be great. You would have seen from our reports that sometimes we like to illustrate themes with examples and have little boxes of short studies so if you were able to do that, I would certainly welcome it.

MR WALSH: I think it's great that you came forward.

MS SMAIL (CSL): Thank you very much.

MS SCOTT: Ideal.

MS SMAIL (CSL): Thank you.

MS SCOTT: Very good, thank you very much. Thank you very much for attending today. It's good to have so much interest in participation. We are going to be back tomorrow and we are going to be starting at 9.25 in the morning. We won't be going all day, it's a morning tomorrow. Then Friday it's a morning also. So if you do wish to come back tomorrow, it's a slightly later start at 9.25. Thank you again, it's very encouraging to see this level of interest. Thank you very much.

AT 4.02 PM THE INQUIRY WAS ADJOURNED UNTIL
THURSDAY, 14 APRIL 2011