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TRANSCRIPT
OF PROCEEDINGS

PRODUCTIVITY COMMISSION

INQUIRY INTO DISABILITY CARE AND SUPPORT

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

TRANSCRIPT OF PROCEEDINGS

AT PERTH ON THURSDAY, 22 JULY 2010, AT 9.01 AM

Continued from 21/7/10 in Sydney

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MS SCOTT: Good morning. Welcome to the public hearings for the Productivity Commission's inquiry into disability care and support. Thank you very much for attending today. My name is Patricia Scott and I'm the presiding commissioner on this inquiry. My fellow commissioners are David Kalisch, who is here today, and John Walsh, who will be joining us after lunch by Skype.

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

The Australian government has asked the commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. We have already talked to a range of organisations and individuals with an interest in these issues and we released a discussion paper in May. We are grateful for the submissions already received and I think they are numbering about 110 or so. These can be downloaded from our web site or viewed from our web site at www.pc.gov.au.

The commission has extended the due date for initial submissions to 16 August 2010. The commission also welcomes second or even further submissions after the due date for initial submissions. These submissions may include additional points people wish to make, comments on other submissions and the results of community consultations. The purpose of these hearings is to provide an opportunity for interested parties to discuss their submissions and their views on the public record.

We'd like to conduct all hearings in a reasonably informal manner but I do remind participants that a full transcript is being taken. For this reason, comments from the floor cannot be taken but at the end of today's proceedings, I will provide an opportunity for anyone who wishes to come forward to make a brief comment or presentation.

Participants are not required to take an oath but are required under the Productivity Commission Act to be truthful in their remarks. Participants are welcome to comment on the issues raised in other submissions or on testimony that they hear today. The transcript will be available from the commission's web site following the hearing. Are there any media representatives here today? Okay, thank you. To comply with the requirements of the Commonwealth occupational health and safety legislation, you are advised that in the unlikely event of an emergency requiring evacuation from this building, please follow the instructions of the hotel staff. If you require assistance, please speak to Ineke, who you may have met on the way in or have spoken to in arranging to be here today or to myself or David. We're only too happy to help.

We are going to try and take a morning tea break at 10.45 and we will try and finish for lunch at 12.20 and then resume back at 1.10. I would now welcome to the table the Liquor, Hospitality and Miscellaneous Union and I will for the record get you to state your name and then look forward to hearing your opening remarks and then we might have some questions and answers and see how we go. Thank you very much.

MS SHAY (LHMU): Kelly Shay, assistant secretary, LHMU.

MR DOW (LHMU): Richard Dow, I'm a carer with the Activ Foundation.

MS SCOTT: Irene Snow, I'm a social trainer with Activ Foundation.

MS VOAK (I): Wendy Voak, I'm a social trainer with IdentityWA.

MS CREASY (LHMU): Michelle Creasy, I'm an organiser at the union.

MS SCOTT: Thank you.

MS SHAY (LHMU): Commissioners, thank you for the opportunity to make a submission this morning. The LHMU supports the establishment of a disability long-term care and support scheme or a disability insurance scheme. We support anything essentially that will deliver more funding to the disability sector and importantly to the wages and conditions of direct care workers across the disability sector, whether it be residential or home care.

The LMHU will be putting in a formal submission by writing before the due date on 16 August and today we will be speaking about some of the key issues around implementation issues and specifically workforce capacity. Our members and delegates today will be addressing some of the workforce issues raised in the issues paper, page 39. Specifically, questions such as: how can workers be attracted to the industry? What role should government play in this process and what is the appropriate level of training required before commencing work in the industry and should any existing certification requirements be altered to reduce obstacles? Other important issues are about ensuring that we have quality disability direct care workers and ensuring that we improve the sector and professionalise the industry.

The LHMU is Western Australia's largest union. We have close to a thousand members in the disability sector. We have agreements with the five largest disability employers in Western Australia. We have a strong and active disability direct care workforce and a strong and active delegate structure. Our delegates meet monthly and set the direction of the future of the union in this important area. It is an area of increasing membership for the union and increasing activism and it is an area which requires significant resources and a significant increase in funding by both state and federal governments.

The LHMU represents all workers in the non-government sector in disabilities in WA, so we don't just represent those workers who work in the Disability Services Commission, we represent social trainers, residential aides, providers of accommodation services, property care and business services for all supported employees. Our members provide a pivotal role when it comes to looking after people with disabilities and improving their lives and contributing to their lives.

The disability sector's workforce has some quite astounding characteristics. The majority of the workers are female, about 75 per cent of female. The majority of the workforce is ageing, with over 40 per cent of the workforce being over 45 years of age. The majority of the workforce, 75 per cent, are part-time or casuals. The workforce is characteristically non-unionised or has a low level of unionisation. There is a high turnover of the workforce and there is a history of non-bargaining. Most workers are reward reliant or simply completely at the mercy of their employers.

The LHMU recognises, as I have said, that funding in the sector is woefully inadequate. It results in significant levels of unmet need. In formulating a new funding model for disability and long-term care and support, account must be taken into - care for direct-care workers' poor wages and conditions in this sector. Low pay, poor conditions, poor jobs, is the main reason why there is significant difficulty in attracting and retaining quality staff in this sector.

The LHMU believes that there are some pretty fundamental keys that must be addressed, what - we have put to both the state government and the federal government and that we appreciate being able to put to you, the Productivity Commission, this morning. The LHMU believes that the federal government must assist or all governments must work together to provide sufficient ongoing funding to ensure that direct care workers in a non-government sector are paid in alliance with those working in the government sector. That means in Western Australia a minimum of $20 per hour average base rate for unqualified support workers and $25 per hour for qualified cert IV social trainers and other workers.

We also think it is fundamentally important that we standardise conditions of employment other than wages across the sector. For example, comparable allowances, overtime rates, entitlements, annual leave, long service leave and so forth - we need to ensure that there are minimum conditions across the entire sector and standardised conditions. Finally, on the issue of wages, we think it is fundamentally important that indexation reflects the actual cost of living and ensure that the indexation component of funding for wages flows through to workers' rates of pay by appropriately worded registered industrial agreements. We can no longer assume that employers will pay annual increases in wages and flow through the indexation that applies. We know that the indexation that currently applies to the sector is woefully low.

It is the LHMU's experience that providers often do not pass on indexation of wage increases to their workforce. It is recommended that the government mandates that as a prerequisite of its funding. The following example illustrates the kind of salary review clauses that in this union's opinion is unacceptable and is counterproductive to ensuring and encouraging worker remuneration and retention. This clause is from a major current provider's non-union negotiated enterprise agreement. The agreement is for a five-year period. It provides for an hourly rate of pay of $16.05 for a carer and makes no guarantees for any wage increases for the life of the agreement. $16.05 for five years with no increase. In Western Australia our electricity has just gone up by 35 per cent, just to name one of the costs of living. So the increase says that:

> The salary rate for each employee shall be reviewed each year with any increase to take effect from the first pay period commencing on or after review,

and that -

> the annual salary increases should not be automatic and shall be subject to the employee's demonstrated efficiencies -

not really sure how you get efficiencies in the disability sector.

> The annual review will also have regard to other factors including -

and it lists a couple of other factors but specifically it says -

> where an employee is not granted an annual salary increase for performance reasons those reasons shall be stated in writing to the employee.

On the other important issue, Western Australia has had individualised funding arrangements in place for about 20 years now. It is becoming increasingly common for people with disabilities or their representatives to enter into a direct employment relationship with carers. These arrangements are usually facilitated through a service provider. In our submission we will also attach other examples of what these contracts look like.

The contract often describes the arrangement and the employee as one for private and domestic purposes. This is actually incorrect. When this occurs the care providers generally does not only do domestic care - cooking, cleaning and laundry - but also performs personal care such as bathing and dressing and toileting and other care: administrating medications, medical procedures, managing challenging behaviour and a whole range of other issues. The characterisation of workers employed under these individual contracts as domestics has significant adverse effects for workers in Western Australia.

Workers employed as domestics in Western Australia, because they're employed - if it's individualised funding and they're employed directly by the client, as the employer is the client they are not a constitutional corporation under the WA Industrial Relations Act. That also means that the employee - under the act a person engaged in a domestic service is expressly excluded as an employee and is declined the protections of the act. Essentially they are at the mercy of the individual. They have no rights and they have no - they have no rights under workplace relations law. Obviously this is a significant issue for us. Further, under section 3 of the Minimum Conditions of Employment Act it defines an employee as a person within the meaning of employee as defined by the Industrial Relations Act. So you also are not able to - you're not entitled to the Minimum Conditions of Employment Act.

So while currently the current adult base rate of pay in WA is $15.45 per hour, the union is aware of unqualified persons being employed under this arrangement who provide care and are being paid an hourly rate well below the minimum rate, often up to $10 per hour less than that minimum hourly rate of pay. Employers are not obliged to make superannuation guarantee contributions for workers employed to do so for a domestic or a private nature for under 30 hour per week. Salary sacrificing benefits available to employees of public benevolent institutions are also not available to people working directly by people with disabilities or their representatives.

The LHMU recognises that people with disabilities - favourable views on individualised funding arrangements and the direct employment of care workers as expressed in submissions lodged to date. However, we do have legitimate concerns that the trend towards consumer-directed choice will cause difficulties for care support workers to maintain their professional standards and lead to decreasing quality of care provided. I'll just hand over to my colleagues to touch on some of the key issues about wages and conditions, what it's like to work in the sector and what we think needs to be addressed. Richard?

MR DOW (LHMU): Good morning, commissioners. Good morning, ladies and gentlemen. My name is Richard, and I'm employed by the Activ Foundation as a social trainer. I worked in this organisation and with the Disability Services Commission since 16 years now. My main concern is the flow of staff through the organisations is horrendous; so we have a turnover of staff, and it puts an onus on the core staff in the houses. The certificate III and certificate IV have considerable knowledge on seizures, on behaviour management. When you have people coming into the industry with no training, you're there and people's lives are in your hands. If you're employing - casual staff coming in, you know, there's no onus on these people with no training to look after these people. It's up to the core staff.

So, you know, my shortest buddy shift has been 15 minutes when somebody has come into the house and said, "I can't do this job. This is horrendous." So you continually train people. There's a downturn in the market, you'll see people coming from the mining industry coming in and, you know, you'll they'll come in for 10 minutes, away again and we're left to pick up the pieces over and over and over again. The reason we can't attract people is - you know, I did the - went to TAFE and trained, you have all this experience in dealing with people for 16 years. You think you're getting some knowledge in the industry. You see people come and go. You're left to deal with these problems, and it's not good enough. You're paid $19.70 an hour. We just got a wage rise of 70 cents and hour. So I had to work two jobs to support my wife and family. That frustrated my marriage, which has ended.

So really at the end of the day what we're looking for - we need to attract people to the industry by paying a decent wage, a livable wage. We shouldn't be working two jobs in 2010 to survive. Paying people - I know people in my industry that get less, as a residential aide, $16.40 an hour. They just got 70 cents as well. It's hardly going to make people millionaires to get $17 an hour in this day and age when you consider in the mining - this mining state $150,000 a year to work up in a mine without any qualifications.

I came into this industry 16 years ago. I'm a vehicle body builder by trade and I came into it for two weeks and I loved the job. I don't get up in the morning thinking, "I'm going to work," it's a job that I love and I stayed in this industry for 16 years. I'm a professional. Like a doctor you're going to see for 15 minutes twice a year I've been in a certain area in Perth for 16 years. I've been in people's lives for 16 years. We find that this relationship develops with people. You need consistency in service delivery because people with disabilities require that. We deal with psychological problems, not just intellectual disabilities. There's a - primary disability's intellectual will come to us but have many secondary disabilities.

So we're handing out medication, we're dealing with seizures, we're making life-threatening decisions - life or death decisions; so, you know, deserve to be professionalised? Absolutely. Do we need to be recognised as professionals? Absolutely. It's long overdue that carers are not just carers and we need to attract more people to the industry.

MS SCOTT: Thank you. Just conscious of your time. Do you have anyone else to present?

MS SHAY (LHMU): Yes, we're going to speak briefly.

MS SCOTT: Okay.

MS SNOW (LHMU): Good morning. We have an ageing workforce. Not many young people are coming in or staying, mainly this is due to lack of permanency, low wages and not seeing it as a job with a career path. High turnover is not good for the industry or the people we care for. When I came into the industry, which was nearly 20 years ago now, it was a 12-month full time TAFE course. Now it's a six-week course that they do to get certificate III and IV, which we consider is inadequate. We'd like to see more young people coming into the industry, but without proper training they won't stay in the industry. There's too much to learn in just six weeks. You need more than six weeks to get to know most things and then of course it takes 20 years to know most things as well, the experience helps. So yes, thank you.

MS VOAK (LHMU): My name is Wendy. I work at Identitywa. I'd just like to touch - to reinforce what Richard and Irene have said, but I would like to touch on the casuals that work in this industry. Most casuals, the majority of casuals, are not casuals. They are actually working for other organisations. It reflects the wages. To make ends meet they then have to get casual work at Identity or Cerebral Palsy or wherever. This impacts on our clients because they're tired. The casuals are tired. They think interacting with our clients is watching TV while the house staff then have to pick up all the work. Anybody who works in disabilities would understand what I'm talking about.

We've got a lady, and I won't give names, who is a residential aide in a house that I work in. Her daughter has actually left school. She's been in a Homes West home for years and years and years. She's on a poor wage. She has now been told by Homes West she has to get out because it's a three bedroom house. So she is stuck in a grey area. She has not got enough to get a home of her own privately. She can't stay in her Homes West house. She is absolutely frantic. She doesn't know what she is going to do. The wages that are paid in this industry need to be really, really looked at because we have a transient workforce, we have people doing two or three jobs and that means they're working 20 hours a day to make ends meet. It isn't good enough.

MS SHAY (LHMU): Thank you. Ray?

MR PARRINGTON (LHMU): Thank you. Thank you for coming, everybody. I'm Ray. I'm a social trainer with Activ and I work in the people skills and community area. It's on a day basis. I'd like to talk about my concern about the overuse of casuals and even volunteers that we use. The use of casuals is fine to a limit but a lot of cases people don't turn in because they don't have to. It affects the quality of our service to the clients. We can't set out activities. You can't prepare and carry out activities and also that means that we're short staffed.

It affects the quality of our service on a daily basis. We're continually training staff and then they stick around for a few months and they get a better job somewhere else and then we've got to retrain staff again. It falls back on us. We've been accused of not mentoring staff correctly but we've also got to carry out our own duties. We can't always be looking after new staff all the time. Also, they're not trained. No manual handling training, no medication and then it falls back on us. So the quality of service is not always there but we do our best. A lot of the needs are not being met because all this happening I just feel sorry for the clients in a lot of cases because we can't meet up with their demands, because of their behaviours it's becoming very hard work for us.

I mean people are certainly casual, they don't really understand people's behaviours and what their needs are and we're not meeting their needs. I realise that we do need casuals to carry out the service but the overuse of them means that it's more work for us. We really need more training for people, where they are casuals just so that we can increase the service to our clients and carry out the needs that we need to meet. Okay, thank you. Thank you, folks.

MS CREASY (LHMU): My name is Michelle. I've worked in the industry for 16 years and the entire time that I've worked there I've had two jobs, a full-time job plus another job in order to make ends meet. My other job is now currently - I'm a - host family, so I'm not employed to take care of this wonderful young lady that I've been taking care of for 15 years but I'm paid an allowance, because it's the cheapest way to do it because - they say it's a favour to me because I pay no tax but it's a benefit to the organisation that administers it because there's no - I have no leave entitlements, no annual leave, no sick leave, no long service leave entitlements. I have no superannuation paid. I have no workers compensation.

I do it because I genuinely care for this woman I've been caring for. It's very intense. She has got epilepsy that's not well controlled. She's blind, she's got profound intellectual disability plus a lot of other issues. She needs total personal care. The only way to provide the service to her is to do it through this model because the funding isn't there to do it through a wage model. So I do it because I love it but I know on the other hand I am putting myself at risk. What happens if I do get sick, you know, those sorts of things. It's becoming an increasingly popular model to deliver services, a way of keeping people in their homes because keeping people in a family situation is ideal. But it's - there's so many dangers and there's no - I haven't been offered any training. I've been told I have to have a first aid certificate.

Her needs are very complex and her needs can't be done by a casual. Her needs are so high and so specific. That's why I take it on, because no-one else can walk in there, even with an induction of a day. Myself and her main carer would not feel comfortable with that. That's the only respite that her main carer gets, is what I provide, because she doesn't sleep properly. So you can go for three or four days where you haven't had a lot of sleep because of the nature of her needs. It comes down to there needs to be more funding provided so that people have those protections - and that she has protection of having people that are employed to take care of her. Thank you.

MS SCOTT: Thank you very much.

MR KALISCH: You touched on - sorry, Kelly, the issue of individualised funding. That has obviously come up a lot in terms of our hearings to date. Certainly the families and people with disabilities that have also been presenting at our hearings have been, I have to say, very strident, very strong and very consistent in their desire to have greater individualised funding packages and the opportunity to hire the staff that, as you recognise, provide often very personalised and very personal and intimate care needs for them. How does this fit with a - I suppose what I'm hearing is a much more regulated, much more defined labour market that would actually, I think, remove those flexibilities from this individuals.

MS SHAY (LHMU): I think we need to find a balance between individualised funding that can be delivered through a central service provider so that we have some minimum in terms of wages and conditions. We need to professionalise this industry. We need to make suer that we recognise the quality care, support and development that our workers provide. People with disabilities absolutely have complex needs and are very individualised in their requirement for care.

What is happening in this sector and what continues to be the case in this sector is that the workforce is undervalued and under-recognised for the professional contribution that they make and, not meaning to be harsh about it, they are often taken advantage of, because our members and the people who work in the situation do it because they are passionate about delivering quality care and about making sure that they improve the lives of people with disabilities.

Therefore, they often do extra hours, extra work, unpaid night-shifts and a whole range of different things and put themselves and their families at risk because of the care that they want to provide to people with disabilities or to particular clients, because they have got that individualised relationship. We need to find a model which strikes the balance between those two. We need to ensure that workers in this sector have minimum conditions of employment, get recognised as professionals and have minimum wages and conditions.

The reason that people with disabilities often want individualised funding is because the funding is so low that they want to try and manipulate it the best way they can to get the most amount of hours they want. If we can address the fact that the funding is so low and increase that funding, then people with disabilities can have quality care and not have to try and eke out, you know, $100 over five days, like they can actually can have $500 for five days or whatever the equivalent required.

MR KALISCH: We're certainly hearing a different perspective, I'd have to say, in terms of people with individualised funding, to hire the people that they want, that they believe will provide a good service and have more regard often for aptitude and attitude, the sort of things that Ray and others were talking about in terms of your love for the job. That's certainly the sense that we're hearing from people around that. I suppose the aspect I'm struggling with here a little bit and getting a sense of is that you seem to be thinking about a particular segment of the disability services market, around the more complex needs. That's certainly part of it, but - - -

MR DOW (AFI): Yes, one shoe doesn't fit all, David.

MR KALISCH: Yes, I think that's the issue I was wanting to raise with you, that one model, one approach doesn't seem to fit all right across the sector, that others that we're hearing about with individualised funding have lower professional needs, but also are paying above-award rates to keep staff.

MR DOW (AFI): But you can have this low funding and somebody in a house situation that's getting paid $15 an hour to do the job. Now, that's not a livable wage, $15 an hour. Can you raise a family and buy a house and provide for that family on $15 an hour, that's where you've got to ask the question. You're administering medication and dealing with behaviours, or whatever the needs are. As we said, one shoe doesn't fit all, we have got to look at each case as it is and fund it appropriately.

But the lower part of that funding has to be a livable wage, that's basically what I think. To be professional in your job, if you went to the hospital and you were lying on a hospital bed and I came in and said, "Dave, I'm looking after you today. I've not had any training in this, but I'm muddling my way through the day," how would you feel about that?

MR KALISCH: Yes, certainly the sense from those with individualised funding is that they sort of hire for attitude and aptitude and then provide training on the job essentially. The other aspect I wanted to just come back to was the comment that you'd get a cert III and IV within six weeks. I'm doing a study on the education workforce at the moment, on VET in particular, and I just haven't come across that. How can you do that, get both of those quals within six weeks?

MS SNOW (AFI): From what I've seen myself, they have like a whole stack of papers and they have to fill in the answers virtually. I think there is like one day here and there that they go away and do the course, but my course was 12 months full-time. That was every day of the week and - - -

MR KALISCH: I'd be interested in further information, if you could get it to us on that.

MR DOW (AFI): Most of it was done at home, because a lot of it was a self-paced training - - -

MR KALISCH: It's obviously competency based in VET.

MR DOW (AFI): You did one day a week for so many weeks and then the rest was like, "This is what you'll be doing at home," and you've got a certain date by which to hand it in, a lot of it. But there was a lack of follow-up, from what I can gather. If you were stuck on a certain area there was a lack of information. Basically it was up to you to muddle through the paperwork.

MS SHAY (LHMU): Different RTOs have different levels, in terms of quality of cert III and cert IV that they provide, absolutely, and I think that there's not nationally-consistent professionalised quality training that occurs in the sector. That's the feedback that we get from members. Who you to go to depends on the quality at the outcome of the certificate, and that's a real concern.

MR KALISCH: If we're going to use this in our material we'd obviously need a bit more substantive evidence, and so we'd encourage you to provide that.

MS SNOW (AFI): Yes.

MR KALISCH: We obviously won't disclose particular names.

MS VOAK (I): Could I just say something here, and I don't mean to be rude to anybody, but there is a glaring thing here, there is not really one very young person in this room. If we don't attract younger people to this industry, who is going to look after us in 20 years' time. We have an ageing disabled population happening out there. We have an ageing carer population. We need to do something to attract younger people to come into this industry and stay in this industry. They need a career path, they need higher wages so that they can look after their families and not just use this as a stepping stone to their other career.

MR KALISCH: Can I ask Richard just one question about your transition. You mentioned you worked in the vehicle industry and then you moved into this industry. In terms of attracting people, they have got to come from somewhere, and often from other industries, or, as you say, from younger people leaving school and then training. Can you envisage it being an attractive industry for people who are retraining?

MR DOW (AFI): I had come back from Scotland and I saw the advert in The West Australian, and I went to the workshop which was like a sheltered workshop, it was antiquated, it was Dickensian, and I thought, "My goodness, I don't know if I could work here." There was a bit of a downturn in that time, 16 years ago, I don't know if you remember, there was a bit of a recession going at that time too. So I took the job for two weeks. We were making outdoor furniture at that time, and I was making jigs and patterns for the guys in the machine shop. I didn't get another job, and eventually two weeks was two years. I then trained myself.

I went in to get training at Mount Lawley TAFE and I moved into various areas within the organisation myself. Is it attractive? Not for everybody. It's not attractive for people now, because younger people now want everything now. As you know, as we get older we think a wee bit differently, and I think giving back to the community is what when you get older is all about. But when you're 22 and you want to buy a house and you want to have a family, what is going to take you to the disability field?

If my son or daughter came to me and said, "I'm thinking about going into the disability," I should be going, "Yes, let's get in there, get a job," not to go, "Ooh, I don't think you should." Obviously the wages is a huge thing. If you can't pay the rent or pay the electricity bills or pay anything, who is going to go there? You may take it and struggle for a little while till you find something better, and that's the way it is in the disability field.

MS CREASY (LHMU): A large portion of people that do come into the industry come in through volunteer work. They come and do volunteer for a little bit of time, which is how I started in the industry.

MR DOW (AFI): Me as well.

MS CREASY (LHMU): Then what happens is they need casuals, they say, "Would you like to come and do casual work?" Then you get a part-time or a full-time job. A large portion of the industry does start off as volunteer work. The people generally want to do the job, but there's perception out in the community that we are only a little bit more than volunteers, they don't see the complex work we do.

Also, I have not yet met a disability worker who has not been told they must be special when they have told someone the job they do. If you say, "I work with people with disabilities."   "You must be special to do that." We are professional skilled workers. People don't see that.

The other thing about attracting people to the industry is that, unless you have a family member with a disability, who out there in the community really has anything to do with people with disabilities. We all come from working with people with severe disabilities. They are living out in the community but they are not part of the community. The neighbours only know them because they have had to retrieve things that have been thrown over the fence or, you know, the bin has been stolen, or whatever.

You take them out into the community and you go and sit somewhere, and you watch everyone look around and leave. It's about also I think making the community more aware that people with severe disabilities do exist and they do deserve to be part of the community, and it's raising that awareness so that it also is then seen as an attractive career path. But then who wants to go and work in an industry long-term when they're going to be paid $16, $17 an hour.

MS SCOTT: Michelle, we don't have sufficient time to go into it now, but I would welcome if you could give a bit more information in your submission about the circumstances where you are paid an allowance. I'm not too sure I've got the right gist of it, so it would be great to have it written down. Of course you'd have to leave out identifying details, but I'd be very interested to have some information about that. It sounds like you've got a day job and another job. Have I got that right?

MS CREASY (LHMU):   I've done that since I was 21. I do it now, while I'm working as an organiser, because I'm committed to this young lady. In a nutshell, it's similar to a fostercare arrangement.

MS SCOTT: Got you, okay. Just to get that detail would be very helpful. Thank you very much for coming along today. I'm sorry we have to be so short with everyone, but we do have lots of other people who wish to present. We look forward to getting your written submission. Thank you.

MS SCOTT: I now invite Ethnic Disability Advocacy Centre to come forward. Good morning. Thank you for attending. Could you identify yourselves, for the transcript, and then would you like to make an opening statement, please.

MS AU YEONG (EDAC): Thank you. I shall start first. My name is Jenny Au Yeong. I am the CEO of the Ethnic Disability Advocacy Centre, also known as EDAC. EDAC represents and safeguards the rights and interests of people with disability from a culturally and linguistically diverse backgrounds of family and their carers. My colleagues on my right, Miranda Ali and Karen Soldatic - they will speak later - have decided we share a number of issues, given the time constraint.

We will be providing a written submission that gives more detail at a later date, but today we have chosen to share some key issues that we think might be important for you. As I mentioned earlier, our target population people are from diverse backgrounds, culturally and linguistically diverse backgrounds and they face a number of barriers and issues, one of which is service access. The first issue I want to raise is about the barriers relating to service access and that's relating to the definition of "disability" and eligibility in particular.

Definition of "disability" and eligibility I think is interrelated to service access because many people with disabilities need to prove their level of disability and types of disability before they get any services and people from culturally and linguistically diverse backgrounds often face a lot of barriers because services are not culturally and language appropriate and they sometimes have difficult proving their disability and the eligibility required for a particular service.

For example, if you look at intellectual disability it's based on your limitations as well as your intellectual functioning and your adaptive behaviour. That needs to be originated before the age of 18, and people from culturally diverse backgrounds have difficulty proving their disability and the medical records and their education background prove that they have intellectual disability prior to the age of 18, particularly refugees and migrants.

Refugees may not have any language or they may come from refugee camps or they have no education, and it's very difficult to have this piece of paper to say that, "I've been to school and I have been diagnosed as having intellectual disability." Here in Australia, and in Western Australia in particular, to qualify for many services you need to be registered with Disability Services Commission and you really need to be assessed, and we found that some of our clients had great difficulty proving and obtaining medical records.

The other issue I want to raise is also eligibility concerning Centrelink payments. Some services require, in particular HACC services, that you need to have a pensioner health care card or a health care card in order to get service. We all know that migrants when they first arrive cannot obtain any Centrelink benefit unless they have been here for two years. For many migrants, unless you have been in residence for 10 years, you are not eligible to apply for a pension, and that really provides an extra barrier for people with disabilities in obtaining services.

For any model or approach on which the commission decides they will need to consider the approach to include the needs of people from culturally and linguistically diverse backgrounds, and in particular look at the culture, language and social perspective based on the needs of the individual, not just the severity of the disability and the conditions. I should probably stop for a little while and let the others speak.

MS SCOTT: Thank you.

MS ALI (EDAC): Thanks, Jenny. My name is Maranda Ali, I'm assistant systemic advocate at EDAC. The key issue I'm going to focus on today is really looking at the isolation and the language difficulties of people from culturally diverse backgrounds. For a lot of people, migrants, family members may have a disability, they are coming from a country where their concept of disability is quite different to what we have here in Australia. They may be working on a medical model. There are some concepts of shame and it is quite highly stigmatised. With that it does cause a lot of people with disabilities to be quite isolated within their communities plus also isolated because of racism within the general community. What we are really looking at and proposing is the idea of having localised decision-making. So they, generally when they come to Australia, will find themselves within their local community groups. With that, localised decision-making helps engage the community. You're bringing in people, professionals from the disability sector but community members as well, and helping them to create ownership and to look at it in a very positive manner than the negative perspective. It's also using the local resources and the local knowledge. So this may be within the form of local councils, whatever, but they have a knowledge of what are the issues facing their community groups. Some of it is, what are the language barriers?

MS SCOTT: Ali, would you mind if I asked a few questions as we go? Would that be all right?

MS ALI (EDAC): Sure.

MS SCOTT: A lot of people have pointed to the local area coordinators here in Western Australia as a good model. Now, I imagine we'll hear a variety of views over time but you're talking about localised decision-making in your proposal. Would you like to comment on local area coordinators and how you see them fitting into your proposal? That's question number 1.

MS ALI (EDAC): Yes.

MS SCOTT: Question number 2 is, given that often when people come to Australia for the first time they tend to, quite reasonably, form contacts with their language community or the cultural community that has already settled here. Wouldn't one way to reduce isolation and improve services be to actually use community structures rather than to go on geographic location? So that's my second question.

MS ALI (EDAC): I'll answer the second question first. One of the main problems with looking in community groups is they can be quite diverse, and I really think whichever model you look at there are going to be disadvantages. Looking at how it can fit it in with the rest of Australian society as well. It is better to kind of look for a local area, but in saying that I don't think the supports that they get should be centralised in that local area. There should be choice amongst where they get those choices, but we're looking at the decisions first; what are they needing.

MS SCOTT: Fine, I've got that.

MS ALI (EDAC): Now, local area coordinators. I think the model of local are coordination, it is a good model here in WA, but at the same time I do feel that it doesn't have enough safeguards and there's still areas where there are gaps, and they don't get to make the decisions. So they then have to go back to the government and using that very fine definition of disability all they're doing is really - they do do advocacy, do a little bit of information and a little bit of community development, but I think it should be a whole holistic package.

MS SCOTT: I just want to check on one thing and maybe both of you can help me here. Does WA use a more limited definition of disability than in other states? Are you conscious of that?

MS YEONG (EDAC): I think it depends on the service that you are obtaining from. Obviously if you are autistic, you will go to the autism association and that, or intellectual disability Activ or MS society and so on. I think the definition various from department to department and agencies to agencies. In WA I think the history of the disability services commission and the history of it being they were originally intellectual disability concerned and it's based from historically intellectual disability, most of their services are for people with intellectual disabilities. Having said that, the different levels of level 1, 2, 3 services are obviously people with the most severe disability, the intellectual disability would obviously get the services that they needed. So the definition, as I said, differs.

For the people we represent - it's mentioned earlier about the marginalisation, the isolation and the language barriers - they don't necessarily know where to go for services because most services do not promote themselves very well and in different languages, or if they promote themselves within their English-speaking community and then don't necessarily go to the ethnic communities. Having said that too, because disability is so marginalised and stigmatised, even people from culturally diverse background face additional stigma and therefore they do not always claim a disability among the community. They may do so through applying for Centrelink payment, but often in obtaining care services or independence, or employment or recreation, it's well known in reports that the uptake of services of that kind is very, very low. Even in West Australia it's about 2 per cent compared to the other disability population.

So obviously there's a lot of work to be done on both sides in promoting disability and raising disability among the ethnic communities and raising their rights to access services. At the same time services need to be cognisant of their issues and be culturally and language appropriate.

MS SCOTT: Thank you.

MS ALI (EDAC): I think I'll just finish off there so I can let Karen have a chance very quickly. The other thing, if you're looking at localised decision-making, you've got to also bring in the opportunity for people to narrate their stories. I think that's a key part of it. Not everyone is effective in writing on forms what their issues are, and especially for people from a CALD background or with complex issues. So the idea of being able to talk to a panel and say, "Okay, these are my concerns. This is how things have changed lately." It brings more of the realisation and looking again at that holistic component to it. Again, as we say, there needs to be appropriate safeguards for something like this to be implemented.

MS SCOTT: Thank you.

DR SOLDATIC (EDAC): My name is Karen Soldatic and I'm a board member of EDAC. My role is to talk a little bit about funding. I guess when we're talking about funding we're really drawing on the Nobel Prize economist's work, Amartya Sen, and his work in collaboration with Martha Naussbaum, which is commonly referred to as the human capabilities approach. So what they are argue is that issues of public policy and its funding should actually be founded on notions of democratisation, participation and representation, rather than narrow definitions of marketisation. I guess some of the things that we want to cover is actually the relationship in the ethnic community between those who receive care and the increasing numbers of women from immigrant communities who provide care, and the impact that low wages and conditions in the long-term have on their bodies.

We also want to talk about a funding system that provides funding for dignity; dignity for people with disabilities from CALD and ethnic minorities and also dignity for the women from immigrant communities who provide care. So I guess the first thing that we do want to talk about is a little about what the people before us were talking about and that's particularly around issues of wages and conditions for immigrant women who are increasingly coming into the system as carers. We feel that there needs to be regulation and conditions to support their professionalisation and we don't see that individualised funding stands as an antithesis to this position. We think that they can work collaboratively. We think that's particularly important because we understand in our experience as advocates that when workers are provided with dignity and respect then disabled people receive their supports with dignity and respect. So we'd like to see a system that appropriately funds not just the workers and carers, but so that people with disabilities can actually receive the support services that they need for the length and time and duration that they require.

Our second issue regarding funding is in regards to whether that's a centralisation system, a taxation system, or whether that's an insurance system based on issues of risk such as some of the models proposed in the larger disability investment group paper. We don't support a funding system based on risk assessment. Again, particularly for issues of the migrant and CaLD communities who are largely in low-paid, casualised contingent labour markets which are more likely to lead to issues of impairment and disability. Therefore the risk on their bodies is more likely to end in a disability; so therefore in a risk-assessment situation they would be extensively disadvantaged in such a system.

We do support a centralised taxation levy. However, we do not want to see it consumed within the Medicare levy; we wish for it to be a stand-alone system. That's primarily because we're seeking a broader, universal definition of disability such as that within the UN Convention. Therefore, if it's contained within the Medicare system, it risks becoming a highly-medicalised funding system and the problem with that system, it doesn't actually recognise the multiple roles and identities of people with disabilities. They're not just a disabled person; they're a person from an ethnic minority and they have different responsibilities within that community beyond their disability. So we're looking for a funding system that supports them to participate in those different roles.

So therefore we'd like to see a shift in the funding system so that it does increase their participation and their representation and takes account for their unique identities as immigrants within Australia. That's it.

MS SCOTT: Thank you.

MR KALISCH: Just a question about funding. The Medicare levy doesn't actually go to Medicare, it's actually just a notional funding and it just goes then into general revenue, which I think was the sense of what I'm hearing from you as well in terms of a levy that's there in the taxation system. Well, it's actually probably a bit different to the Medicare levy in that this instance it would actually be directed towards funding disability services. So I suppose my question is - I mean, the funding is one aspect. How it's then used is perhaps also some separate decision-making and would actually be quite distinct from the collection of the funding. Is that a reasonable - - -

DR SOLDATIC (EDAC): Yes, that's how we see it, absolutely; that there would be a separation. Coming back to Maranda's point, we're actually interested in very localised decision-making in the distribution of those funds.

MS YEONG (EDAC): I think we - - -

MS SCOTT: I'm sorry to interrupt, Jenny, but could you articulate a bit more about what this local decision-making body is, what it would look like? I mean, who would it be? Would they approach - and I guess maybe a harder question, the money comes in from a centralised tax or levy in your model. That money goes, I imagine to - are you seeing it as a national tax, it goes to the Commonwealth government?

MS ALI (EDAC): Yes.

MS SCOTT: Okay. Could you then follow the money train from the Commonwealth government right down to the localised decision-making body. Could you just give us an idea of how many - I mean, do you see the states in it?

DR SOLDATIC (EDAC): There are other models internationally. For example, if you think about the UK, they go through local councils or local shires. So that's a centralised system where the funding is just really to local shires and then they have a framework to distribute money locally, either directly to individuals or to services, depending on where the individual decides where they wish or how to receive their services. I guess in terms for us, we would see that idea highly transferable to the Australian context. We would also though, in regards to issues of representation and democratisation, like to see those local decisions including extensively the voices of people with disabilities on those decision-making structures and also, of course, families and carers who are largely the support network.

That representation obviously for us, particularly in communities where there are high populations of different groups, to include representation from those ethnic groups. So when they're actually giving money they're not just giving it based on, "Well, you need four hours of support because that's what your medical diagnosis says," but, "You need four hours of support at home but you also need additional support because within your community context you have other responsibilities." So it's looking at the person in the complexity of their identity rather than just narrowing it down to disability alone.

MR KALISCH: Karen, I understand those last two issues. I just want to check around the local structure again, whether you actually envisage it being local councils or something around those sort of broader - - -

MS ALI (EDAC): It doesn't have to be a local council. It could be a separate identity, but it could be where representation is from the local council. We can't deny knowledge that local councils have of what's happening in the community.

MR KALISCH: So if I can just check this a little bit. You're envisaging a local body that would be separately established for this purpose.

DR SOLDATIC (EDAC): It doesn't have to be separately established. It can sit within local council or it can be separately established.

MS ALI (EDAC): Yes.

MS YEONG (EDAC): Can I comment. The reason why we considered that was because of centralised - - -

MS SCOTT: Can we just make sure we're picking up? Are we okay? Yes.

MS YEONG (EDAC): I think a centralised distribution could - sometimes, as we know, if you upset some agency or you criticised or complained then you're a marked person and the retribution will follow you; it's a trail. We just want in a way to make sure it's being fair and there is also built in place some governance and appeal system. Because we see it happen constantly, when families are afraid to complain because they know what the consequences might be. I guess that's one of the reasons we suggested that.

MS ALI (EDAC): That also highlights that - the trend that we really do have is that a number of people from CaLD backgrounds are quite hesitant to make complaints, to want to improve their situation. They're kind of complacent to what's happening because what will happen if they make a complaint? Other issues are, "Okay, well, I'm quite grateful for what I've got. I'll just accept everything." But it's not looking for the best interests of the person with the disability. This is a way of, we're giving them more empowerment in a local level where they don't feel so intimidated to address these concerns.

MS SCOTT: Okay, got that.

MR KALISCH: Just one more. Just on that aspect, is that, I suppose, a perception or a fear or is it actually based on reality - just in terms of the fear of retribution and that they'll miss out on services?

MS ALI (EDAC): It has happened.

DR SOLDATIC (EDAC): It's both.

MS SCOTT: We've had a number of people present to us safeguards, and clearly that's a nominal thing that we would think about in terms of design. People have suggested to us we think about Office of Public Advocates, Visitor Programs, Ombudsman - quite an array of arrangements. I'd welcome any views you have on those arrangements and also any material you can provide us that would point to either experiences of retribution or concerns about it. That would be quite useful as well. Thank you very much for coming along today.

MS YEONG (EDAC): Thank you.

MS SCOTT: I now invite the Muscular Dystrophy Association of Western Australia to come forward. Thank you. Good morning, Lesley. For the record, could you state your name and then your organisation and then make an opening statement, please.

MS MURPHY (MDAWA): Sure, absolutely. My name is Lesley Murphy. I'm here today representing the Muscular Dystrophy Association - - -

MS SCOTT: I'm sorry, could we just pause for a second. Because we've got a hearing loop it would be good if we could - - -

MS MURPHY (MDAWA): No, it's cool, no problem.

MS SCOTT: Please feel free if you want to catch up with some, to go outside, and if you have got a mobile phone would you think about just turning it to silent or off. Okay, sorry for that interruption, Lesley.

MS MURPHY (MDAWA): That's fine, no problem.

MS SCOTT: Let's start again.

MS MURPHY (MDAWA): My name is Lesley Murphy. I'm here today representing the Muscular Dystrophy Association of Western Australia and I'm also here wearing the hat of the primary carer of my son Connor who has Duchenne muscular dystrophy. For those of you who don't know what that is, that is a severe degenerative neuromuscular condition, usually diagnosed between the ages of three and five, resulting in death at the age of about mid to late-twenties. It's a genetic condition so there's no treatment and no cure, as is the case for all muscular dystrophies of which there are about 60 different named types.

So my comments today will be based on my personal experiences as a carer but also on my experiences in dealing with the wider muscular dystrophy community. At present I do try to go into the office two days a week but I perform my role on an entirely voluntary basis and I have been doing that for about the last four years, basically since Connor finished school - and I'll comment on that in a minute. The first thing I would like to bring to the commission's notice - and again, this comment is based on - I think I know personally of the 50-odd people with Duchenne alive in WA today so these figures would very much be relevant to all of them and anyone else who has a child with a severe muscular or neurodegenerative condition.

Connor was diagnosed at the age of three in 1992. We had just moved into our dream home, a home which we then discovered was entirely unsuitable for an electric wheelchair. In fact, we asked the architect if we could modify the home and his comment was, "Well, you could, but you'd have to pull it down." So we were then faced with the prospect of rebuilding, a cost that we estimated to be in the vicinity of 500,000 to 600,000 thousand dollars. We did receive about $6000 towards the cost of wider doorways and bathroom taps and so on through the CAEP program. We've also had to purchase two wheelchair-accessible vehicles over Connor's lifetime and we may need to purchase another, depending on how long he survives. These two vehicles between them have cost us around $100,000 and we have received no financial assistance to purchase any of those.

Furthermore, since Connor finished school in 1996 I've had to leave paid work to care for him. This has not only meant the loss of my income but it has impacted on our superannuation contributions and therefore our ability to finance our retirement - that is, assuming we live long enough to enjoy any retirement and, quite frankly, with the burden of care that we are undergoing at the moment there's much we might not actually need. To put that into further perspective, there are 168 hours in a week and we receive support for Connor for 38 hours. That means, roughly speaking, we provide something in the vicinity of $150,000 of care for Connor a year for free.

MS SCOTT: I just want to make sure I got those numbers.

MS MURPHY (MDAWA): I'll give you a copy of this if you like.

MS SCOTT: All right. Yes, thank you.

MS MURPHY (MDAWA): That's not to mention the housing, the vehicle and so on and so on. I mean, obviously he's our son. You expect to have some burden of some costs with any 21-year-old son who's living at home; that's not counting that. In return for this we get $50 a week - well, I get $50 a week roughly, and the $600 a year that the federal government gives me. I don't even want to think about what the costs of that would be compared to if our family situation breaks down to the point where he would have to go into institutional care - and don't even get me started on crisis intervention and all that.

So I just wanted to then go on to address some of the Part 3, 4, 5 and so on in the paper. Starting with part 3, I was quite surprised in my reading of it to see that in Australia we still don't actually know how many people have these conditions. We are in fact actually now a laughing stock in the world because we do not have a rare diseases registry. If we had a rare diseases registry we wouldn't have to say, "There are about this many people," "There are estimated that many people." I'm talking about things like muscular dystrophy, spinal muscular atrophy, osteogenesis imperfecta, motor neurone disease, Batten's disease, Huntington's disease - the list just goes on and on and on. These sorts of conditions are hugely debilitating and obviously extremely costly to provide care for. So surely to goodness for the cost of a small outlay - and I'm talking a minimal amount of money - to set up a rare diseases registry would massively help in the planning of the costing of those kind of costs - you know, down the track.

The next thing I'd like to comment on is part 4 and the need for people to have more control over the resources that they are allocated. At present we receive - or Connor receives about $33,000 which we manage in a shared management arrangement and we use that to buy care and support for him so that he can attend university and have a life. However, this is the interesting fact: up until a few months ago this same amount of money through a different agency bought us 17 hours a week. Hello. Yes, so how can this be? Clearly it depends on which agency you choose to go to. Now, I'm sorry, but there's something severely wrong with that. That cannot be right.

MS SCOTT: So if I'm getting it right, 38 hours a week for $33,000 a year - - -

MS MURPHY (MDAWA): Sorry, I'll just start - the $33,000 a year buys the 25 hours of support for Connor. The other 13 hours are provided through other support agencies for personal care and respite, and I get a couple of hours a week for someone to help with some housework and stuff like that.

MS SCOTT: Okay.

MS MURPHY (MDAWA): So that funding of $33,000 a year buys him 25 hours of support to attend university, social events and whatnot and, like, I say, I did a bit of shopping around and discovered if I changed to a different agency that instead of getting 17 hours a week, for the same amount of money I'd get 25.

MR KALISCH: Was there any difference in the professionalism or the quality of care?

MS MURPHY (MDAWA): Vast.

MR KALISCH: Which way?

MS MURPHY (MDAWA): The professionalism and quality is vastly different with the agency with which I'm getting more hours.

MR KALISCH: Is it better or - - -

MS SCOTT: Better.

MS MURPHY (MDAWA): Better, dramatically better. I guess it's the case of larger is not better. Smaller agencies are able to provide more direct and more personalised care and support for what you need, whereas with larger agencies - you know, my two most hated words on the planet are "eligible" and "entitled". They're right up there with the F word, the E words; they're my two most-hated words - and the bigger the agency the more you hear you're not entitled and you're not eligible, which brings me onto the whole issue of self-management of funding. Now, I know that there's a lot of people who are not capable of managing their own funding but clearly there are many, many people who are.

I really believe if we had that $33,000 to manage totally on our own we'd be able to even buy more hours because we wouldn't charge to manage that money. Anyway, I just think that there has got to be another way found for people to be able to self-manage their own funding. Now, I know it has been abused in the past, I understand all that, but there has got to be a better way of giving people who are willing and able to manage their own funds the opportunity to do so. This brings me to another point in the issues paper, section 4, and this is about the inconsistent assessment methods for allocating services and funding.

In WA for all funding for respite, family support and so on we use a form called the Common Application Process. This form is heavily weighted in favour of people with intellectual disabilities and behaviour problems. For instance, in many of the sections people with disabilities but normal intellect and communication skills get no weighting at all from any of those sections. So it doesn't take much to work out that they are never going to get to the top of the heap when it comes to getting funding and I can attest to that. I have been in that pool waiting for some funding for extra help for three years.

The physically disabled applications are then assessed by the same criteria and in the same pool of applicants. Not surprisingly, we rarely, if ever, get funded by this method. Usually, and I am not exaggerating, what happens is that we have to actually threaten suicide or to harm our children before we get some funding. I illustrate this point by the fact that the Disability Services Commission themselves say they have three levels of services, and this was alluded to by the previous speakers. Level 2 is for people with profound or severe disabilities and level 3 is for people with intellectual disabilities, so in fact people who are intellectually disabled will qualify under level 2 and level 3, but people who are physically disabled would only qualify on level 2. Therefore, by definition, much, much more of their funding must be being directed towards people with intellectual disabilities. They would argue hotly that this is not the case but obviously, clearly it is. That's on page 3 of their CAP form. So the bottom line for me is that the physically disabled should not be assessed for care and support funding using the same assessment tools which have been largely developed for people with intellectual disabilities.

The next section I would like to address is section 6. It is my belief from personal experience that the physically disabled are the most disadvantaged by the current care and support arrangements in the nation and particularly in WA. I'd like to highlight the plight of people who are in their 20s, 30s, 40s and 50s who are diagnosed with degenerative neuromuscular conditions. For these people, the support and funding networks are appallingly limited, if not non-existent. Many of these people have known all their lives that there was something not quite right. They have known that they were a bit weak, couldn't run, but didn't really know what the problem was, and they have soldiered on with their lives, studying, working, marrying and so on. Now they're faced with an almost certain premature death, drastically diminishing physical capabilities, limited employment options and so on. They need advice on how to perhaps retrain into a different job or career pathway. They need advice on equipment and housing options and they need counselling about the genetic consequences of their condition. What they get instead is waiting lists and not much else.

To give you an example of this, I know of many people with muscular dystrophy who are virtually housebound because they are not eligible for an electric wheelchair. Under the current CAEP guidelines in WA, you are not eligible for an electric wheelchair if you can still walk around inside your own home. If you have one of the many adult-onset types of muscular dystrophy, you can still walk around inside your home but you can't get out of your home. So these people who are usually quite capable of maintaining some kind of contribution to the community literally become prisoners in their own homes because they cannot get up and down their own front steps. I mean, I just think that's beyond belief really, but that's the rules.

To answer the question in section 6 about who should be eligible, obviously in my opinion, it should be to new cases of people who are disabled, but also to people who have existing diagnoses. In terms of reassessment, genetic and chromosomal conditions don't improve and they can't be cured, so what's the point of constantly having to reassess, except for the point of increasing needs. As their physical capabilities diminish, their needs will increase.

I believe that some sort of funding should be available for people to have a one-off sum of funding to either rebuild a home or redevelop a home and to purchase some kind of wheelchair vehicle. In terms of ongoing funding and means testing for large amounts of ongoing funding, I am a bit ambivalent about that. I know of people who are multimillionaires and who receive every single dollar they can get from the state, because they're eligible, so I'm a bit sort of ambivalent about that one.

Section 7 touches on the issues of who makes decisions and again, I suggest that there are many people who are more than capable of managing the funds they're allocated and who are denied the opportunity to do so. Again I direct you to my example of the discrepancies between different care providers and how many hours can be purchased with the same funds. Primary carers should not in my opinion be allowed to pay themselves directly from a fund but they should be considered to be an employee, in the same way as any other support worker that comes into the house, so they should have the opportunity to have holiday pay, workers compensation insurance and so on.

MS SCOTT: I just want to check that I've got that right. If someone receives an individualised package, they would be able to have their primary carer, even if it's a family member, paid a salary?

MS MURPHY (MDA): Yes.

MS SCOTT: Okay. I just wanted to understand that.

MS MURPHY (MDA): Yes, they should be allowed to pay them a salary, but that person should be considered to be an employee in exactly the same way as any other support worker would be an employee that comes into the home, so they get the same benefits. Individualised funding could be monitored by many kinds of different acquittal processes. You know, it's not rocket science.

A national disability insurance scheme should provide people with the opportunity to buy vehicles, housing and so on. I've said that. The other thing that is sorely lacking for people who are in their 20s to 50s and diagnosed with degenerative conditions is access to therapy services. I've been told this directly: that the funding is directed towards early intervention because that is where you get the best outcome. That's fine. However, people who have degenerative conditions also need access to physiotherapy, occupational therapy, and unless they can afford to pay for it themselves, they don't get it.

MS SCOTT: I just want to check that. Aside from the $6000 in home modification and the attendant care package that you have, your son Connor currently is not in receipt of any assistance in terms of therapy services?

MS MURPHY (MDA): He's a client of Rocky Bay and he attends there twice a week for some physio and that's purely because in the end, I decided I was his mother, not his personal physiotherapist and there's a limit to what I can do for him, what I'm prepared to do for him. They have other clients in the Muscular Dystrophy Association who have different conditions who don't actually become clients of Rocky Bay because they're not eligible, who have no access to physical therapy services.

MS SCOTT: Okay. You will have to be a little more understanding with us.

MS MURPHY (MDA): Sure.

MS SCOTT: Is Rocky Bay a government-provided funded service?

MS MURPHY (MDA): It's an NGO - it's funded by DSC via Commonwealth and state joint arrangements. A bit like - are you from Victoria - Yooralla?

MS SCOTT: We understand that - got that.

MS MURPHY (MDA): The same sort of arrangement.

MS SCOTT: Okay. In the assessment process, does anyone assess Connor's demonstrated need and then say to you, "Look, we can't achieve that. This is what we can give you?"

MS MURPHY (MDA): No.

MS SCOTT: They just tell you what you can get?

MS MURPHY (MDA): Basically, the CAP applications are three times a year. They go into a funding pool and if you're not successful in that round, your application will automatically go into the next round. But if you miss out, you miss out.

MS SCOTT: So it's like some sort of hierarchy of need and Connor is in the pool, but if he was unsuccessful in one round, he'd go into the second, and it's all rationed and this is what you've got.

MS MURPHY (MDA): Yes.

MR KALISCH: Is there a sense of how likely you are to get funding?

MS MURPHY (MDA): No.

MR KALISCH: Are you given any indication when you apply?

MS MURPHY (MDA): No.

MS SCOTT: As Connor's circumstances worsen, are you confident that you will be able to get more care?

MS MURPHY (MDA): No. I have no confidence at all that we will get any because he can communicate, he can express his needs. He doesn't have behavioural issues. He's not intellectually disabled. Therefore we will never - unless I physically threaten to either abandon him or physically harm him myself or he becomes unsafe in our home situation, I very much doubt we will get any further funding to support his care.

MR KALISCH: The 25 hours that you are getting, how is that allocated and received?

MS MURPHY (MDA): That comes through the Disability Services Commission in the form of what's called alternatives to employment, which allows him to attend university and to have a social life, you know, to go out and just do all the normal things that 21-year-olds do pretty much within the constraints of his condition, but because of what he has, he has to have someone with him 24 hours a day.

MS SCOTT: So in terms of attendant care at home, there's just your family members?

MS MURPHY (MDA): My husband and I, yes, and support workers that we buy in for those hours. So about 38 hours a week there will be a support - like, I have someone to come and help me get him up some mornings a week, but there's no-one there - as I said, it works out at 38 hours a week which leaves whatever it works out to, 100 and something hours where my husband and I provide the sole care.

MR KALISCH: That 38 hours, is that funded through DSC as well?

MS MURPHY (MDA): No, some of it is through HACC, through a different agency. I mean, that's one of the issues and I'm sure the people here will agree that there's no one place. If you want something, you have to go out and basically find it for yourself, so you will cobble a little bit from here and a little bit from there and you will get a few hours there and a bit of funding from there, and then over time, you manage to put things together and eventually you sort of, if you're lucky, come up with something that works.

MR KALISCH: So just in terms of a situation of a parent who has just had a child diagnosed, would they come to the association and the association would be able to tell them, "This is the maze of the system"?

MS MURPHY (MDAWA): Yes, that's what happens now but when Connor was diagnosed he's - what's that, 17, 18 years ago - there was nothing. That's the reason why I've gone out and started volunteering to the Muscular Dystrophy Association so that other people who find themselves in that situation at least have somewhere they can go, someone they can talk to, because there was absolutely nothing up until about three or four years ago.

MR KALISCH: Are there other associations, other disease conditions, where that's still the case, you suspect?

MS MURPHY (MDAWA): I suspect so, yes. I mean obviously there's multiple sclerosis, they have a strong organisation; motor neurone disease have a fairly strong organisation, Parkinson's have a fairly strong organisation. But for all those other people out there with what they call orphan diseases there's very little. I mean some of them do have national sort of Internet-based support things but not a lot of local stuff.

MR KALISCH: I suppose the sense I'm hearing from you is that at a statewide level the services and supports can be quite different?

MS MURPHY (MDAWA): Absolutely, yes.

MS SCOTT: Are you conscious of what is available in other states?

MS MURPHY (MDAWA): I'm vaguely aware of what's available in other states, yes.

MS SCOTT: But there's not a strong national network of - we met with Muscular Dystrophy in Sydney but it sounds like the relationships between each of the organisations is not necessarily very strong.

MS MURPHY (MDAWA): We've got a peak body - - -

MS SCOTT: Yes.

MS MURPHY (MDAWA): - - - who act as a lobbying group, if you like, for parliamentary-type lobbying but other than that it's informal networks. I mean I've travelled around to the other states. I've met a lot of the other people but the fact is we live in WA and they live in New South Wales.

MS SCOTT: Yes.

MS MURPHY (MDAWA): What's available there is completely irrelevant because that's - you know what I mean?

MR KALISCH: Do you have a sense that one state provides better services than others?

MS MURPHY (MDAWA): Again, as this paper very well highlights, it's completely hit and miss. Some states are better at providing some things and other states are better at providing others. We are actually, I think, from what I've discussed with several of my counterparts in Queensland, extremely well off. One of my friends who has a child with Duchenne went to university and got four hours a week of support. So we are relatively speaking, well off.

MS SCOTT: You know how you said you had to navigate arrangements through, do you now have the support of a local area coordinator and what value do you place on that?

MS MURPHY (MDAWA): I was going to comment on that, actually. I've had an extremely positive experience with my local area coordinators and I do think that it's a great model. Having said that, I've also heard of a lot of people who haven't, and that is not necessarily a criticism of the individual LACs themselves but more a criticism of the fact that they are expected to be across such a massive range of conditions and problem that it's literally impossible for them to be able to do that. That brings me to the point that I wanted to make is that I honestly believe that that LAC model, which is a good one, should be translated into individual organisations so that the role that I am playing in the Muscular Dystrophy Association as a community support person is in fact an LAC role. What I do is an LAC.

So I think funding should be made available to individual organisations to provide an LAC-type role within those organisations because I know about muscular dystrophy. I know what people need. I know what their equipment needs are. I know what their psychological problems are. I know what their grieving and anger and - I understand all of that. But, you know, with all due respect I haven't got the faintest idea about what a blind person needs. That's one of the biggest problems with those whole disability dog's breakfast, is that you can't ask a person who is deaf to advocate on behalf of somebody who is blind. You can't ask somebody who has a neuromuscular condition to advocate or talk on behalf of somebody who has an intellectual disability. It's just - it's the oranges and apples thing. You just can't do it. It's not possible.

MS SCOTT: Would there be merit, Lesley - this is not something that we've spent any time thinking about, in fact, I've just thought about it then. Would there be merit in sort of like a mixed model where you could have the advantages of a locally-based person, like a geographic person, but also then the advantages of being able to draw on almost like a specialist service for those conditions which have very particular needs and very particular sequences and cycles and requirements and, "This is a good specialist and here's a great doctor".

MS MURPHY (MDAWA): Absolutely.

MS SCOTT: So maybe a combination of the two?

MS MURPHY (MDAWA): Absolutely. I mean that's the service that I provide to the people who come to the Muscular Dystrophy Association. Obviously I rely on them coming to us through word of mouth or whatever, because confidentiality issues. I have to wait for them to come to me even though I might know who they are.

MS SCOTT: Yes.

MR KALISCH: Do the LACs themselves contact your association?

MS MURPHY (MDAWA): Some do, yes. A lot do, actually.

MR KALISCH: Yes.

MS MURPHY (MDAWA): Yes, a lot do. But as I say, my opinion is the organisations like the Parkinson's Disease Association, Motor Neurone - all of those that deal with specific conditions should have a funded position with acts as an LAC-type role.

MS SCOTT: Okay.

MS MURPHY (MDAWA): Because that's what I basically do, but at the moment I do it for free. I've been doing it for three, four years.

MS SCOTT: Now, having said in our issues paper that we didn't expect everyone to address every issue - and thank you very much for going to particular areas - can I just test a few views on you?

MS MURPHY (MDAWA): Yes, sure.

MS SCOTT: I'll make sure that you have - - -

MS MURPHY (MDAWA): I don't want to hold up whoever is next in the queue. Sorry, folks, whoever you are.

MS SCOTT: No, we're going okay on time. You're in favour of some national funding?

MS MURPHY (MDAWA): Absolutely.

MS SCOTT: Okay. So it's national funding.

MS MURPHY (MDAWA): Yes.

MS SCOTT: Do you want to see the money go to the states or would you prefer it to go somewhere else?

MS MURPHY (MDAWA): I really like the English model, I have to say. I like the idea of being able to go to your local council or some sort of local - and that's one of the good things about the LACs, they've got local offices in local - - -

MS SCOTT: Yes.

MS MURPHY (MDAWA): My personal LAC is literally around the corner, which is very handy. But I do think that that sort of localised, regional, accessible way of getting funding or access to information and advice is far more viable.

MS SCOTT: Now, you've already indicated the services that you would expect to be included, so that's fine. Is there anything else you want to - - -

MR KALISCH: I suppose the other thing I was just going to ask about was assessment, whether sort of commensurate with your views around national funding and then local services that - how the assessment will be done. Would the be also done locally? I mean what's the situation now with you - - -

MS MURPHY (MDAWA): Assessment of needs?

MS SCOTT: Yes.

MS MURPHY (MDAWA): The two E words?

MR KALISCH: Yes, two E words that I know you're not keen on but they're important for the scheme.

MS MURPHY (MDAWA): I think that should be done locally as well, definitely, and in conjunction with the client, the support workers, the carers and that sort of person who is in that LAC-type role. That's what happens with the CAP applications now, that you do those in conjunction with your LAC and other - you know, maybe a social worker or from another organisation that you might be associated with.

MR KALISCH: Just on that assessment, people have sort of talked to us about the opportunity or the contribution of self-assessment. What's your view on that, say in Connor's case?

MS MURPHY (MDAWA): Well clearly - I mean Connor filled out his own CAP application, basically.

MR KALISCH: Yes.

MS MURPHY (MDAWA): Then we just sort of took it away and tweaked it a bit because he's nothing wrong with - as I've always said to him, "Nothing wrong with your brain, love."

MR KALISCH: "Here it is, you do it."

MS MURPHY (MDAWA): I believe?

MR KALISCH: "Here it is, you do it."

MS MURPHY (MDAWA): Absolutely, yes. So self-assessment, I think there should be a part of that for that but obviously, you know, as everyone else has said there has got to be other independent assessment. I like that whole idea of the advocacy, advocate-type thing.

MS SCOTT: You know how the - this is my last question, sorry, Lesley.

MS MURPHY (MDAWA): That's all right. I'm enjoying myself.

MS SCOTT: Okay, all right.

MR KALISCH: So are we.

MS SCOTT: You know how you compared it to the UK model, we are going to be, very shortly, talking to the UK people - not travelling but talking to the UK people. But I wondered whether you would know if this is possible: is it possible that someone in the UK, maybe in a similar association as yours, would know that for someone with Connor's type of condition this is the package they would have got, the amount of care or the services or the home modifications or the assistance with vehicles, because it would be extremely useful if we could do a comparison - - -

MS MURPHY (MDAWA): I can find that out.

MS SCOTT: Do a comparison between what you've been able to have from the system here in Australia and Western Australia versus what Connor would have got if he'd been born in Birmingham.

MS MURPHY (MDAWA): In the UK, yes.

MS SCOTT: Yes.

MS MURPHY (MDAWA): I can find that out.

MS SCOTT: Great.

MS MURPHY (MDAWA): I can do that.

MS SCOTT: Well, that would be extremely useful.

MS MURPHY (MDAWA): Sure, I can do that, that's easy.

MS SCOTT: All right.

MS MURPHY: So yes, I'd just like - I guess I'd like to say thank you. Thank you for your time. I did want to say something else about what the previous speaker said about people being reluctant to complain. I have to say that people of CALD backgrounds are not on their Pat Malone there. I've been witness to a number of occasions where people have been unhappy and not wanted to complain because they felt that they would be victimised or miss out or diminished in some way. I have to say from my own point of view I have found complaining to be an extremely beneficial thing to do because it - you know, as long as you do it with respect I've always found it to be - I've had positive outcomes. I just hope that what you've come out with is something better than the currently dog's breakfast that we've got.

MS SCOTT: Thank you very much.

MR KALISCH: Thank you.

MS MURPHY (MDAWA): Thank you.

MS SCOTT: We're now going to stop for morning tea, so we've got 15 minutes. We'd like to start again with William Booth at 11 o'clock. Yes, okay, see you then.

MS SCOTT: I call for William Booth to come to the table, please. We will now hear from William Booth and then after that, Brian O'Hart, and then the National Ethnic Disability Alliance, all before lunch. So, Bill, we have about 20 minutes with you. Thank you very much for coming along today. Thank you for providing your material and also providing the photographs here. Would you like to make an opening statement and then we might have a chat and a discussion?

MR BOOTH: Yes, I'm just a bit hard of hearing.

MS SCOTT: Okay. Thank you very much for all the material you have provided us. We've got about 20 minutes.

MR BOOTH: Right.

MS SCOTT: Would you like to make an opening statement and then we might have a discussion?

MR BOOTH: Yes.

MS SCOTT: How does that sound?

MR BOOTH: Right, good. I hope what I have to say is good stuff and stop me when I've said enough.

MS SCOTT: Okay. For the record, can you state your name and whether you're representing an organisation or representing yourself and your family.

MR BOOTH: My name is William Booth and I'm a father and a carer and I'm representing myself, although I'm a member of a number of disability organisations.

MS SCOTT: Thank you.

MR BOOTH: I have an informal submission and I've given you several papers. I'm not going to read the whole thing. I just want to point out a couple of issues that I think are important, probably a little personal information about ourselves. My wife and I are 74 years old. 40 years ago we adopted our only child, who was abandoned in hospital in New South Wales. She has a borderline intellectual disability and we have lived in Queensland and over east, and for the past 34 years, here in Western Australia.

Our daughter married an intellectually disabled man 13 years ago and lives in a cluster of seven two-bedroom homes where all the residents are intellectually disabled. So they don't live in a group home, but rather in a group of homes. That helps their living arrangements in a more normal atmosphere. Management of the property and the provision of daily support services is by the local council. Do you want to know the name of the council?

MS SCOTT: No, I don't think we need to know that.

MR BOOTH: They rent for life as the housing project is a public housing authority and they're pretty happy. We have no other family. My wife and I, our health has deteriorated seriously over the years, and when we die, she will be looked after. We are very pleased with the local council. We have heard other speakers mention local council and for the past 13 years, the local council has provided the management of the property, as well as the care, which is roughly two hours every morning, seven days a week, and about two hours in the evening. However, this partial care is a problem. If my daughter and her husband want to go to Fremantle for fish and chips, we take them. But when we cark it, they can't go. They're not crippled. They can walk, they can talk with difficulty, but they can't handle money. They can't handle shopping. They need help along those lines.

One of the great problems we had is it took eight years to obtain the funding so they could live independently. Most people leave home when they're 19, 20, 21, and when our daughter was 18 or 19, she wanted to move in with her boyfriend, get married. She wanted to have 10 babies. She will never have any children and in a way, we're thankful about that. Getting care for her was difficult enough. So the shared care is sometimes a problem. Since she's already funded and since she's not considered in critical need, she's always at the back of the queue and you wait and wait and wait for care.

I just want to comment very briefly on my paper that I've presented to you. I have a couple of extra copies; if anyone here wants a copy, it's free of charge, I'm not anonymous, and if something helps someone, fine. How will it be funded, this national disability insurance scheme or care scheme? I suggest that there are more motor vehicles in Australia than people. Each of these motor vehicles, trucks, buses, motorcycles, has compulsory third party insurance to cover personal injury sustained by vehicular accident, so I suggest that this compulsory insurance charge be paid into a national disability insurance scheme and distributed as required. This will eliminate what I feel is costly litigation as all people with disabilities would receive support services when required, as needed. This funding alone will be insufficient and additional moneys can be acquired through national disability lottery. Australians love to gamble, so let's gamble on providing funding for all Australians who never know if or when they might become disabled. Life itself is a gamble. Note the government would still continue to add its normal funding allocation.

Portable funding, item 4 on the paper that I gave you: the problem is if the family moves interstate, the state disability funding is cancelled and then they join the end of another queue for new funding arrangements and assessments and so on. I believe - I'm not sure on this - state funding is cancelled at the age of 65 and is not portable into old age. Now, I am disabled. A lot of people would look at me and say, "Well, what's your disability?" Most of them say, "It's your tongue." But I can tell you that at the age of 52, I had a serious operation and Commonwealth doctors put me on a disability pension. That was over 20 years ago. Recently I went to Homes West for housing and so forth, but at the age of 65, that disability pension turns into, "I'm cured," because they put me on an old age pension. So I'm an old age pensioner and I don't consider myself old. I'm 75 years old this October. I'm young. So I think that's a problem, the portability of the funding, you can't carry it to another state, and when you get into old age, the funding circumstances of your life changes.

Item 8, family supports and whole-of-life planning, I've just given very brief items here: too much reliance upon the family to continue to provide support. I know parents who are in their 90s that are still working on, providing support for their disabled son or daughter and so forth. Families stress out, burn out, wear out and finally fall out as aged parents despair. Some families, like myself, have no relatives to assist. We have been fortunate that we have arranged the care for our daughter, but it was a fight. I've heard disability services called a dog's breakfast; a good analogy. I've always called the disability field a battlefield.

Item 10, I've got accommodation and congregate care. We wanted to individualise funding, which I'm not opposed to, but congregate care and a combination - because they were going to deinstitutionalise everybody and, "We're going to put everybody in the community" - it doesn't work. Someone here spoke about being in the community but not being a part of the community. My daughter - and I think many intellectually disabled people choose their own people they want to live with and associate with. Birds of a feather flock together. If the wrong type of bird gets into the nest, gee, there's a hell of a fight. My daughter is 39 and a half years old now and her only friends are like her; they talk the same lingo, they share the same lifestyle.

She tried open employment, been in a number of places. They were very nice to her but she got upset and didn't like it. At lunchtime the other girls who weren't disabled talk to her. Well, they couldn't talk her language and she couldn't talk their language. She's 40 years old. If you ask her to go to a movie, she wants to see Bambi. She is the Slow Learning Children's Group; we had it here for years and then they changed their name. So I believe in choice and a mix of everything - congregate care, congregate funding, individual funding and so on. There's limited choice in accommodation and congregate care; they take whatever and wherever is available.

So the solution is to increase the choice by proper planning with the public housing authority to build more cluster housing, small cluster housing. She lives in a place where there are seven units, all two-bedroom, so that a carer or a family member could stay overnight if they're not feeling well or something like that. It has been open 13 years, run by the local council. I heard a lot here of people wanting the local council to be involved. Here's a successful place that's been running for 13 years and I think it's very good. I believe that congregate care is more affordable than individualised funding. If these seven people who live in these units were scattered throughout the community the cost of care would be considerably more than in the one location.

Parking at this complex is outside, so that there's more room in the complex, on the grounds, for a gazebo and sharing barbecues together and so forth and when they have a fight and an argument, as we all do, they can move into their own home. But if they're in a group home it's very difficult. So it has helped there; it's called semi-independent environment and they share company. It eliminates loneliness. We can talk all we want about community living. The community does reject some people with disabilities, others will love them and care for them, but they themselves don't want to be associating with other people who are not like them.

Item 11, who should be eligible and identified in this new national insurance scheme? Well, who indeed? All people assessed as disabled and receiving a disability pension. This includes people born with a disability and those who acquire it later in life. Item 16, charity. Now, I belong to one of the world's biggest charity organisations so I'm not opposed to charity but the problem is that charity targets specific people and they miss others who have equal needs. For example, a wonderful charity recently paid $25,000 so a young girl about nine years old, an amputee of both legs, could have prosthetic legs. Her mother said - it was very tragic - her mother said, "Now I can watch my little girl who is no longer a baby, instead of crawling like a baby she can walk like a young girl."

But in three years, four years, she'll need another pair. Will that charity come to her aid again? And what about the other little girl down around the corner? She's still waiting. So this national insurance scheme needs to provide services when needed, not being put on a long waiting list. Charity should be used for things that one might not expect to receive through government funding - spa, barbecue, gazebo, furniture. When my daughter moved into her - well, the group moved into the complex, they all received lottery funding for furniture which was a big, big help. The parents themselves built the gazebo because this was public housing and we can't expect public housing to build everything, so we work as a partnership. Closets - the Homeswest didn't build closets so the parents all got together and built closets and so forth.

Local council - I hear more and more that they're to be involved. I fully support that, I think it's marvellous simply because there's not enough agencies to provide the services and a lot of agencies are underfunded and are struggling to get people to do the job. So involve local councils in the provision of services. The people with disabilities don't have to move out of their area to find services. Item 20, I mentioned, adequate remuneration for carers. We've heard that today. I can tell you that I know of four carers - there's about nine carers that provide the care at the local council where my daughter receives care and four of them have been there the full 13 years which tells me that they're reasonably well paid with reasonable benefits and the boss if a pretty good boss.

The council meets regularly at any time with the parents, with the families, altogether or individually, so it has been a very good partnership with the local council. Item 23, choice. Who decides where one lives? How and who provides the services? We've heard this before: it's my disability and my solution or my choice.

MS SCOTT: Okay. Bill, could you talk about sort of a normal day now for your daughter in the cluster housing and the sort of support that she gets and, I guess, the sort of support she needs. I think you indicated that she's okay for shopping and getting around but if she has to go somewhere outside the cluster she relies on you for transport. Could you talk a little bit more about what she's able to do and then what she needs support for and what support is available there or from the council or from the West Australian government.

MR BOOTH: Because of the group's low level of disability, I suppose - they all can walk and talk to some degree; the shopping centre where they live is just across the street so they can just walk across the street. The bus is right there, virtually at their doorstep. So the location of the complex is very, very important for all people with disabilities because none of them will ever drive a car. I've reached a stage where I won't be driving next year, so you've got to be near public transport. Look, two days ago she telephoned me outside a bus stop. She has to take several buses to get to her - she works for the Good Sammies doing simple jobs and it keeps her busy, keeps her out of trouble. The others all have jobs. Some of them work at Activ Foundation and so on. But she was crying, the bus driver didn't stop, he just went right by her and she's stranded - doesn't realise that another bus is coming or she'll be late for work. So we had to drive down and get her.

The carers, they've already spent their two hours there and they're gone. So who does she call? There's no-one. There's mum and dad - and my next heart attack will probably kill me, so what happens when mum and dad are gone? There is no-one else she can call; that's a problem. So we need probably an emergency number where they can call. So the agency needs that, but when we've called the emergency number it never answers or it's an answering service from Queensland or something - and these people are intellectually disabled and can't really effectively tell what their problem is so that's not very good. So that's of great concern.

Rather than have more hands-on care for this group, I believe if they had a place they could contact at any stage - if they're sick they want mum to come and stay overnight. Okay, well, the carers aren't paid to do that so they're not going to do it, or if they feel she's sick enough they'll take her to the doctor's or to the hospital. So it's very limited care, which I accept. You know, you can't have anything in life.

MS SCOTT: Could you talk about the arrangements you've - I mean, clearly you've been very effective in getting this housing and a support arrangement, not perfect but a support arrangement.

MR BOOTH: It's pretty good.

MS SCOTT: Who will make the difficult decisions in the future when your wife and yourself are not around?

MR BOOTH: Yes, we're a bit concerned about that. There's the public advocate, but yes, I'm still a bit wary of that. I don't believe the public advocate, the people that are involved, have the experience in dealing with people with disability, what their needs are and what their requirements are. Recently our daughter went on a cruise to Bali with her husband and my wife went as the carer, so the first time in her life she ever was away - I didn't go - but I remember a few years ago when a disabled person wanted to do that and had to pay for the carer, but the advocate that had control of her money said, "No, the money is only for you to spend, you can't spend it," so she couldn't go and there was a big stink about that. I think that's eased up a fair bit, but that's a problem.

The carers will now take her across the street to help her do her banking and to do the food shopping, because they can't read or write or anything like that, but they won't take her to another shopping centre further away because it's out of their area. So the local council only works in the local area and if my daughter and her husband want to go to Fremantle for fish and chips, they can't go. I take them, my wife and I take them, so that's a concern.

I just want to comment on getting this development - it took eight years and as a parent, we had to go on street rallies and jump up and down, write hundreds of letters. No-one should have to go through that. I'm still stressed. This was over 13 years ago - eight years to do that, and as soon as I got the letter of support from the Disability Services Commission that they would support this group of people, I took it to the public housing authority and within a couple of days, their architect called me and said, "I want you to work with me on this development," because I had already designed it. "Who are we building it for?" Although none of them were at that time in wheelchairs, it does happen, so they wouldn't build it to handle wheelchairs. Now that their health is deteriorating and it's possible as they get older - they're all in their 40s and 50s now - one is looking at going in a wheelchair, the house is not suitable so then they have to move again. So all of this disabled housing, whether they're in a wheelchair or not, should be built to handle people with disabilities, whatever your disability is.

MR KALISCH: Just on that aspect, Bill, are you aware of others that have learnt from the experience of this cluster housing and sought to introduce it in other places?

MR BOOTH: Am I aware of others?

MR KALISCH: Yes.

MR BOOTH: Yes. This would be the second complex like this built in Western Australia. Some years before that, there was a place called Philos, it's a Greek word meaning friend or friendship, and they built one for people with cerebral palsy, all adults, and it's a six-unit development and a cluster. They all have their own home and it's built under a shared equity, so they just about all own it today. Those same people still live there. I visit them every now and then. I know them quite well. So that was probably the first maybe in Australia, I don't know, but it was really independent living, controlling their own funding and so on. But with the intellectually disabled, they can't control their own funding, so it has to be done by someone else.

MS SCOTT: Yes. Bill, thank you very much and thank you for the extra material. We did have a look at the photos, so thanks very much for that.

MR BOOTH: Yes. You will remember the photos.

MS SCOTT: Thanks, Bill, for coming.

MS SCOTT: I now call for Brian O'Hart to come forward, please. Thank you very much. For the record, Brian, could you state your name and in what capacity you're presenting evidence today and would you like to make an opening statement.

MR O'HART: Thank you. Brian O'Hart, representing our family and daughter. Just to give you some background information of my experience and where I'm coming from, I'd just like to quickly run through a list of my involvement with people with disabilities over the last 44 years.

I'm a father of a 44-year-old severely disabled daughter who was a twin. She has cerebral palsy, epilepsy, hearing and sight difficulties and skeletal problems. She has a very rare form of epilepsy and when she goes out, she can be out for eight to 10 hours. She has to be under 24-hour surveillance, which we have for her. I was a school principal for 33 years and during that time, I served from Rottnest Island to the Eastern Goldfields, and from the lower south-west to principal of Broome District High School. I've had a lot of experience with children with disabilities. In the goldfields, I was chairperson for the Goldfields region clinic from 1979 to 1980 and there was an intake from 43 schools.

In the north-west metro area of WA, I was principal, administering the reading clinics and also the gifted and talented student programs. In the 90s I had in excess of 90 schools contributing to both these cohorts, so you can gauge from that that having the reading clinics and the children coming from in excess of 90 schools, I have a fair understanding of ADD and ADHD, Tourette's, Asberger's, autism, Down's and so on. I've made it my purpose to read thoroughly on them. I was vice-president of FOCUS which was a group called Friends of Children Under Stress, in Carnarvon in 76-77. I've been on numerous organisations, assisting people with disabilities for many years. Crossroads Uniting Care WA, I was chairman for two years, supporting for about 30. In-Home Support Group, Western Suburbs Housing Group, a member of NDS, PWDWA, DDC, Carers WA. I have put in many submissions over the years and attended public hearings.

The Disability Discrimination Act inquiry I attended on 30 June 2003 to the hearing and put in submissions. I've been heavily involved with the Special Disability Trust from the inception, from 2005 to 2010, put in numerous submissions there and contact with the advisory committee. I also attended the DIG meeting with Allan Fels; CSTDA hearings. The most notable one that I had real achievement at was the WA tax review of 2006. After 10 years struggling away through State Revenue and the financial services, we finally got it through, that parents who owned property in WA in which a disabled person who met the Commonwealth criteria, those premises would be land tax exempt and the parents owning that premises would have the concessions for water rates, council rates, similar to seniors. I think WA is the only state that has that or that has been publicised Australia-wide.

Family Carers Voice, I was heavily involved there, with Judy Brewer Fisher. I had a huge input into the accommodation blueprints steering committee in 2002-2003, Shut Out and Who Cares, attended many meetings here in WA of the Older Carers meetings and submissions. I was instrumental with a law firm in publishing that book here, which is entitled Residential Property Ownership for Disabled Persons; I instigated that and a very prominent law firm here put about fifty, sixty thousand pro bono behind me in my efforts and produced that, which went Australia-wide.

Involved with a wide range of politicians, state and federal; many letters to FaHCSIA and Dr Jeff Harmer. So we won't go into those. Served as a member of the Removing Barriers group in WA of the chairman of the Disability Services Commission. In 2006 I was a recipient of Making a Difference award for making a difference to the those people with disability in WA. So that basically is the essence of my background and that's what I draw a lot on. Now, you'll gather from my presentation it's very, very different. I've read all the submissions so far on your web site and all the transcripts and, just surveying mine, I see it is quite different. That's what I'd like to go through, if I may, in the order that I've got there.

It is my intention to address aspects that may impact upon a proposed national disability insurance scheme. Now, at the outset may I advise the audience if they want copies of mine I'm prepared to email them copies, so they can listen rather than taking notes. (1) overseas practices, problems and outcomes experienced in the implementation of social disability insurance in other countries. In other countries they're commonly referred to as "pay as you go" schemes, more often than not called "multi-pillar" or "multi-tiered" schemes. (2) concern and opinion expressed by the Honourable Bill Shorten MP, Parliamentary Secretary for Children and Disability Services. In Hansard, the House of Representatives, his statement: "Paying a lot of money for an inefficient system." I'll enlarge on that as I go through.

Relevant Australia data for consideration and reflection. I've only put this up to look at, to reflect on and make considerations. The PricewaterhouseCoopers final report, October 2009, with emphasis on option 6 outlined as the recommended model for consideration. The current Australian system with emphasis on practice within West Australia. (6) statistical data on current unmet need in West Australia. (7) comment on a number of submissions so far presented to the commission. So, addressing number 1, significant factors raised in a publication drawn up by Leo Aarts, Philip de Jong, University of Amsterdam, November 99, and the paper was prepared for the World Bank Conference in Washington in September 1990.

Now, the relevant points that came out of this submission, that wherever you go, whatever form you take or how you manipulate or construct this, there are five very significant points in the design. The program has to be socially acceptable and financially sustainable; that is number 1. Number 2, most programs in existence are multi-pillar to varying degrees and that ranges very widely over the international scheme system. Based on loss of earnings; that is a very significant factor. That if it's designed on base of loss of earnings, if someone has never earnt, the consequences are quite huge. Social insurance, other government benefits are supplemented by a private pension - co-insurance - and most have incentive structures in place to return to the workforce.

Disability policy and design. Now, I don't have time here today to go into every country and how they get around this problem, but they are very varying in the degrees which they attack this problem. In some of the submissions already that have come in from New Zealand, little bits in the PricewaterhouseCoopers report, indicate what can happen when this does happen. The two important things, from my perspective and my experience, that in designing any program are the conceptualisation of severity of the problem and permanency of the problem. Now, with severity, you can have two people with Down syndrome, they can function hugely differently. We have now five categories of foetal alcohol syndrome and those children are different; same with autism; right across the board. So it's fraught with danger if a person is born and is categorised immediately. As one of the previous speakers mentioned, "There's a difference between apples and pears," and there are here because each person with a disability is uniquely unique.

In the report also, assessment involves very difficult and painful judgments, and we hear it around Australia and even in WA. They are extremely subjective, and one of the previous speakers mentioned this. Now, you can imagine the subjectivity when we have 251 LACs in this state making judgments and helping people fill in these forms, and also in the agencies who have this right. The presence of impairment is necessary but not sufficient. Some do not have any incapacitating effects at all, and in the book they quote one; you can have a hearing impairment. Now, for a violinist that's a huge factor; for a labourer, maybe not. So these are very significant points.

The nature and the severity of the underlying pathology determine the extent and permanency of the impairment; the functional limitations of that person. Thus, two people with exactly the same limitations may suffer different degrees of disability. Now, I just want to quickly reflect on a few countries with their general disability insurance schemes, which are public monopolies, pay as you go contributions. Most of them have what they call a base pillar. Now, once they establish the base pillar they then run into the problem of the gatekeepers and moral hazards. Just going through a few of the first pillar welfare states: you have Norway, Sweden and Switzerland that have one national pillar.

Sweden has four classes of disability, starting at 25 per cent disablement. Chile; four categories between - the first bracket is 15 to 40 per cent. Switzerland; second level through firms who contribute on a percentage of a person's earnings. So you can see the array that's coming up through this study. In Holland in 1995, 75 of the Dutch disabled beneficiaries were on the full entitlement and they had seven disability categories. 85 per cent of the Swedes were getting full entitlement of their base pillar. Now, when you have people subjectively administering these things, you run into these problems that they call "moral hazard" and the outcomes vary from nation to nation. You find that people applying, there's a degree of unwillingness to work and it's difficult to predict behavioural change among the insured population.

It affects employers and the gatekeepers; these are the people who are administering the programs. More often than not they do not have the skills or the capacities. What they find is they develop attitudes to reduce their workload, the psychological burden on them for being strict, they become more lenient. Screening lacks consistency and it's very difficult for the gatekeepers to disentangle medical and labour-market factors that produce the disability claims. Just as a side issue, I'd like to mention here, if this ever gets off the ground and it is being run through Centrelink or FaHCSIA or these states we will have a huge problem here.

We have already seen the tyranny of distance. In the steering committee of this program I raise the point that at that meeting the steering committee didn't have one representative from WA. A budge of $5 million had been put forward, no-one knew about it, not here. So we have the tyranny of distance. Also in the demographics of this state, when you think about Sweden, Sweden would fit five or six times in WA. You have a huge barrier there in the demographics of this state. I won't labour that. I just read you a quote from The Netherlands Experience, it highlights this.

> Between 1970 and 1980 the Dutch beneficiary volume more than doubled and it kept growing until 94. As a result, until today, Dutch social welfare system is kept hostage by a massive volume of disabled beneficiaries. The Netherlands is the only country that does not distinguish between general and work-related disablement, irrespective of cause.

So they have a huge problem there. A fascinating thing, in about the 12 or 18 months when this program was mooted and I wished to do a bit of background research, I contacted the Dutch health system via email, they just didn't want to answer any questions, it was as simple as that.

I now go on to the statement by the Honourable Bill Shorten MP, The Parliamentary Secretary For Disabilities and Children's Services, who should have his finger on the pulse, in the second reading of the tax laws amendment bill he came out with a statement:

> We are currently spending at all levels of government over $22 billion on

> disability services, payment to carers and disability support pensions. I do not believe that we are getting sufficient value for money. We are paying a lot of money for an inefficient system. Whilst I do not believe that the amount of money should be reduced, I believe that we can do better.

I totally concur. It would be very beneficial to have the background evidence, data, statistics and information supporting this statement, as it may give in-depth insight into the perceived current problems with an existing system.

If you look at data and what is transpiring, at least you have got some foundation to make judgments and that would be very beneficial. In the same period I was a little bit amazed at another statement that he made. We were talking about carers, and you know that the older aged carers funds have been curtailed as from 30 June, they have gone into the new Commonwealth agreement with the states. They were earmarked before, but they have gone into the mix. He made a statement - and I have got to be reasonably fair here - that:

> The older carers have been DNA endowed with love and whatnot to look after their severely-disabled offspring.

They are. But they need help. I have put here relevant Australian data for consideration and reflection not only in disability, you know we have Medicare and that is an impost upon the Australian taxpayers, income earners.

The current number of disability support pensioners is 724,000, the amount of money is $12 billion as at 11 June 2010. The current revenue from the Medicare levy in 2008-2009 was $8.3 billion, in 2009-2010, $8.2 billion, the forward estimates for 2010-2011 is $8.47 billion. You can make comparative judgments on the system when you think that 1.5 is paid by the Australian income earners.

MS SCOTT: Bill, we have about five minutes left, and we would like to ask some questions.

MR O'HART: Yes. I will bypass the details from the option 6 of PricewaterhouseCoopers. You have it on record.

MS SCOTT: Yes.

MR O'HART: Those stats speak for themselves for what they may have to pay. But I am coming from the angle that there is a lot in the Western Australia scheme that I acknowledge as founded on good judgment. It can be improved. I have put this down in a four-tiered strata. Disability support pensions which is Commonwealth-funded is $644 a fortnight, you have the pension supplement of

$56.90 a fortnight, you have the Commonwealth rent assistance of up to $113.40. Then in the second category I put the mobility allowance that is from $80 to $112, carers allowance for those who meet that criteria $106 per fortnight, the annual supplement of $600, and the carers payment which is means-tested. So from my perspective there is a comparable second stratum.

The third stratum, for WA purposes, you have the taxi vouchers where people get the 50 per cent subsidy, which my daughter uses because she has to be under surveillance all the time; you have the WA unrestricted travel voucher which is $93 a half-year, which she wears around her neck, no questions asked, and that is terrific for her; you have the companion card, where she can take someone with her so she once again has access and is under surveillance; other things like mobility, continence aids and whatnot are there. Of course in the fourth structure here you have capped funding in WA. I mustn't bypass cap funding in WA, because this to me is the crunch of the matter, if I may.

I have presented you with the data there that currently we have 780 outstanding applicants. I have presented to you from the last cap bulletin, the funding that went in and what it serviced. The total cost of the service was $6,522,000. I have worked out on the same ratio as the outstanding balance to cap and get those off the record the 780 would cost $50.36 million. When you look at the PricewaterhouseCoopers report to clear in 2011 the backload Australia-wide would be $0.97 billion.

I have highlighted how this background could be cleared. Because they should not be as severe as the previous ones funded, if you have got 80 per cent of those, of the funding of the previous rounds, you'd come out with a figure of $40.2 million. The Western Australia budget last was $540 million, an increase of 10.6 per cent. The figure to clear this would be 3.7 per cent of the previous budget. So if it was in the realms of the management of the Disability Services Commission to put these disabled persons as their number one priority it could be cleared, on a dollar-to-dollar basis for the Commonwealth, by 20 million each party. Now, when you look at that, it's a strategy for a state to act on. When you look at the figure by PricewaterhouseCoopers of .975 billion it is far more economical to take that approach and you keep the state functioning intact.

So that basically is my perspective on this problem. As you said you'd like to ask some questions. I would just like to mention that Richard Cumpston in his running the figures through his modelling indicated that the beneficiaries could be as high as 50 per cent higher than those in PricewaterhouseCoopers's. Another actuary did also the same thing. He didn't come out with a definitive statement. So I come from the angle if there's a will, there's a way, and if your priorities are to help people with severe disabilities, it can be done.

MS SCOTT: Okay, well, thank you, Bill. So I guess - - -

MR O'HART: Brian.

MS SCOTT: Brian, sorry.

MR O'HART: That's all right.

MS SCOTT: Bill was my fault; Brian, thank you. Brian, your final position, I guess, is that $20 million from the Commonwealth and WA government, continuation of existing arrangements would address most of the unmet need in this system.

MR O'HART: Yes.

MR KALISCH: Just one about, I suppose, your experience travelling through WA.

MR O'HART: Yes.

MR KALISCH: I mean do you see that being different in different locations?

MR O'HART: Yes. The problems in the Pilbara in the north-west - to get something comparable up there to the metropolitan, yes, you can load it by 50 per cent, without a shadow of a doubt; and the difficulties of staffing and houses.

MR KALISCH: So that 40 million is sort of statewide?

MR O'HART: That is statewide, yes.

MR KALISCH: But you'd actually, from what I'm hearing, distribute it quite differently?

MR O'HART: I would say they're suffering disproportionately to the people down south, I've got no doubt about that, with the indigenous situation and foetal alcohol syndrome, yes. So you can see I'm an advocate.

MS SCOTT: Thank you very much, Brian.

MR O'HART: Thank you.

MS SCOTT: We now call on the National Ethnic Disability Alliance to come forward, please. Welcome, we have approximately 30 minutes for your segment. So could you identify yourself for the transcript and then would you like to make an opening statement?

MS ISCEL (NEDA): Thank you very much. My name is Zel Iscel. I'm the acting executive officer for the National Ethnic Disability Alliance. The National Ethnic Disability Alliance, which we call NEDA for short, is the national peak organisation which represents the rights and interests of people with disability from culturally diverse and non-English speaking backgrounds, their families and their carers throughout Australia.

We're funded by the Commonwealth Department of - well, we're funded by FaHCSIA to provide policy advice to the Australian government and other agencies on national issues affecting the people that we represent. So NEDA actively promotes the equal participation of people with disability from culturally diverse and non-English speaking backgrounds in all aspects of Australian society. We manage a range of projects relating to ethnic communities and work closely with our members to ensure that NEDA's policies reflect the lived experiences of people from culturally diverse and non-English speaking backgrounds.

The Productivity Commission report on government services in 2009 estimates that one in every four people with disability is a person of either first or second generation of culturally and linguistically diverse backgrounds: approximately one million people across Australia, represents a quarter of the total population of Australians with disability. So that makes people from culturally diverse and non-English speaking backgrounds the second largest population of people with disability after women with disability.

So NEDA's main concerns around a national scheme for the long-term care needs of people with disability from culturally diverse and non-English speaking backgrounds is around eligibility and the need to build social networks. What we would like to see in the scheme is the inclusion of - sorry, the adoption of the non-negotiable principles that were agreed at meetings of disabled people's organisations. I will talk more about that later. We would also welcome the establishment of a disability resource centre in every municipality in Australia, disability coordinators to organise the services and supports for people who require this service, all disability agencies to carry out their work in a linguistically and culturally competent manner, the maintenance of specialist services and advocacy organisations who work with people with disability from culturally diverse and non-English speaking backgrounds and finally, funding of interpreters and translators to be provided within the scheme but separately from the individual's package.

There are many examples of people with disability from culturally diverse and non-English speaking backgrounds who are living successful lives and making valuable contributions in all areas of Australian life. A small sample of us are here today and there are people with disability who are creating fascinating artworks and also contributing to their family, if not necessarily working - contributing to their family in ways that can't be measured financially. So given the right kind of supports it does make a difference in the lives of people with all kinds of disability, and especially those from culturally and linguistically diverse backgrounds. So I'm going to hand over to Angelo now and - sorry, Angelo is actually presenting with me, Angelo Cianciosi, and he is going to be talking about his experiences as social worker working with people with disability, particularly from culturally diverse and non-English speaking backgrounds.

MR CIANCIOSI (NEDA):   Thanks, Zel. Apart from being a counsellor of NEDA, I've also worked in the disability field for the last probably 17, 18 years. The major issue which really sticks out like a sore thumb is the quality of the people working on the floor. I think whoever you talk to that have been around for a long time have said that the standard in service delivery has fallen sharply. We do not - and I think it has been brought up before but I just want to reinforce it, that the quality of people working on the floor has dropped a lot. We have - I've worked for government agencies as well as non-government agencies. It seems to be a lot worse with non-government that we have uni students that just want to pick up a bit of extra money for their studies. They do not see the disability field as a career. We are really, really scraping the bottom of the barrel, and that seems to be a pretty common comment that people make.

If we are not addressing the needs of the person with a disability, how are we supposed to improve their lifestyle? How are we supposed to improve their skill level? Part of my job is teach a person skills so they become more independent of staff. That is not happening. We are just there as a carer to meet their needs. Community integration or community participation has gone out the window. I just feel that whatever incentives the government are going to make within the insurance scheme, whether that's giving direct funding to the agency, will not improve the situation if we can't get better people working on the floor.

MS SCOTT: Thank you. That's very clear.

MR KALISCH: Do you mind if we ask a few questions now?

MR CIANCIOSI (NEDA):   Sure, go ahead.

MR KALISCH: Just about the workforce. I mean what aspects or strategies would you suggest to improve the quality of the workforce?

MR CIANCIOSI (NEDA):   I think you've got to improve the conditions that we work under.

MS SCOTT: So the pay and the other conditions?

MR CIANCIOSI (NEDA): Yes, pay but also you have to look at - you know, there's people that are doing 16 weekends in a row without getting a weekend off.

MS SCOTT: Yes.

MR CIANCIOSI (NEDA): You know, that's horrendous.

MR KALISCH: And is the difficulty with attracting and retaining the workforce one that is more apparent in Perth or is it in the outlying areas of Western Australia?

MR CIANCIOSI (NEDA): I think it's probably more prominent in WA because whenever we have a mining boom it's the disability field that suffers in a big way, because people are drawn away from the disability field to go and work elsewhere, whether it's in the mining industry or other places because conditions are better because they're working Monday to Friday. They're not doing weekends. They're not worried about being beaten up by a client.

MR KALISCH: So you're aware of people that have - individuals that have moved from providing disability support - - -

MR CIANCIOSI (NEDA): Absolutely.

MR KALISCH: - - - into the mining industry?

MR CIANCIOSI (NEDA): Not just the mining field. A few - they've had enough of it after a certain amount of time. We're losing people with a great deal of skills and experience. They've come to the point where they are fed up and they've moved on. We've really got to do something about retaining these people.

MR KALISCH: Just moving on to the sort of local structures that you talked about in terms of the - also the disability resource centres and the local area coordinator-type approaches, one of our previous - one of the previous presenters this morning talked about providing possibly funding to advocacy services or other specialist associations to assist local area coordinators. Is that what you're thinking about in terms of the disability resource centre as well as then the local area coordinators?

MS ISCEL (NEDA): We were looking at them as two separate entities. They could work together but - you know, from the resource centres. But in terms of the coordinator it would be somebody who is coordinating the services and advocacy, if a person needs it, to - just to make it easier for people to get through that maze of disability, I suppose, information and organisations that they need to get through.

MR KALISCH: If I can just ask a question around how you envisage the system moving from where it is at the moment in Western Australia. Are you looking for a system that just has more funding or is dramatically different in terms of the way services are arranged and provided?

MR CIANCIOSI (NEDA): I just want to get back to local area coordinators in WA because most of them come from an English speaking background there is a problem where they don't understand the values of a person coming from a non-English speaking background. They seem to impose their values on the family, which is quite different from the values that they've had, maybe.

MR KALISCH: So you see an opportunity or a reason for change where the family and the person with a disability exercises more control and more influence over what services they receive?

MS ISCEL (NEDA): That's right, yes. I was actually going to talk more about that further down but I'll mention it now. We are saying that - I suppose if you take a system like the local area coordinators, the local area coordinators would probably be what I call - what we've been looking at as coordinators. I mean we're just calling them coordinators for now as something to refer to. They could be anything. Some people have suggested personal assistants for people with disability. That - and there are other terms for it as well. But the general idea is that this person helps to navigate people and their families around the disability system.

But what NEDA is saying is people from culturally diverse and non-English speaking backgrounds should have coordinators who are also from culturally diverse and non-English speaking backgrounds, preferably from their own background but if that's not possible, somewhere close by or at least, you know, someone ethnic, someone who is a migrant who has some kind of understanding of the needs of this group of people in terms of what it will take to integrate them into their community. One of the issues that we face is that there - in some communities there are a lot of negative attitudes towards disability. So a person aware of that would be able to deal with it more effectively and know people to approach or find out who to approach more effectively.

Say for example if we had a Muslim coordinator for a Muslim person with disability. That coordinator would be much happier to enter into mosques, for example, and talk to the imams than somebody who is not Muslim. It's something that has come up, actually, that I am aware of where service providers and advocates have been hesitant to help people from other religions because they themselves were not aware of the - didn't fully know about the religion or culture.

MS SCOTT: Thank you.

MS ISCEL (NEDA): So I can go on - - -

MS SCOTT: Yes, please.

MS ISCEL (NEDA): - - - with what I was going to say. Angelo, did you have anything else to say?

MR CIANCIOSI (NEDA): I also wanted to make the point that with the funding that goes directly to the families of the client we have a pretty high percentage of clients that have no family contact and no family input. I mean, what happens with them? Are they going to be administered by a person in Canberra or somebody who has no experience in the disability field? It's a bit of a major concern.

MR KALISCH: Could you imagine in that circumstance that there might be someone in their local ethnic community or their circle of friends that could assist in that process?

MR CIANCIOSI (NEDA): I think regardless of who it is they would have to probably have skills and knowledge of the disability field. It would be sad to see somebody given a lot of money and spent in the wrong way, that their needs have not been fully met.

MS ISCEL (NEDA): Again, it could be something that the disability coordinator could do. The key point there would be that the coordinator would have to have regular contact with the person that they're representing so that they can build a relationship and a bond in an endeavour to make the best decisions in the interests of that person. It's no guarantee but it's one way that we're looking at, that hopefully, because of the relationship and the bond, can aim towards working towards the best interests of the person.

MS SCOTT: Zel, do you want to continue with your testimony?

MS ISCEL (NEDA): Yes, sure.

MS SCOTT: Thank you.

MS ISCEL (NEDA): So I just want to touch on the meetings that we've been having with the disabled persons organisations. The meetings were organised by the Australian Federation of Disability Organisations and People With Disability Australia. So what we're calling is a rights-based approach to a disability and carer support scheme. We came up with some non-negotiable principles, there's seven of them. I was going to actually read them all out but I think it's going to take too much of my time.

MS SCOTT: We've got them here so you could take those as a given.

MS ISCEL (NEDA):   I'll just mention two of them though that I think are quite important and easy concepts here: firstly, that people with disabilities and disabled people's organisations must be involved in all levels of governance in a new funding model - so involved from this point on through to the implementation of the model and all future aspects of the model as well; and, secondly, to use the UN convention - the United Nations Convention on the Rights of Persons with Disability, to use that as the framework for the design of a new system for framing a significant - so this will cause a cultural paradigm shift based on a social model of disability. I know the scheme is looking at the social model of disability as well, so we're hoping that the UN convention can be used to guide that paradigm.

NEDA also calls for substantive equality where people from diverse cultures and languages are provided support and services that are culturally and linguistically appropriate for them. We're also calling for substantive access so that all available services and supports are accessible for everyone. Some services are available but because of lack of information in a variety of languages people aren't accessing them, or because of lack of physical access to buildings, to wherever needs to be, is not available. So we're hoping that whatever the scheme does it's actually accessible and available to everyone.

We believe that it is imperative that the scheme funds translation and interpreter services but that this is not going to be a part of an individual package. So we're envisaging a pool of funds that can be set aside that can be used to provide linguistic support and it can be used for people from non-English speaking backgrounds but also for people who are deaf and need sign language and also possibly Aboriginal languages as well. The scheme also must include training in cultural competence across the sector so that people can benefit from any services and supports that they choose.

The issue of eligibility is of particular interest to NEDA in terms of new arrivals and those living in Australia on temporary visas. An inquiry into the treatment of people with disability in the Australian migration system commissioned by the Joint Standing Committee on Migration clearly highlighted the unjust treatment and discriminative treatment of people with disability and their families who endeavour to obtain permanent residence in Australia. Those who do receive residency in Australia must struggle for 10 years without support and services as they are denied the disability support pension.

MS SCOTT: We're now fast approaching the end of the time set aside for your organisation. Is there some final points you'd like to make?

MS ISCEL (NEDA): Yes, sure. So we're hoping that the new scheme will include migrants and will eliminate the 10-year waiting gap that people have to endure before they receive the services. If everybody has to pay into a scheme then everybody should be able to benefit from it as well.

MS SCOTT: Can I just test you out on that just a little bit, because clearly the money for existing schemes comes from largely taxpayers now.

MS ISCEL (NEDA): That's right.

MS SCOTT: So the arrangement of a 10-year exclusion period, that same argument could be used now - the taxpayer is paying for it now. So why do you think the new scheme would have this larger - what's the logic of the larger eligibility for newly-arrived migrants and so on?

MS ISCEL (NEDA): We don't see the logic in that anyway.

MS SCOTT: Right, okay.

MS ISCEL (NEDA): We're just hoping that the new scheme doesn't carry on, I suppose, the weaknesses of the old scheme, of the old system.

MS SCOTT: I understand.

MR KALISCH: Just on that 10 years, I understand there's a 10-year wait for residency for a disability support pension. Is that what you're referring to? I wasn't aware that there was a similar rule around waiting for other services.

MS ISCEL (NEDA): The disability support pension is related to other services as well. So, for example, if you are on the DSP you can also get a travel concession card and you can also get various medical treatments and so on, which you can't get if you're not on the DSP.

MR KALISCH: So you get other concession arrangements through being on another allowance.

MS ISCEL (NEDA): That's right.

MR KALISCH: Thank you.

MS ISCEL (NEDA): Just before we have to go as well, I just want to mention about eligibility in terms of people over the age of 65. We're hoping that people with a disability and people with age-related disabilities continue to remain on the scheme once they turn 65. What NEDA has found in a paper that we've released called What Does the Data Say is that although most migrants come in as being healthy, after they reach 45 their health starts to deteriorate and so I guess it becomes worse as they get older, not better. So it just doesn't seem to make sense that the scheme does not carry on once a person turns 65.

MS SCOTT: I wonder whether that's a case where drafting hasn't been as good as it could be, because there terms of reference suggest that the model should be lifetime so maybe you could take comfort from the fact that it refers to lifetime care.

MS ISCEL (NEDA):   That's great, yes. So just quickly to mention one of the other things that we've found is to do with - a lot of our consultations have shown a lack of social networks for people with disability and so we're hoping that this idea of the disability resource centre will also provide an opportunity for people with disabilities in the same area, whether they are from non-English speaking or culturally diverse backgrounds or not, a venue for them to actually meet and make social networks.

MS SCOTT: Okay. Thank you very much to Zel and Angelo for your evidence today. Angelo, we're very keen to get a better handle on workforce issues so I know you covered that in your presentation. Anything you've got further to add on how workforce issues could be addressed, especially in a tight labour market, we would certainly welcome. Thank you.

MR CIANCIOSI (NEDA):   Thank you.

MR KALISCH: Thank you very much.

MS SCOTT: We're now going to have a break for lunch and we're going to resume with Headwest Brain Injury Association at 1.10. So we'll be coming back at 10 minutes past 1. Thank you.

(Luncheon adjournment)

MS SCOTT: Welcome back to our public hearings. We will now resume with Headwest Brain Injury Association of Western Australia. I'll ask Helen to come forward, please.

MS LYNES (HBIAWA): Thank you.

MS SCOTT: Well, Helen, thank you for attending today. Could you state your name and then make an opening statement, please.

MS LYNES (HBIAWA): My name is Helen Lynes. I work as the executive officer at Headwest Brain Injury Association of WA, which is the peak representative body in Western Australia for people with acquired brain injuries. Acquired brain injuries are defined as any kind of injury to the brain that occurs after birth. So it includes a wide range of conditions including brain injuries that are caused by catastrophic and traumatic causes such as assault, road crashes, other types of accidents; but also apoxia, suffocation-induced brain injury, it could be strokes, also substance-induced brain injury.

MS SCOTT: Sorry, this is our third commissioner. Is that you, John? Great, well, we'll just interrupt the testimony just for a second. Helen Lynes was just about to take us through Headwest Brain Injury Association of Western Australia's presentation. So John, we're pleased to have you here. So for everyone's benefit this is John Walsh, who is the third commissioner.

MS SCOTT: So Helen, I'm sorry for the interruption, back to you.

MS LYNES (HBIAWA): Okay. Do I have to say all that again?

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

MS LYNES: No? Okay. Well, really, today is just a preliminary submission to the inquiry because Headwest has been conducting a number of focus groups on the inquiry's behalf in order to ensure that the issues that are raised from the field in response to the inquiry's questions can be addressed from the experience of individuals living with acquired brain injury but also service providers and academics who have a lot of experience and knowledge in this particular area. So there will be a final submission put to the Productivity Commission by the closing date for applications on 16 August. That final submission will include evidence that has been gathered from focus groups that will be conducted between now and then. In particular they will be with Aboriginal people and also academics and people with acquired brain injury, carers as well as some service providers across a number of sectors, in particular justice and mental health, because both of those areas also do provide services for people with acquired brain injury.

Now, in particular, this submission is just a preliminary response to the Productivity Commission request in its issues paper for comment on the design implications for a national disability insurance scheme or a similar scheme for the long-term support and care of people with disabilities. So just want it noted that the aim of the inquiry, which is to address systemic and enduring inadequacies or the brokenness of the disability sector is commended.

For many people with acquired brain injuries and their families in Western Australia it has to be said that the system is not just broken, it barely exists at all. Whilst some people with acquired brain injury are able to access disability services per se, many people remain serviced by the health system or as outpatients or in long-stay wards or they're in mental health institutions or are in prison. So Headwest, you know, really commends the consideration by the Productivity Commission that the scheme design should address the systemic failures of the current disability sector and build on elements of the current system that demonstrate an effective response to the needs of people with disabilities and their families.

Headwest considers that the following principles should inform the design of the national disability insurance scheme. The first is substantive equality or equity. Headwest believes that the scheme should be broad and based on disability support and rehabilitation needs and considered with contextual variables such as social, economic and cultural disadvantage. Second principle that should inform the design of the NDIS - the scheme should encompass a social model of disability and promote self-determination has held by the Convention on the Rights of People With Disabilities and the scheme should redress Aboriginal disability disadvantage, closing the gap.

The other principle that should inform the scheme is efficiency, so the scheme should facilitate a person-centred approach and inter-sectoral collaboration. That's to optimise health, rehabilitation and recovery outcomes and to minimise the disabling effects of brain injury with the person at the centre, rather than services. The final principle is sustainability. The scheme should focus on reducing the incidence of brain injury and should facilitate rehabilitation, recovery and social inclusion. That's inclusion in social, cultural and economic terms for the long-term social and economic sustainability.

So in response to the Productivity Commission's statement that the focus of the inquiry is on how to build a good system, Headwest recommends that the new system is established to firstly, reduce the prevalence of acquired brain injury. Secondly, to provide a comprehensive early intervention approach. Thirdly, promote best practice pathways to rehabilitation and to recovery.

So on the first point, reducing prevalence of acquired brain injury, it has to be said that brain injury is mainly preventable. By contrast, there is no health and disability prevention strategy in place in Western Australia and indeed, I believe, not across Australia either, to systematically reduce the incidence of acquired brain injury. Rate of incidence of acquired brain injury - and the figures I'm about to give you are actually considered to be very low estimates of the prevalence of acquired brain injury but the stats currently indicate that the incident rate could be as high as 377 people per 100,000.   Now, the incident rate of brain injuries for people leading to hospitalisation for Aboriginal people is considered to be a lot higher. So about one in 45 Western Australians have an activity or participation restriction due to disability from an ABI. Of this group about 16,000 people have a severe or core activity limitation and two-thirds of those people are under 65. I have to say these figures are a bit of out of date.

The prevalence of acquired brain injury in Aboriginal communities is considered to be much higher than it is for the non-indigenous population, particularly with respect to catastrophic brain injury. I have just recently had some stats through from the Health Department that indicate that the prevalence of brain injury in Aboriginal communities is between two to three times higher than it is in the non-Aboriginal community. That is not taking into account the amount or the extent or prevalence of brain injury acquired through substance use.

People with acquired brain injury tend to have needs that are more complex than the average person with a disability. This is in part due to the very high prevalence of co-existing health problems and other disabilities and also very high risks in the key social determinants of health and wellbeing, including substance use, imprisonment, homelessness and service fragmentation. So for example, of the people who are aged under 65, the majority of people living with acquired brain injury disabilities and/or other debilitating health conditions include a prevalence of - about 80 per cent of people also have a co-existing physical debilitating condition such as a neurological condition, a cardiovascular condition, a respiratory condition, cerebral palsy, arthritis et cetera. 42 per cent of people with acquired brain injury have a psychiatric disability and nearly 40 per cent of people with acquired brain injury also have a sensory or speech disability and about 30 per cent have an intellectual disability or mental disability.

The other point I want to make is that while the prevalence of substance-induced brain injury hasn't been accurately assessed or identified in Australia there are no actual prevalence data about the extent of acquired brain injury through substance use. However, overseas evidence suggests that about 68 per cent of people with an acquired brain injury have a experience of substance misuse - have a history of substance misuse and about 14 per cent go on to develop an alcohol and drug problem after a head injury. Up to 80 per cent of clients in alcohol treatment show some form of cognitive impairment. Studies of prisoners in the criminal justice system indicate that between 25 and 87 per cent of people in gaol have an acquired brain injury. Now, recent figures out from a national study conducted indicate that the figure is around 35 per cent, but this is an internationally-recognised range that - the range is quite similar in the USA as well.

So the recommendation in relation to brain injury prevention from Headwest is that the national disability insurance scheme or a similar scheme established following this inquiry be designed to have, as a risk management and as a costs-saving imperative, an interest in the development and implementation of a comprehensive approach to brain injury prevention.

Secondly, in relation to - I now want to talk about the need for the scheme to make provision for a comprehensive early intervention approach. The literature on rehabilitation or recovery in the area of acquired brain injury is conclusive, that people with acquired brain injury who receive an early assessment and diagnosis have much better long-term outcomes - and that means outcomes in social, cultural and economic terms - than people who are not assessed and who do not have an early diagnosis. But what happens in practice is that people who acquire injuries through trauma or catastrophe or substance use are not routinely screened for brain injury. As a result, many people with an undiagnosed brain injury end up in crisis. They end up in mental health institutions, in prison or on the streets. So those who are sent up for a neurological assessment have at times to wait up to two years and those assessments can cost $200, and that - - -

MS SCOTT: Can I just check, Helen?

MS LYNES (HBIAWA): Yes.

MS SCOTT: Is that figure of two years, is that West - - -

MS LYNES (HBIAWA): That's a WA figure, yes.

MS SCOTT: Okay. In your final submission can you reference that figure?

MS LYNES (HBIAWA): I will. I absolutely will, yes.

MR KALISCH: Is that because of the lack of clinical care?

MS LYNES (HBIAWA): Yes, there's a shortage of people who can actually provide those assessments in WA. In addition to that there's a shortage of people who can provide neuropsychological assessments. So there is - I'll come on to that issue, because that issue of assessment is really critical. I think an investment made in that area could bring about huge cost savings, not only in economic terms but the cost in loss of quality of life and participation for people.

Assessments tools that are used by disability services. Now, disability service sector, but also through the Commonwealth government's disability support pension and job capacity assessments - they're not actually suitably tailored to the assessment of people with cognitive disability, therefore many people with serious cognitive disabilities fall through the gaps as they do not meet the eligibility criteria for income support, disability employment services - which is a critical point, I think, in terms of people's capacity to participate in economic terms and also in terms of disability support services. Also an aspect of a cognitive disability is an incapacity to organise daily affairs. Medical evidence required for an assessment is frequently lost by people with acquired brain injuries. So such people also have difficulty obtaining an accurate assessment as they often do not have an insight into the extent of their disability. Now, in this case, and I hear this very often, people report to assessors that they have a capacity to live in the community or they have a capacity to hold down a job when it is clearly not the case.

So the recommendation in relation to early intervention is that the national disability insurance scheme or a similar scheme that's established following this inquiry be designed to have, as a risk management and a cost - and cost in human and financial savings terms as an imperative in both those areas - have an interest in the development and implementation of a comprehensive approach to early intervention which would have the - and it's recommended that that approach have the following features. Firstly, an early comprehensive - and when I say comprehensive we mean for all people with post-traumatic and catastrophic injuries and in substance syndrome cases - that they all have a brain injury assessment that's done in a timely, reliable manner and that it's kept on an electronic database so this doesn't get lost.

Secondly, that there is an approach taken for care coordination, that there's family support in place for the acute early post-injury phase. Now, families quite often do break up because of the personality changes that can occur. So there's tremendous cost there to families as well as to the individual. Now, it features also a rapid response, crisis intervention capacity - and that's because people can leave and go home for a period of time and appear to be quite normal and then things can fold into crisis. So there has to be follow-up capacity for crisis response. Because of the complex nature of the disability it's very important that there's inter-agency - and that means in particular across health, disability and mental health sectors. There need to be inter-sectoral care protocols, particularly in the case of people with mental illness and an acquired brain injury diagnosis.

It needs to include prison diversion schemes to reduce the incidence of incarceration. If you look at the cost of - what it costs to keep someone in prison and indeed what it costs to keep them in a mental health facility, an early intervention should be - you could put your actuaries on to it, please, commissioners. That way you could really gather some evidence there that would demonstrate the efficiency of this approach. Also, that include provision of affordable housing. Now, also the model needs to - further research is needed around this issue of service provision for people with complex needs and also what strategies are needed to address the systemic barriers and promote best practice based on close and ongoing collaboration between institutions and relevant community based organisations. So I can't emphasise enough the importance of systemic advocacy and the commission's support for systemic advocacy in this area, and indeed in all areas where there are people in particular falling through the gaps in service provision.

We recommend that the model promote best practice pathways to rehabilitation and recovery. So there are some models of care in Western Australia under development to facilitate pathways to rehabilitation and recovery and organisations that have worked long and hard to establish those really need to be recognised and commended. However, the services, to address the disabling effects of acquired brain injury and associated problems, tend to be very undeveloped or in short supply and there are problems associated with a lack of service continuity and coordination.

For example, people who are discharged from hospital are often sent home with their parents or their partners and then they and their families are not provided with the information and services that they need to facilitate rehabilitation and support, nor do they get counselling to help with the grief and the loss and the tremendous sense of isolation that people experience after acquisition particularly of a traumatic or catastrophically-caused injury.

So this problem is particularly serious for people who are noncompensable under the WA fault insurance scheme. It has been described to me that people come out of hospital and then they fall off a cliff, and I've had those words said to me from a number of people who have not met each other so it's obviously a clear experience from people in the area. There's a significant shortage of physiotherapy and speech therapy services in the Perth metropolitan area, and in most rural and remote areas there are none. Disability and aged care support services do not tend to know how to provide effective treatment as rehabilitation services to people with an acquired brain injury and this is a particularly serious problem in rural, regional and remote ares.

Workers in the disability and aged care sectors - because there are a lot of people with acquired brain injury in aged care services, and in particular in remote, rural areas there are a lot of Aboriginal people in long-term residential care - workers in those services tend not to (a) know how to work with people with acquired brain injury and (b) they don't know how to work with Aboriginal people in a culturally secure way. So an approach based on evidence about what constitutes best pathways to rehabilitation recovery has not been developed across the sectors that people with acquired brain injury and their families encounter. When I say across the sector, it's across health, mental health and disability sectors in Western Australia.

There's anecdotal evidence that the current fault insurance scheme in Western Australia may at times be a perverse incentive as it's not in the interests of the individual nor the service to facilitate an early pathway to rehabilitation and recovery because if the person gets better, the amount of compensation he or she may win could be less than if the person's condition were to stay the same or deteriorate. So recommendations to the commission are that the disability insurance scheme or similar scheme established following this inquiry be designed to commission research to identify inter-sector - and that's a health, mental health and disability - best practice pathways to rehabilitation and recovery. Secondly, that it fund models of care designed on best practice so identified and to assertively redress the shortage of qualified physiotherapists and speech therapists, particularly in regional areas.

So address gaps in service delivery and identify training needs and establish a comprehensive national training program for disability and aged care working in the delivery of effective rehabilitation and recovery services. In the event that the national disability insurance scheme or similar scheme, if it's not established in Western Australia, then we'd just like to find a way for a no-fault insurance scheme similar to the model in Victoria to be established in Western Australia. Finally, that systemic advocacy services are funded to promote the development and implementation of best practice pathways to rehabilitation and recovery and the establishment of a no-fault insurance scheme in Western Australia.

So I'd just like to thank you very much for the opportunity. Do you have any questions?

MS SCOTT: Yes. Thank you very much, Helen, for presenting such a clear paper. I'm interested that you refer to the Victorian scheme and wonder if it's within your capability as an organisation to maybe make a comparison between someone who has a motor vehicle accident in Victoria and suffers a severe brain injury, and maybe what you think would be the typical experience of someone with very similar or the same injuries here in Western Australia where the case is not compensatable. That would be quite revealing for us. Would that be possible for you to do?

MS LYNES (HBIAWA): I have to say I have spoken to some people in Victoria but I haven't actually had a look at their evaluations yet to see what difference it has made. I can tell you that in Western Australia there was a recent study carried out by a woman called Dr Caroline Bulsara. That study was commissioned by the insurance commission and it actually outlines the costs of and the services required for people who receive a catastrophically-acquired injury. What is really clear in that study is that for people who don't receive insurance cover because the accident was their fault basically when the move out of hospital really are the people who move off the cliff into the world where nothing is provided.

MS SCOTT: So nothing from the Disability Services?

MS LYNES: There's nothing in terms of the kind of access to physiotherapy services. There's nothing in terms of speech therapy. People have to pay for those services and very often they are in a situation where they are not able to afford to do so. They usually are unable to access the kind of case-coordination services that are required in order to bring services together. There's also a situation where families don't access the kind of information and support that they require at that time, so there are very high rates of family breakdown and enormous amounts of family stress.

In particular there are situations where there are people who find it very difficult to basically access any kind of disabilities. When I say this, I need to explain that for people with an acquired brain injury to be able to access disability support services they really need to go on to have a very serious physical as well as cognitive disability which is an ongoing or residual disability. So what happens for a lot of people is that they come out with a condition there is the capacity to be rehabilitated from but because they are unable to access the services they can then start to pick up drug-taking, alcohol, behaviours can start, because people have cognitive disabilities people can without intention steal things, walk out of shops.

I personally know 10 people, and I have only worked in the organisation for six months, who have actually got a criminal conviction for stealing and they were not aware that they were stealing, for example. So you see people who go into hospital or they go into gaol or they go into a situation where they pick up other risk-taking behaviours, and invariably have another accident. I was just talking to someone the other day and all of the people on her caseload are people like that: they were noncompensable the first time; the second time, after they had had an accident or they tried to commit suicide, they became compensable and also, ironically - and I think this is a perverse incentive, if any - they became eligible for disability services.

MR KALISCH: Is that situation you're describing, Helen, a dimension where they're missing out on services from the health system as well as missing out on disability services? Caught between the two systems.

MS LYNES (HBIAWA): Yes, absolutely, "caught between the two" is a good way of putting it.

MS SCOTT: John, do you have some questions?

MR WALSH: Yes, thank you, Helen. I'm interested in the earlier comments you made around prevention and early intervention and assessment. Could you describe for me the trauma system in Western Australia? Is there a specific dedicated tertiary trauma hospital, an injury rehabilitation unit, anything like that?

MS LYNES: Yes, in Western Australia there is a unit called the head injury unit. Sorry, before I answer your question, can I just say something about the Victorian model, and I'll come back to that. The other thing that's very good about the Victorian model is that they have an episodic crisis capacity. So if people are supported and they're going through a rehabilitative process and they're held within a case management system but then everything starts to undo - and that quite frequently happens in the pattern of rehabilitation and recovery with people with acquired brain injury - they have a team that can actually come in and provide an intensive program that can support that person so that they don't then slip back into that hole.

Going back to your question, commissioner, there is a head injury unit in Western Australia and it's located at Sir Charles Gairdner's Hospital. That service is a statewide service and it provides a service for people who have acquired a brain injury through catastrophic or traumatic causes or a stroke. Those are people who have gone into hospital and when they have exited from hospital some of those people are brought into a case management program.

However, with people who go into hospital because they have had a catastrophic injury they have actually got a very serious brain injury, a lot of them with catastrophic injuries don't get an assessment to see whether they actually do have a brain injury. What that unit picks up are people who are released from hospital who then have a subsequent injury or crisis and then are later diagnosed as having a brain injury. This is information has actually come from the head injury unit. That is one unit across a whole state. It's supposed to be able to provide a service for people across the state and it doesn't have the capacity to do that.

Moreover, it's a system that exists within a hospital system. So it's a biopsychosocial model but it has been designed in such a way that it's not able to provide the kind of services that are needed to be able to directly link into people and provide support to them in that regard in their communities. The other problem that the head injury unit has when it does try to case-coordinate across the state is that there are insufficient services in many areas for them to coordinate. There are none there.

The other is that they haven't tailored the service to work effectively with Aboriginal people. Another major issue is that they don't provide a service for the majority of people who acquire a brain injury, because they don't have a mandate to work with people with substance-induced brain injuries. So it's a very small, very limited service. It's quite poorly funded. The staff are quite stretched. It's like the sort of pimple end of a very large hospital institution. It also doesn't integrate in with any kind of prevention approach.

MR WALSH: Do you have any idea how many people go through that unit every year?

MS LYNES (HBIAWA): I'm sorry , I was told but I don't have that number in my mind. But I can send that figure on to you, if you like.

MR WALSH: That would be useful. My other question is with respect to discharge and follow-up from that unit, is there any distinction between people who have a compensable injury through WorkCover or the insurance commission compared to those who don't?

MS LYNES (HBIAWA): I'll need to get back to you on that. But my understanding is that there is quite a difference, in terms of the capacity that people have to be able to tack people into services. I don't think that there's any difference, in terms of the actual type of service or case-coordination that the workers try to provide in the unit, but in terms of what they're able to tack people into becomes very limited when people are noncompensable, because the money is not there to provide the service.

MS SCOTT: Helen, could you give us an example in nonmedical terminology, if you could, of why someone might appear at hospital with a range of injuries but an acquired brain injury wouldn't be diagnosed?

MS LYNES (HBIAWA): Acquired brain injury is called the invisible disability. I actually couldn't tell you right now who in this room has an acquired brain injury, because someone can appear to be completely without a disability or health-debilitating condition of any kind, can appear to be talking quite normally. However, when they actually try to carry out a task, for example to go to the bathroom and clean their teeth, the person may not be able to organise a simple activity like that. You can have for example people who are able to bluff their way through.

Certainly when people have a catastrophic injury, like a spinal injury for example, people are focused on the spinal injury. If the person seems a bit disoriented when they leave hospital people just think, "Oh, well, you know, they're a bit disorientated," and it isn't till much later people start to realise, "Okay, well, their personality has changed," you know, they're doing things like having to press the button on the television all the time, losing jobs, not being able to keep a job. All those things start to come up, and that's when the family starts saying, "There's something wrong." At the same time the person themself may have absolutely no insight, because of the nature of the damage to their brain, that they are actually manifesting these types of behaviours.

It's a complex thing and it's quite a subtle disorder. This goes back to the assessments, where a lot of the assessments don't really accurately pick up on the nature of this disability. So the fact that it doesn't get picked up in hospital is partly the fact that it's not a routine activity that occurs. Secondly, I think it's because the symptoms don't manifest easily and readily and they can be quite often masked by the individual and not picked up until later, until the person starts to try and live a life in the community and what is happening then suddenly becomes evident.

MS SCOTT: My second question is - and I appreciate that the Western Australia labour market is quite unique and very different from other places - what is the explanation for the long-term shortage of physiotherapists and speech therapists?

MS LYNES (HBIAWA): I don't know the answer to that.

MS SCOTT: I can put it to other people. That's fine.

MS LYNES (HBIAWA): I could say that in Western Australia there has been a lot of investment put into ensuring that there's some infrastructure in place for the mining companies. I'd certainly say that there hasn't been an enormous amount of money put into building the infrastructure of the health system in Western Australia in real terms for people. I think it's complicated, because the health system isn't oriented to have a focus on early intervention. I'm sorry, I don't know the answer to that question. But the issue of shortages of qualified physiotherapists and speech therapists is actually a problem worldwide in the developed world. So I think it' about there needing to be a focus. Also in Western Australia you can actually earn more money in other areas.

MS SCOTT: I appreciate the particular, but if someone has studied for four or five years to take a particular profession I thought they might be more likely to continue through that. But maybe not. Thank you very much for your testimony. John, have we finished?

MR WALSH: Thank you, Helen.

MS SCOTT: I now invite representatives from the Development Disability Council to come forward, please. Good afternoon. Thank you for attending this afternoon. Could you state your names for the transcript and then make an opening statement. We just should be conscious that we have got about 30 minutes for your presentation and questions. I 'm sure we'll have questions. Thank you.

MS HARVEY (DDC): My name is Taryn Harvey. I'm the chief executive officer for the Developmental Disability Council of Western Australia. We're a peak body representing the interests of people with intellectual and developmental disabilities in this state. Our membership includes people with intellectual disabilities and their families and also some of the specialist service providers who support them. We also include within our membership organisations such as the Muscular Dystrophy Association of Western Australia, who are here, so organisations that often represent particular diagnosis groups of people with an intellectual and developmental disability. I have with me three members of the Developmental Disability Council who will give the lived experience and will be here to respond to some of your questions.

The Developmental Disability Council has been a lead campaigner for some 20 years on the need for a long-term and sustainable solution to the issue of unmet need for specialist disability support services, so we have a significant interest in this current inquiry. We have consistently told our members over the last 12 months that we believe the Productivity Commission's inquiry is a significant step and is quite a different inquiry to parliamentary inquiries because we recognise that from a public policy perspective an inquiry such as this is a significant precursor for a political and policy response to this issue.

Our key focus will be on ensuring that any such scheme responds to the needs of people with an intellectual and developmental disability. Most of our input will tend to reflect the experiences of people with intellectual and developmental disabilities who are in a relationship with their families and who have the support of their families, though we are very highly aware of the unique needs also of people with disabilities who are disconnected from support networks, including family, who have some additional vulnerabilities.

We're particularly concerned to ensure that a system such as this is responsive to the day-to-day needs of people with an intellectual disability and their families. We really feel that there strongly needs to be a balance between governments objectives around accountability and transparency and the need for the system to respond to the lived experiences of people with disabilities. We know that when governments design systems we often design them from the point of view of managing risk and we believe that if that's a fundamental basis for any such system that that's going to create huge barriers for people actually interacting with the system.

We also very strongly believe that people with disabilities are the experts in their own lives and know best what their needs are, and that the system should not be designed from the basis of assuming that people might seek to use the system in order to get the maximum benefit. We really think that the scheme needs to understand that for the most part people will access where and when they need them rather than seeking to manipulate such a system, if you will; though we also recognise the need for safeguards of course. We call for an aspirational scheme that will enable people with an intellectual or developmental disability and their family to make normative decisions about their family's future and the future of their son or daughter with a disability, and one which seeks to minimise any disadvantage experienced by people because of the presence of disability.

We think the scheme must respond to the fundamental need for people with disabilities and their families to have trust and confidence, that in the future when they need support and assistance it will be available. It needs to include a principle of early intervention, with the view to preventing crisis situations arising, but also an assurance that when personal crises do occur, and they will, that there will be an immediate response. The scheme should encourage and support families to plan for the future and should pay heed to initiatives in Western Australia such as the community living plan and another scheme such as microboards and planned individual networks that work to support people and their families to plan for the future and develop informal support networks. But we must also recognise that will be some people for whom a significantly higher level of formal care and support will exist.

We strongly advocate for a principle of universal access once eligibility is passed. One of the most significant issues we experience in Western Australia is that while people might be deemed eligible for services, and that for many people is a struggle in itself, once one is assessed as being eligible for services one doesn't automatically get access to services. We have our combined application process which is the means by which we allocate funding which effectively prioritises people according to their personal circumstances and which effectively creates what is perceived to be a crisis-driven system where those who are in most personal crises finally get access to supports. So that tends in many ways to compromise the principle of early intervention.

The question of eligibility, which is a significant component of the initial scoping inquiry, is quite difficult at this stage. We feel that very much the question of eligibility will come down very much to what the scope of the scheme is. A scheme that's aspirational in nature might have a very different sense of what eligibility is compared to something that is just a reinforcement of a rationing exercise, which in most states is what is currently the case. So to be able to respond definitively to eligibility is quite difficult to do at this early stage.

I think quite probably the more difficult question is in fact how we measure and understand and define need. The Developmental Disability Council does not necessarily support the use of severe and profound because we strongly believe that these categories fail to capture the personal and contextual experience of disability. We've heard very clearly today the message that two people with very similar profiles of disability will have totally different experiences. The scheme must also respond to changing needs as people's needs change during the life course, and also respond to key life transition events which we'll hear a little bit more in today's testimony.

We wouldn't support means testing as a way of regulating access to support. We believe it must be universal in that sense. We do however believe that there should be greater support for those people with disabilities and their families that choose to make personal contributions and that encourages people where they can to make personal contributions to care and support. We believe that just in the say that government supports private health and insurance and private education decisions, that personal contributions around care and support by people with disabilities and their families also need to be supported but we also need to recognise that many will face some experience of financial disadvantage.

We support people with disabilities and their families having control over their funding if they choose to, with appropriate checks and balances in place. We strongly support the idea that people with disabilities and their families will know best what suits them but we also know from our own membership that there are many people who won't want to have that level of control over the budget but they will want to have a greater deal of influence over the way that services are provided to them. We also strongly believe that the scheme must ensure that whatever funding mechanism is used accurately reflects the costs of care and support - and you've heard a lot today about the labour costs in this sector and the significant gaps there; indexation has always been an issue in this area as well - because failure to address that issue of the cost of support has a significant impact on the viability of service delivery.

We understand from some of our members who have connections with the aged care sector - and I believe the commission is also doing an inquiry there - that many of those providers are facing significant issues there where the level of cost of service provision hasn't been met through funding mechanisms. Finally, at this early stage of the inquiry, we believe that some highly political and very fundamental questions about the scope of the scheme have yet to be clarified and that we feel we would be able to give much more practically based input when we have something more substantive in that sense to help engage with us.

MS SCOTT: Thank you very much. Maybe I could start with a few questions and then maybe go on to the experiences of each of the people here. You talk about in your testimony and in your written material about how early the inquiry is. Now, I appreciate this is a very large task and we're asking lots of questions. I don't think any organisation is well placed to answer all of them, but by the time we get to our February draft report we will have to have answered these questions. So I know it requires organisations to chance their arm but I guess I would encourage you to think about that because we're going to have, and you'll have to react to our report in February if you're going to have an impact then. John or David, do you wish to ask any questions now before we go on to the narratives that people have?

MR WALSH: Just a quick one. Taryn, you might want to answer it or one of the people with you. You mentioned early intervention, but I think you mentioned it in the context of prevention of a crisis situation. I'm interested in your views and experiences on the potential for early intervention in developmental disability at very early childhood age, whether that can have a (indistinct) disabilities..

MS HARVEY (DDC):   I guess that the concept of early intervention in most parts tends to get talked about in that early experience of disability. We often hear people say that when a child is diagnosed, if they've got a child who has a condition that can clearly be diagnosed, that quite a great deal of early intervention is available to people through therapy services, for example. What we often see happen though is the benefits of early intervention - you know, therapy services, for example, tend to taper off as people age. So there's an issue of how you maintain the benefits of early intervention. When I talk about the prevention of crisis, I guess the thing that we hear most about from family members is that idea that, "If I got a little bit of support earlier in the way that I needed it I would be able to provide that informal care and support that I want to as a family member for longer. So that's the context that we tend to talk about early intervention, in that more - in terms of the developmental disability itself I'd say the most consistent message we hear is that those early interventions are great but that they need to be maintained, that the gains that we gain - the benefits that we gain from early intervention in the disability, it's not a once-off. Early intervention is not just about coming in once and everything will be okay but actually maintaining those interventions to some degree into the future so that we continue to get the benefits.

MR WALSH: Thank you.

MR KALISCH: I've just got one question really about, I suppose, the role of mainstream services as opposed to services that are paid for out of say a disability care scheme. To what extent should some of these services be available as a matter of course from the health system or the education system?

MS HARVEY (DDC):   I'm so glad you raised that, commissioner, because it's probably one of the - second to the issue of this area is probably one of the things I hear most about is people's experiences of the health and education systems. Judy Willock, who is joining me today, will be able to speak very well to that point. The responsiveness of mainstream health services to people with an intellectual and developmental disability is significantly problematic, particularly in relation to - there are many issues but one, for example, that refers to specialist care. Many people with an intellectual disability, for example, often need the support of a neurologist.

Significant workforce planning issues in relation to making sure that there are specialists with some degree of knowledge and experience of working with people with an intellectual disability. I'm aware of many families who continue to seek the advice and support of a paediatric neurologist because they are confident that he has the experience and understands how to interact with that person with an intellectual disability in their family; who understands the way in which you might need to tailor the way you provide that medical care to cater for the needs of people with an intellectual disability.

The hospital system is another example. We recently had an issued raised with us that related to the carer's payment and eligibility for caring for an adult, as opposed to caring for a child. If you're a family carer of someone with an intellectual disability who needs to spend time in hospital, just because that person is in hospital doesn't mean you're not providing the same level of care you would at home. So we have a family who is concerned about - that they may become ineligible for carer's payment because of the amount of time someone is spending in hospital. Just because that person is in hospital doesn't mean they're not needing to take that time off work because of the communication issues and the consistency that a person with an intellectual disability would need in a hospital environment.

MS SCOTT: Okay, thank you for that. I'm going to set some homework, I think, that's really tough, and that is people have encouraged us to think about - and you have encouraged us to think about the contextual setting of the family or person in terms of the needs. So I'd like you to work through some worked examples of that. So for example, if a person has - sole carer was their mother, would that family get more assistance than a family with two parents and an adult sibling?

MS HARVEY (DDC): I can address that question now.

MS SCOTT: You're going to do it now?

MS HARVEY (DDC): And Deidre Croft, who is our resident expert in our combined application process. It came up a little bit today. The combined application process in many ways addresses those personal situations. It really provides an assessment framework that helps people to tell their story about what's happening. It looks at the families, the situation that the person is living in. Where it becomes difficult is where we start to prioritise. So we might assess someone - you don't even get to the point of assessing someone's need until you get past that point. So you would be more likely - if you were in a personal situation that was closer to crisis than someone else because you were a single parent, because you had a parent who was in very poor health, because you were at risk of homelessness, that would make you more - that would shift you up the rung, if you like, in terms of the allocation. So the information is collected, it's how that impacts on final decisions. So we collect that information. It does eventually inform the decision but it's often informing that when people get support, in a sense.

MS SCOTT: In another jurisdiction people described their arrangements in another state as like the misery Olympics, that you had to sort of count the number of points of misery and the accentuate the misery before anyone would pay you attention. I'm just interested in what the behavioural response is. A family might already be under stress and in crisis, the marriage is already subject to a certain strain, and you actually can get more assistance if the family breaks up than if the family stays together. I don't know if you've got a comment on that.

MS CROFT (DDC):   Can I just make a reference to that and perhaps a little bit of context? I actually have personal experience of a 30-year-old son with intellectual disability whose father is his primary carer but I have had quite an extensive look at the way the combined application process works, and particularly in the context of interviewing families that were subject to that process. I guess the point that I would reinforce is that the criteria seems to be that the caring situation is at immediate risk of breaking down. So the focus is on the capacity of whomever is providing the care rather than the needs of the person with disability.

Now, in the intellectual disability field many people with intellectual disability can't write and have communications difficulties. The application is expressed in the first person. So they say, "Are you parents able to take care of you," or something similar. Of course the person with the intellectual disability is not going to be capable of writing that themselves, and how would they know what their parents' caring capacity is? Many parents will say that the application process is basically about your ability to argue the case, irrespective of your needs. So some people have been counselled how to suggest that, "Yes, I'm on the verge of suicide," or, "Yes, I'm about to kill my child," whereas others might be more restrained in how they express themselves irrespective of their level of need. So it is indeed a race to the bottom and it requires families to portray their family member in the worst possible light rather than looking to enhance their skills. So I guess my key point is, are we talking about the capacity of carers or are we talking about the needs of the person with the disability, taking account of the unique needs of people with intellectual disability.

MS SCOTT: It just seems to me that in some places the focus is on needs of the individual but you have regard to the living in a remote area. The other one is that you focus on the capacity for the carers and then secondary is the needs of the individuals.

MS CROFT (DDC): That's right.

MS SCOTT: I just want to be certain that that latter one here in WA in terms of your assessment - the assessment approach is the capacity of the carers in the first instance and then the needs of the individual.

MS CROFT (DDC): Can I just refer to that again? I think the criterion is that the current situation, caring situation, is at immediate risk of breaking down.

MS SCOTT: Yes,

MS CROFT (DDC): So if a person is living independently then that might bring forth a whole new set of criteria. If they're living in rehabilitation facilities that might bring forth a whole new set of criteria. But if the person is living at home with family the only basis on which it would be at immediate risk of breaking down is that the capacity of the carers is diminished.

MS SCOTT: Thank you very much. We've got about 12 minutes left and I know you've got three speakers. I don't know how you want to play this but could you just keep it in mind that we might want to just ask a clarifying question?

MS MURPHY (DDC): Okay. I'm Dianne Murphy and I'm a member of DDC as well as a carer and mother to three children. I'm a hardworking woman and I have just clocked up 30 years in the workforce. I'm a daughter, a wife and a very proud mum to my three kids and all of my three children have special needs. My eldest son Ryan was born with a medical condition called bladder exstrophy and in simplified terms his bladder was outside of his body when he was born. Specialists advised us that he'd require a couple of major surgeries and would lead a fulfilling life. 13 years later Ryan has endured 38 surgeries, over 300 trips to hospital and has to take medication three times a day to prevent infection, catheterises every two hours and is connected to a drainage bag at night-time. He now also lives with chronic renal disease.

My son Kieran is 10 years old. Kieran is autistic and intellectually delayed. Kieran requires constant care and support due to challenging behaviours, poor comprehension, obsessive behaviour and poor communication skills, and the list goes on. Our daughter Erin turns 10 in November and she was also diagnosed as being autistic and intellectually delayed around the same time Kerrin was diagnosed and that was back in 2002.

Erin is our little princess but is challenged by most aspects of life all of the time. Life dramatically changed the year Kieran and Erin were diagnosed. We juggled hospital, work, medical appointments, therapies and family life the best we could. Unfortunately we were already trying to support my parents who moved over from Sydney due to my dad suffering a major stroke just prior to his retirement after 50 years in the workforce. My parents of course were hoping to travel and have an enjoyable and relaxing life during their retirement but this wasn't the case.

I'm lucky that I'm married to a really wonderful man, my husband Shaun. He's here today and he spent the morning at Princess Margaret Hospital with our son. Shaun gave up full-time work, or should I say paid employment, six years ago because I suffered a breakdown. Our journey together has been a very difficult one and to survive, we have needed to advocate very strongly for ourselves, our family and our kids. Organisations that are funded to assist families like mine don't always do so. Services are not flexible enough to cater for our needs and we often don't fit into their criteria and guidelines. We have successfully advocated our case to receive funding through the Disability Services Commission here in WA which enables Shaun and I to purchase some care for our children.

Prior to receiving this funding, we became an isolated family. Services knew about us, so did family and friends, yet we still became isolated. I became clinically depressed and relied on daily medication to get me through the day. Shaun and I gained inner strength through the love of our children and we started to take on some organisations such as Centrelink. I increased my hours to full-time to financially support us and Shaun tried to apply several times to receive the carer payment. After two appeals, we took our case to the Social Security Tribunal and won our case. But no-one seemed to give a toss about the mental distress this process put us through.

We didn't realise how undervalued we were when we became carers. For me, in particular, to have been born in this lucky country, I wasn't feeling too lucky having to fight for the wellbeing of my Australian-born children. Over the years, my husband and I have attended numerous sessions about our children's conditions to gain knowledge and skills to support our children. On one particular occasion, I looked around the room and wondered if others in attendance had gone through what I had even been through to get there that day. Had they had to work numerous extra hours to have the time off to attend? Did they have to use up sick leave days and annual leave days to attend to their children's needs, such as being a long-term patient in hospital et cetera? Have they had to scrimp and save so that they could pay for the session? No way they have. They're living a different life to me. Their attendance is a professional development day and not only does the organisation they work for pay for their attendance, they drive themselves there in a work car and can claim a travel allowance to go back and forth. Where's the equality for me?

When my husband takes over full nursing care of our son when he recovers from major surgery at home, is my husband offered manual handling sessions et cetera? No way, he's not, nor is he offered in-service education for occupational health and safety purposes. Where is the equality for carers here?   When I had a hernia operation years ago, I was sent home for my husband to also care for me for six weeks. We tried to get help but nothing ever happened. We weren't a priority. We were left once again to fend for ourselves.

Over the years, our own health has deteriorated, not only our physical health but our mental health. It's hard to function each day when you're constantly tired because of the lack of sleep and mental strain, caring for a disabled person or persons. I still go to work each day, to my paying job, because we have a mortgage, bills to pay et cetera. My wonderful husband takes care of our beautiful children and oversees the care of my dad. Unfortunately my mum passed away five years ago. Having to provide constant care for my dad affected her physical and mental health and she struggled most days.

When Shaun and I just couldn't care for dad any more, he had to sell his house to enter into a residential facility. He needed to pay a $250,000 bond just to secure his place. The facility takes most of his pension too, yet my husband and I are still required to accompany dad to hospital appointments et cetera because staff are not covered by insurance when leaving the facility, nor do they have the capacity to go either. There's not enough staff. Dad is no longer entitled to HACC services, Home and Community Care services, because he's in a residential facility, so here we go again with our fight to get appropriate care for a loved one with a disability.

I'm still working on our own family submission to the commission and I'll expand on some of the examples highlighted today in that submission, but I must ask you today: what's going to happen to my kids when my husband and I can no longer care for them? I'm traumatised by this. The reason I am is because there's no family member to step in, nor are my children able to look after themselves in the future. At the moment our only hope is to form some type of network for our children of attendant sessions through two Perth organisations, as Taryn mentioned earlier, PIN, which is Planned Individual Networks here in Perth, and Vela Microboards Australia which helps to set up a microboard which is a small group of committed family and friends who join with a person who has life challenges to create a nonprofit community board. The microboard supports the person to plan for a good life and to achieve their goals, dreams and wishes.

We attended one of the first microboard meetings in WA years ago and realised we didn't have one person we could invite to assist us. With the funding we received from DSE, our main goal was to be more involved with our community, for our children to participate in community activities, the things in life most people are able to do. We started to make some friends and hoped that we could explore the possibility of a network in the future with the friends we've made. In our particular case, we aim to establish a family-type network because not only do our children require support, but Shaun and I do too. The reality of this is we shouldn't have to rely on our friends to be our main support in the future. I never thought I'd be in this position but I am and my husband and I do the best we can.

The current systems are failing in this country and systems seem to be crisis driven. I believe the push towards more individual funding in the future will enable families like mine to seek out and purchase the services we require which in turn will determine which organisations remain operational as well. People with disabilities have a right to a good life and so do their carers. The only chance we have is through a levy-type taxation system so that all Australians gain that right to living a good life.

MS SCOTT: Thanks, Dianne. I'm just conscious of time. I know you've come here to say something, so Judy and Deidre, do you wish to add something now?

MS CROFT (DDC): I think that you've encapsulated many of the issues of obviously a younger family and my experience is of a son who is 30 years old and I share fears for his future. In fact when he was younger, I could contemplate him going into some residential care situation; now I don't even want to think about it because basically I don't trust the system. I haven't gone there. Eventually perhaps I will need to, but perhaps just to reinforce the issues that occur across the life course of people with intellectual disability in their families, and the work that I've done reinforces that the time, the transition from childhood to adulthood, is a major point of stress and crisis because what families are then contemplating is, "This is the rest of my life." Whilst we're young we're still hoping for some other outcome. I guess to reinforce, are families, are mothers and fathers entitled to create a life for themselves and their other children and their grandchildren which is not focused on the care needs of one person who has very high support needs?

As the final point, just to reinforce an incredible bugbear of mine, the issue of intellectual disability. Each disability has different needs, but intellectual disability by definition implies significant limitations in adaptive capacity, and if you have limitations in adaptive capacity you need to be transitioned into alternative arrangements very gradually and with a huge amount of support, and that is the fear of parents at every stage, that their children, who they know find it very difficult to cope with change, are only going to get that change at a time of crisis in their life.

All of us find that difficult, and if you have an intellectual disability it is particularly brutal and insensitive to subject people with intellectual disability to a traumatic change at a time of crisis in their personal and family lives. Family want the opportunity to plan gradually so that that transition can take place with minimum trauma to the person for whom the care and love. Judy?

MS WILLOCK (DDC): Hello, I'm Judy Willock. I have two children with a disability. They have a genetic disorder called fragile X syndrome, which raises a whole lot of other issues, simply because some genetic disorders can be tested for at birth and can be gene-tested prior to birth, that's one thing. I have a daughter who is a very mildly-affected child, or adult. I have a son who at 21 has an autism diagnosis as well. So while he has an intellect of about a two-year-old he has the body of a grown man, he has the weight of a grown man and he's sneaky. So all those things have to be taken into consideration.

He has extremely challenging behaviour and extreme violence. Puberty for most children is difficult, but for people with an intellectual disability it's like aliens have invaded their body. They don't know how to deal with it. As a result, in my personal circumstances, he was on the borderline of being expelled from his special school and being home-schooled. Considering I was the one that was being beaten up - as an ex-teacher, I thought I could home-school him - I knew I couldn't, because my life was, well, under threat. We had to put a lock on my daughter's door so that when he ranted and raved she had the ability to lock herself in her room with the possibility of escaping through the bedroom window if things got too bad.

Really what I want to say is there's not enough done for people with challenging behaviour. It would be wonderful if all our people with a disability were cute and gorgeous. They're not. There's the broad spectrum across all disorders. Some are more of a challenge than others. But I think I'm lucky because I have been through that CAP process. Fortunately, we received funding the first round because our circumstances were so extreme, and I can't thank Disability Services enough for what it has done for my life, my son's life and the life of our extended family. It has been huge. It should be something that is there for every single person. We should be allowed to have normal experiences with the rest of our children, but also for our disabled children.

We see our son living in a group home as being a bonus for him, because he has got them and he has got us and he has got a busier, more fulfilled life as a result. We are lucky, we have got a system that works. I'd like to see a system that's there fore everybody so families aren't in crisis. But I also see there are lots of things that need improvement. Health is one of them. I'd like to take my hat off to all those normal GPs out there in the community who are expected to know every syndrome, expected to know everything about every disability, are expected to have kids with challenging behaviours sit in their waiting rooms and behave when they can't even behave in the car getting to the surgery.

I think our hospital and our health system needs to be looked at very carefully. For example, yesterday I took my son to the dentist, we didn't even get him in the chair. I spoke to a friend who has a son of the exact same age in the evening and she said, "He has been to the orthodontist and they have got this fantastic x-ray machine. He stood still for half a minute, the x-ray machine went round his head, x-ray is done." In my son's case we would have had to make three appointments, we would have to wait eight months, we would have to go to a hospital, we would have to have a general anaesthetic and he would have to be knocked out in order to get an x-ray. Yet this woman paid $70 at a private clinic. I could have paid $70 if I could have got him in that door.

There are so many things that can be avoided for people with a disability with a bit of thought and planning. That goes to employment - don't get me started; education - don't get me started. But I would really like to say that one thing is we have some fantastic workers out there in the disability sector who are undervalued and underpaid and we need to promote what wonderful things they do. We have wonderful organisations, lots of people who give up lots of their time to make things right, and I just hope that this Productivity Commission and the National Disability Insurance Scheme gets off the ground but that it's done so well that we blow other countries out of the water and say, "We can do this and we can do it really well."

But there needs to be lots of really pertinent stories like Di's. That's living. She is not alone, there are many stories. I'm lucky, my children are well, it's only violence and aggression with which I have to deal. When you can't have the rest of your family in the same room as your son, you realise you've got a few problems. Please take on board what we have said and let's hope that we have a good result from all of this, because it would be wonderful.

MS SCOTT: Can I just ask one quick question? How many years after you needed help did you get the assistance you finally required?

MS WILLOCK (DDC):   I'm the one-off. The first time I applied I got it. But then I had the education minister, the disability services minister, I had lobbied. I was the true squeaky wheel. I also ran a support group for Fragile X families, and a lot of those people have a disability and have disabled children. They can't advocate for themselves; I can and I did, and so did my sister and other members of my family. Articulate people, unfortunately, get things, they're successful. People who live in remote communities get nothing; Aboriginal people get nothing; and people with a disability who have children with a disability get even less than nothing, because the services provided by local area coordinators and disability services can't stretch to everybody, unfortunately.

MS CROFT (DDC):   May I say that I am aware of families that have applied for 10 years plus. I'm not sure how they can put their case any more poignantly, how much worse it can get, because again it is about how compelling you can frame your case in writing as to whether you get support.

MS SCOTT: Okay. Thank you very much.

MS SCOTT: Good afternoon. We welcome to the table People With Disabilities (WA) Incorporated and could we ask you to state your name for the record and then make your opening statement. You have 30 minutes and we would appreciate it if you could leave us some time to ask you some questions. Thank you.

MS BATH (PWDWA): Thank you. My name is Mary-Anne Bath and I'm president of People With Disabilities.

MS DUFF (PWDWA): My name is Kerrie Duff. I'm the senior systemic advocate for People With Disabilities WA.

MR JEFFERSON (PWDWA): I'm Andrew Jefferson and I'm the senior individual advocate for People With Disabilities.

MS BATH (PWDWA): Basically what we'd like to state to the Productivity Commission is some of the things that we see as our perspective of how we'd like the commission to go about looking at this scheme and then perhaps we can elaborate on further individual stories or circumstances. We believe that United Nations Convention on the Rights of Persons with Disabilities needs to be the framework for a design of a new system based on a social model of disability. The definition of disability used in the convention ought to underpin the scheme, not the current what we see as the outdated Australian Bureau of Statistics' version.

People with disabilities and disabled persons organisations need to be involved in all levels of governance in any new funding model. The proposed scheme is an entitlement for all who are eligible from birth to death. We don't see it as a cut-off at age 65 where you suddenly become someone who is of old age, not someone who still has a disability and is of old age, which is not necessarily old age but someone who is just 65. The whole scheme needs to be properly funded, not just for one-off project that is time limited. It needs to be based on equity for all who are eligible, based on self-determination and understanding of complexity of self. That is, that each person with a disability could be a mother, a father, contributing to society, contributing to a household. That each person's needs are so individual and so different from the next person. Regardless of whether person A and person B are in a wheelchair they are still individual with individual needs.

The system needs to promote empowerment of people with disabilities, not to take away their power and hand them over to service providers. It is portable across states and territories. So if you are set up in one state and you need to move to another, that you can move there knowing that all your systems can be in place wherever you go. It is responsive to changing circumstances of an individual. It doesn't rely on the fact that you are going to have a static condition. Your condition might change in terms that it could be worse, or it could be better, that it could be episodic in the case of people who have challenging behaviours or persons with psychiatric disabilities. They might be quite episodic and appear once a year, once a month.

That needs to be taken account of, that all existing obligations and commitments to non-discrimination and inclusion of people with disabilities are maintained outside the scheme. That means that costs are not to be shifted to individuals and safeguards put in place to stop that happening. So organisations don't suddenly say, "Oh, our building is not accessible. You have funding. You get the building changed." If you want to attend an educational institution and they say, "We don't have the right desk for you or the right ramp system for you, you have funding, you put it in." We still want it to be their responsibility.

The scheme needs to reference national disability strategy, not to be subservient to it. A strong independent advocacy support program needs to be developed to support and protect the rights and interests of people with disabilities and funded under the scheme, so that those people who are having trouble with the scheme have an independent service available to them if they want to appeal. That system needs to be funded adequately with people who are trained and can support those who cannot support themselves or speak up for themselves. That applies particularly to those people with intellectual disabilities, those people who don't have the energy to fight any more, those people in institutions or just those people who need someone else's voice to help them along.

The system needs to be transparent in funding arrangements and appropriate consumer rights protection mechanisms needs to be incorporated. Particularly in Western Australia rural infrastructure needs to be addressed. Rural and remote areas have different needs of transport, communications, health, disability-specific services, employment, education, alternatives to employment and post-school options, housing and access, equipment needs, care needs, support workers. It's often very difficult in rural and remote areas to find any of that, to find adequate health facilities, to find adequate care workers to support your needs. To get aids and equipment transported from the metropolitan area up to rural and remote regions at this stage can take anywhere between three to six months; that is after it's approved. We need that to be addressed. We need that to be considered. This is a large state, so we need it to go all the way up to the top of the state in Port Hedland and Broome, down to Albany, Esperance and anywhere else that it's needed. It needs to go outside the metropolitan area.

People from rural and remote areas have poor access to information in formats that they can access. Without an improved communication with people with disabilities and other stakeholders from rural and remote areas they will not be able to have their say about this service or the future of any service, or how it impacts on them or what they want or need. Reasonable accommodation must be made to maximise full participation in the consultation process for all people with disabilities, including those in institutions.

MS SCOTT: Can I just clarify that. Are you asking for that in this process or in the process of consultation into the future once a new scheme - if a new scheme is introduced?

MS BATH (PWDWA): I think in this process.

MS SCOTT: So just while we're on that, the federal government provided additional money in the last budget to support consultations across the community for input into the Productivity Commission's process. Were you aware of that?

MS BATH (PWDWA): Yes. It provided funding to peak bodies. We're not all considered peak bodies.

MS SCOTT: Thank you; just as clarification.

MS BATH (PWDWA): Therefore PWDA did not get funding. We could have applied to AFDO for a minimal amount of funding which could be used to try and go out to areas or to try and help us with our research for our submission, but certainly we wouldn't reach right across the state with any sort of funding like that.

There needs to be in rural and remote areas and to everyone with a disability access to accurate information, interpreters and equipment; assistance with travel and accommodation; and a long period of notice when inviting people to participate is essential. People may not realise that if you have a disability getting ready to go somewhere can take you up to two hours. You have to book a taxi; you have to make sure your carers are there; you have to make sure that the taxi is booked for when you leave. In my case I have to make sure I'm in time to pick my son up from school after this. If your taxi is two hours late you've missed the whole proceedings; you've let other people down. It's not just a case of getting out of bed, getting dressed, hopping into your car and driving up there. It doesn't happen.

Today I had to make sure I was in time to get dressed. My husband assisted me. My husband drove me up here, my husband will pick me up. We will drive down to the school, hopefully without breaking the speed limit, in order to pick our son up. I'm not just a person with a disability, I'm also a mother. I'm also an advocate. I'm also here to try and raise awareness of people with disabilities and their needs. Attending a routine appointment of any kind and speaking at this function can be demanding and challenging in the organisation of it. I'm lucky, I didn't need a taxi today. If I did, I would have had to add at least two hours to my timetable.

We also need to keep in mind that we should explore the examples of best practices from overseas. There are practices overseas which exist. We don't need to always reinvent the wheel.

MS SCOTT: Which countries in particular do you think we should model the next scheme on?

MS BATH (PWDWA): I don't know that we should model the next scheme on any particular countries but we do need to look perhaps at the system that's available in England and Canada. There's also a system, I believe, in Sweden that works extremely well and in Norway.

MS SCOTT: Do you have views about the accident compensation schemes that operate in Victoria and New South Wales in terms of their suitability for a national disability scheme that provides lifetime care and support?

MS BATH (PWDWA): Kerrie, do you want to address that one?

MS DUFF (PWDWA): It is something that we have explored. It's an option which - the great focus at the moment is on - there's not really a focus there with, if you have a congenital disability or something from birth, so it would need to be brought into - - -

MS SCOTT: Okay, but I guess we would be interested in your views about whether you think aspects of that scheme could be broadened out to cover the wider population.

MS DUFF (PWDWA): Yes, it certainly could. I imagine that the benefits, if you fall in that particular scheme, are you have access to the equipment that you need, the modifications to your home, assistance with getting employment, and that's a lot of areas where a lot of our people that we assist find great gaps at the moment. So it would certainly be beneficial.

MS BATH (PWDWA): I don't believe that scheme allows you to maintain your disability support pension, though.

MS SCOTT: John, in the New South Wales one, what's the arrangements in terms of a person being able to be on DSP? Do you know?

MR WALSH: Yes. If you have a - the New South Wales system is a sort of a two-tiered system built out of an existing common law scheme, which is what you have in Western Australia. If you have a claim under common law, that covers future income support. So if you get a lump sum for future income support, there's a preclusion period during which you can't access disability support pension because you've got the compensation from lump sum. If you don't have access to common law, so if you are just under the Lifetime Care and Support scheme, you can access disability support pension at the same time.

MS SCOTT: Thanks, John. David?

MR KALISCH: I've got one. You mentioned the expectations of what the education system, the housing system and other mainstream services should provide. I'd be interested in your submission to get some real worked examples of what should be the expectations of mainstream services and what you would expect any specialist disability fund or scheme to actually pay for. I think it's important for us to just try and work out where some of those boundaries could actually be in practice.

MS BATH (PWDWA): Most of us believe at this stage that it's up to the education department to provide accessible schools, to educate their teachers in how to teach children with special needs and to integrate students into mainstream services. In terms of housing, in Western Australia we have Homeswest housing. If they're building purpose-built houses for those people on extremely low incomes, then I think that's still the responsibility of Homeswest. At this stage, if you have a private house which is your own house and you wish to apply for modifications, there is a scheme of community aids and equipment to which you can apply.

I imagine that that will come back to the individual so that within their grant they are able to modify their house or build a purpose-built house to their own specifications; that there's enough money to buy a $16,000 electric wheelchair when needed; to modify that wheelchair, to update that wheelchair, to repair that wheelchair or to have a vehicle that accommodates that wheelchair without having to beg to organisations, "Please can I have a grant to equip my car?" and, as DDC was saying, to paint yourself in the worst possible light to get any funds to do that, as you do now. You're allowed your basic and essential equipment. If you absolutely need it, and you're allowed one piece of mobility, so I have an electric wheelchair. Should the wheelchair break down over the weekend I'm in bed or I'm in a chair, an armchair, because aids and equipment don't allow me to have a second mobility aid, they don't allow me to have a standard wheelchair in which somebody else can push me around.

MR KALISCH: So in any new scheme or new arrangement what's your view about, I suppose, the prospects for individualised funding and self-directed funding which would, I envisage, provide you with the flexibility to choose where you spend the money?

MS BATH (PWDWA): That's so, yes.

MR KALISCH: So you're in favour of extending that approach into this broader scheme?

MS BATH (PWDWA): Definitely. Individualised self-managed funding for those who want it without service providers taking up to 15 per cent of your funding would be great. Then it's up to you what you want to do with it, how many carers you want, when you want them, what aids and equipment you want, what you want to do to your house, how much help you want raising your child because you can't do certain things. Many people who have disabilities also have a family and have children.

Now, trying to look after a baby while you can't pick them up properly is very difficult. When I asked for assistance I was told by the children's hospital in the state no, they couldn't assist me. They only assisted children with disabilities. The hospital which delivered my son said they couldn't assist me because they weren't set up to assist people with disabilities. The Disability Services Commission said, "Well, we can provide you with assistance because you have a disability, but we don't actually know what to provide you with to help you raise your son because he doesn't have a disability." It was trying to go through a minefield of agencies to get any help. I think this minefield needs to be made a lot easier to access under any scheme that comes along. To go through agency after agency after agency just continually wears you down to the point where you either give up or you look to an advocacy agency and say, "Help me before I go insane." You're left with, "No, this one doesn't help you. Try this one. Try this one. Try this one." It's the continual roller coaster.

MR KALISCH: Thank you.

MS BATH (PWDWA): Exactly.

MS SCOTT: John, any questions?

MR WALSH: Just one, Patricia, thank you. Mary-Anne, a couple of people today have mentioned the difficulty with taxi transport in Perth or Western Australia generally, I suppose.

MS BATH (PWDWA): Yes.

MR WALSH: Talk a little bit about how that works?

MS BATH (PWDWA): Little bit how that works? You can book a taxi the day before, two days before, a Maxi Taxi, and it's put into the system 15 minutes before you need your taxi, no matter when you book it.

MR WALSH: Is there funding for it?

MS BATH (PWDWA): Sorry?

MS SCOTT: Funding.

MR KALISCH: Funding.

MS BATH (PWDWA):   Funding? No, no specialised funding for taxis. There are, I believe, 88 Maxi Taxis which take wheelchairs within a fleet of about 1500 taxis. I have waited two hours. Friends of mine have waited up to five hours for a Maxi Taxi. We have missed appointments. Some people have missed flights. Some people have missed doctors' appointments. It's only through a system of knowing particular taxi drivers and being able to contact them directly and relying on them that anyone gets anywhere on time.

MR WALSH: Okay, thank you.

MS SCOTT: Well, thank you very much.

MR ....:   I am in full agreeance with that on the taxi providers. I've had trouble with getting taxis in the past for work. They haven't turned up at all.

MS SCOTT: Maybe I should just remind people that - especially for those that weren't here at the start of the day. At the end of our hearing, scheduled hearing, we'll invite anyone who is in the audience to come forward and make a comment. Because we are in public hearings we need to actually get it down on the transcript. So if you have any comments feel free to wait till the end of the day and then I'll invite you forward so we can get them on the record. Okay. Well, thank you very much.

MS BATH (PWDWA):   Thank you.

MR KALISCH: Thank you.

MS SCOTT: Can I invite Carers WA to come forward, please. Well, welcome to the table. Would you like to give your names and the organisation you represent and like to make a short opening statement, please?

MS LUDLOW (CWA): Tara Ludlow, I'm the manager of advocacy and policy at Carers WA.

MS TURNER (CWA): Donna Turner, also at Carers WA.

MS SCOTT: Thank you.

MS LUDLOW (CWA): Carers WA is the peak body for family carers in Western Australia. A report released in Carers Week last year around regional and remote carers suggested that there are over 307,000 carers in Western Australia and we are here to put forth a statement with regard to the family carer side of things.

MS SCOTT: John, are you okay on audio at the moment on hearing?

MR WALSH: Yes, no, it's okay, thank you.

MS SCOTT: Okay. Thank you, please proceed.

MS LUDLOW (CWA): Over the last 14 years Carers WA has been collating carer issues and reporting on them at both a systemic level as well as at a service level quite successfully. We are part of a national network of carers associations incorporating Carers Australia at the federal level. We analyse data obviously to identify systemic issues. It's this evidence that will and has informed our submission and also my comments today. We also expect to conduct further consultations through funding that has been provided to Carers Australia and also through carers that we know locally on the ground within our services currently. The additional information will be included in submissions both by Carers WA and by Carers Australia.

As mentioned in the previous discussion, the Australian Human Rights Commission made the following comment in its report just last week on Australia's human rights record and people with disability and their families do not enjoy your human rights in Australia. There are particular concerns regarding adequacy of care for people with mental ill health, availability of supported accommodation for adults with disabilities and support for disability carers. Carers WA believes that the overarching goals of a disability care and support scheme should be consistent with Australia's commitment to the UN Convention on the Rights of Persons with Disabilities and with the Australian government social inclusion agenda. Eligibility should be based on need, not just on the nature of the illness or disability. Illness and disability affect different families in very different ways and these really do need to be taken into consideration within this inquiry.

A rights-based approach is being used by people with disability to access further services beyond what they were originally allocated. This is detailed by the Victorian Rights Commissioner in other states. A family-centred approach is required. Often the family experience significant impact also and they have their own needs, along with the needs of the person with the disability. These need to be taken account of. The family-centredness needs to be meaningful; meaningful services for people, not just what's always provided all the time. I think sometimes one of the issues that we have as service providers is that we do what we do because we do it, not necessarily because it's effective and of great benefit to the individuals that we are trying to support.

MS SCOTT: Can you think of an example like that?

MS LUDLOW (CWA): I know that there are a number of services available that don't necessarily fit. For instance, there is access to respite that isn't necessarily appropriate for people, especially where there are high care needs - where a child with autism has excessively challenging behaviours. I had one lady talk to me last week who said when she accesses respite, the organisation that she has come in make her the backup person. This is not okay. How can that possibly be respite. Another service where a daughter has many challenging behaviours, the mother finally accessed respite, but because of the daughter's diabetes the organisation would not provide insulin injections after hours because there were no nursing staff on hand. This is not respite. It meant that the parent had to continue, had to go to the respite house after hours, in her time, to provide the injections.

MS SCOTT: Thank you.

MS LUDLOW (CWA): A self-directed model as well, as I expect has been spoken quite extensively about. If the family wishes to have self-directed care and obviously the person with disability, they ought to have that right and that choice, but it needs to be done in such a way that it's flexible. I know of many families who have gone down the self-directed approach in Western Australia but due to transitional issues or personal circumstances at different times have had to let that go, but they only wanted to do it for a short time. It can actually be incredibly challenging for them to then take that back once they are back on the road and feeling as though they can handle it again. It becomes incredibly frustrating for people. So the flexibility of being able to opt in and opt out of self-directed care, I think, is an incredibly important thing for families. When I talk about families I mean the person with the disability and their family and carers.

They also need to be supported to be self-directing. Quite often families do want to provide the services themselves but it also can then mean that they become an employer and this incorporates superannuation and taxation issues if they do become an employer; insurance issues, which is quite a significant issue in the south-west at the moment, particularly around respite and insurance. So effective support and training, and access to expertise is very important, I believe.

MS SCOTT: Tara, can I seek your indulgence again. Can I just interrupt again and ask a question. We heard in Sydney yesterday about a service where people are able to have self-directed care; they have individual packages for attendant care. An organisation exists there - it doesn't offer services all around the state but does operate in some of the major places - where they will take the responsibility for payroll, superannuation, insurance - David?

MR KALISCH: Really just all those employment condition arrangements. They essentially outsource that service.

MS SCOTT: But then you choose the care worker.

MR KALISCH: You're the employer.

MS LUDLOW (CWA):   I love it.

MS SCOTT: They will help you work out the ad for the newspaper. You're effectively the person in charge and able to work out your hours but they do all the back office - - -

MR KALISCH: Admin, yes.

MS SCOTT: - - - every aspect of the back office, 7 per cent overhead. Do you have anything like that here?

MS LUDLOW (CWA):   Not to my …It's 15 - - -

MS SCOTT: 15 per cent?

MS LUDLOW (CWA):   Yes.

MS SCOTT: Well, we might follow that up.

MS LUDLOW (CWA):   I'm not aware of that one but I guess about six or seven years ago Carers WA was asked by Disability Services Commission to put together a package for people who wanted to employ care workers and it was an incredibly extensive and lengthy process which needs ongoing updating and supporting because of legal issues, legislation, all of these sorts of things that Carers WA can't provide in its existing services. So it is just a static pack. I guess one of the big issues that came out of that was the extent of legislative issues and the minefield of outdated things in some circumstances. People were sometimes led to believe that their home and contents insurance was going to cover support workers coming into the home, and that is definitely not the case. So these sorts of things, I believe, need to be taken into account.

Secondly, Carers WA is concerned about the proposal to include only people with profound or severe disability under the age of 65. As with PWD just earlier, the under age of 65 is of concern. It should be a whole of life approach. People don't miraculously become better at the age of 65.

MS SCOTT: Can I just check here because I wonder whether this is misunderstanding. The government's terms of reference talk about lifetime support but it also then has this reference to excluding the natural ageing process.

MR KALISCH: So people that acquire disabilities at a very older age, which might be Alzheimer's or other things.

MS SCOTT: I just want to check; you'd like the scheme to cover someone whether they're 32 or 45 or 65 or 80, provided they had the condition before they were 65, or do you want the scheme to include everyone with a disability, no matter what their age and when they acquired it? They're quite different schemes. So the way the government gave us the proposal, the way we interpret our terms of reference at the moment, is that you're in the scheme for life but you can't come into the scheme after a certain age, like 65. Now, is that satisfactory to you or do you want a scheme that covers everyone, including those over 65 if they then acquire a disability when they're 80, 90, 72? Just want to check.

MS TURNER (CWA):   Well, from a carer's perspective, if you're trying to negotiate care on behalf of somebody else and the person is over 65 and then acquires a brain injury, then you're negotiating the aged care system as well as perhaps this scheme. So from a carer's perspective it's another layer of administration.

MS SCOTT: Fine. That's okay. I just wanted to check. I've got that, thank you. I'm clear on that.

MR WALSH: Patricia, I'm not sure I'm clear on that. That example you just gave is if you were negotiating for someone and they have a brain injury. So what if someone doesn't have a brain injury, they just get Alzheimer's at age 80? Do you regard them as inside this scheme?

MS TURNER (CWA):   So our position is a whole of life coordinated across government scheme is consistent with so many recommendations about bringing all departments together.

MR KALISCH: I suppose that has considerable financial implications when you look at onset of Alzheimer's and dementia particularly amongst older ages. Potentially you could have a scheme such as this absolutely swamped by that older population.

MS TURNER (CWA): A question, I guess, it posed for us when we were talking about this with carers and within our organisation, and it's a question back to the government, is what would be the basis for having different resources allocated on the basis of age?

MS SCOTT: No, that's a very good question.

MS TURNER (CWA): So in terms of our commitment to - - -

MS SCOTT: Yes, I understand. I understand that. That's a very good question.

MS TURNER (CWA): So whichever scheme the money comes out of, if there is a need the money has to be found.

MS SCOTT: Okay. So John, you're right now?

MR WALSH: So I'll just make it clear that the answer to my question if someone acquires Alzheimer's at age 80, you see them as covered by this scheme?

MS TURNER (CWA): Yes.

MR WALSH: Okay, thank you.

MS LUDLOW (CWA): Okay?

MS SCOTT: Yes, thank you.

MS LUDLOW (CWA): All right. The 2003 survey of disability, ageing and carers showed that there were 405 and a half thousand West Australians reported as having a disability. Of that number 71,600 people under 65 were considered to have a profound or severe limitation. This means that more than 80 per cent of West Australians reporting a disability can potentially be excluded from the proposed scheme at the moment, which also then have significant implications for their family members and friends who are providing their ongoing care and support.

Carers WA will provide examples to the Productivity Commission that illustrate the importance of a holistic, coordinated and flexible response which is family-centred. It reduces the administrative burden and the gaps in service provision that currently characterise access to disability support and services. I don't expect that we will want to go into a lengthy proposal around that but there are significant areas that we believe could be improved. One of the biggest issues for carers is navigating the current service - well, even just mapping the current services it can be incredibly cumbersome for people.

Some of the questions that we have are what will happen to those who would fall outside of eligibility? What will be the ramifications with state and federal? Will the end result create more layers of bureaucracy and increase the load on carers and care recipients? Will the likelihood of people falling through the cracks increase or decrease? Carers WA is a safety net for many people who don't quite fit anywhere. There are a number of cases where families have had a person with a disability in their family who may have two diagnosed disabilities and therefore they don't fit into one association but they therefore don't fit into the other because of the compounding issues of these disabilities and illnesses. That's not okay and it's these things that do need - these complex situations that really do need to be taken account of.

There's an interesting thing so many families can tend to have more than one person with an illness or disability in their family. This again compounds the issues. There are differences in eligibility criteria but the same impacts only compounded. I had a case awhile ago where a mother was caring for an elderly father. She had a husband who had a mental illness and she herself had been diagnosed with cancer. Trying to access respite options for this family was incredibly - it was so impossibly complex it was ridiculous. That doesn't need to be the case. That's where, I guess, the family-centred approach where there is more than one caring role and - because every disability and illness carries its own impacts on the family situation.

There are also - I guess this comes down to transition points. As the care recipient ages and the carer ages, of course, the carer needs to work with different agencies to fulfil different issues that are arising as a result of the ageing of the person with a disability, or their own issues. We have many elderly carers caring for their son or daughter who have an illness or disability and there is so much fear and concern and guilt. "Who is going to look after my son when I die? I have never been able to work, so I don't have any assets to pass on to him in my will. Who is going to pick up that slack?" There are very real concerns there.

Finally, carers themselves actually need support in their own right, not just necessarily relating to the illness or disability. I think in a perfect world every carer would want to say, "All I want is for my son, daughter, husband, wife, mother, father to be adequately supported so that we can all live together well." I was talking with respite coordinators within the Commonwealth Respite and Carelink Centres the other day. The issues with supporting a family who just wanted to go on a holiday together and trying to get around the criteria in order to make that happen - it shouldn't be that difficult. Here is a family who just want to live as normal a life as possible and yet it almost becomes a begging session. So many families feel that they have to beg for everything.

I guess one of the concerns that we do have is that so many people become so tired of having to constantly ask and beg and convey the worst possible case scenario in their lives before they actually are able to access services and yet there is still a mentality of - in some areas where people are just out to rort the system, and this is so not the case. People rarely ask for help. All of us want to be self-sufficient, all of us want to cope. I think one of the reasons why many people don't access services is because they don't want to be seen as not coping and they don't want to have to beg because it's quite - well, it's demeaning. I wouldn't like to beg for services myself.

MS SCOTT: Okay. Can I - we've got limited time left and I just want to explore a bit more - you can tell us that you caught us on this issue about the scheme extending effectively right throughout the age care sector. So I just want to explore a bit more and maybe you might particularly address this in your submission because I have to say, we haven't heard this too often, even though we've heard from other carers' groups, so I just want to make sure. It's a bit like going to Bunnings, I guess. You know, Bunnings is a huge place and you can get lost in it and it has got all those different things but it has the advantage that hopefully there's someone who can navigate, you dial 27.

But it seems to me like you want to have Bunnings, Coles and Woolworths all in the one scheme. I'm just wondering whether you think that's - how feasible that is going to be. I can see how it's an advantage for a carer because, "Dad needs care, my son needs care. Wouldn't it be great to go to the one-stop shop? What does it matter how old they are or when they acquired the disability?" But at some point a scheme has got to have - be feasible. I just wonder what the numbers of people in a scheme would be if we included every disability including those associated with the ageing process. Disability Investment Group struggled with this at one stage, didn't they, John? The numbers are very significant.

MR WALSH: Yes, they are. I guess it's not only the numbers, it's also the nature of administration and the nature of support that's required. So supporting a child through early intervention with autism is very different from providing a home and community care place for someone that is on the verge of going into palliative care, I suppose.

MS SCOTT: So we don't expect you to have the answers but if you could have a look at the numbers in the DIG report. I mean in some ways - I know people don't like the terms of reference we got on "severe and profound". So in our issues paper we talked about those most in need and we referred to the fact that some people might only need an hour or two a week but that gets them on and has them having a better quality of life and other people would need 36 hours. We know some people need 24-7. I have to say I'm a little bit flummoxed by the idea that it could be just so big. If you could have a look at those numbers and if you really do think that that's the way to go, then of course we'll consider it. But there certainly is a little puzzle in my mind about just how feasible that would be.

MS LUDLOW (CWA):   I think if we use the analogy of Bunnings and Coles and Woolworths. If we were in Bunnings, which is under 65, it would be wonderful to be able to have somebody who would be able to then transition us to walk us across the road, to be able to go to Coles so that we could do there what we needed to do without having to find our way across the road to navigate across that freeway - - -

MS SCOTT: I agree.

MS LUDLOW: In such a way that it is at the moment. You can see that in ageing at the moment anyway with HACC and EACH and CAC packages, where many people don't want to go into those other packages because HACC is where they have been and HACC is where they're comfortable and HACC is what is providing as many of their needs as possible, and there are real issue around those transition points.

From what we hear from people, I think it's about being able to support people through navigating the two different systems. Obviously where somebody does turn 65 and they have already acquired a disability, that's one thing, but where they're actually in two separate systems because they're caring for multiple people I think there needs to be some real thought put into that aspect, and that sandwich generation is happening more and more now.

MS SCOTT: Yes, all the points you make are perfectly true. The feasibility of running a scheme that big is manageable but you may have more confidence in people's capability than at the moment I do, but that's all right. I look forward to seeing some written material on that from you, that will be most useful. John or David, any further questions? We have peppered their presentation with questions.

MR WALSH: Yes, I just have one more quick one. You follow the taxonomy of a national scheme. How do you see the scheme as running, as a fully national scheme or as a series of state schemes?

MS LUDLOW (CWA):   I wouldn't be in a position to answer that question at the moment.

MS SCOTT: Okay. That's fine. You might be interested, the transcript this morning will show that a number of people advocated, Donna and Tara, a greater role for local government. I think probably during the course of the last couple of days we have probably heard every variation under the sun, but it would be good if you also could form a view about how you'd like it delivered. Who you see delivery being through?

MR KALISCH: I just have two aspects that I would like to see in your submission. I'm still in questions now. One would certainly be the role and the issues for young carers. I think you're probably ideally placed to give us a perspective on the difficulties and also the solutions that might work for them. Similarly, you talked about the UN Convention and I think it has been a recurring theme and we have heard a lot of different organisations.

I suppose we have been providing people with the challenge back as well, in terms of, "Yes, we all see the UN Convention and its aspirations and its ideals and goals," but I suppose what we'd like to see from yourself and from other groups is what that would actually mean in practice, what are the practical ways in which a scheme would be designed that actually meets those fairly aspirational objectives. So if you could back to us on that it would be very good.

MS SCOTT: Thank you very much for a very thought-provoking presentation. We are now going to break for afternoon tea. We'd like to resume at 3.40. Thank you.

MS SCOTT: Good afternoon and welcome to the table, Samantha. Would you like to indicate whether you're representing a group or yourself and would you like to make an opening statement?

MS JENKINSON: Thank you. My name is Samantha Jenkinson. I'm representing myself today just as an individual. I have given some brief points to the commissioners previously. I really just wanted to raise a couple of points from the paper that I put in. I would start by saying that, yes, as an individual my experience living with disability is actually not necessarily why I'm here but more my work with a range of people with disabilities in policy and advocacy.

My own situation is probably fairly unique in that I have had a lump sum payout from a motor vehicle accident. I believe I'm one of the rare people that has actually managed to over 20 years manage my funding myself well so that it's still supportive of me. That's with a system where there hasn't been any support necessarily in place to do that. So I just thank goodness for my mother and good advice.

MS SCOTT: Thank you.

MS JENKINSON: Some of the points that I'd like to raise, there's so much, but what I've done is just split it up into eligibility, assessment, what gets funded and how funding might get distributed, indirect support systems and participation. In terms of eligibility, I was very conscious in thinking about what I might want to put in a submission. The difference in eligibility based on diagnosis and eligibility based on need, and I'm sure that you've heard about this before but, as I point out, somebody's needs are not necessarily related to their disability or their diagnosis, it's often a very contextual thing.

I'm also very conscious of some of the issues that we have currently with the system of people going through multiple assessment processes, which is why I have put forward that keeping eligibility simple is actually a better way to go in an assessment process then worrying about what support people might actually get or what funding they might get, rather than having it all tied up in the eligibility which then involves multiple processes.

I also think there's lessons to be learned from some of the ways that things work in the Disability Services Commission here in WA in the way LACs work, in that people being eligible for funding or support doesn't necessarily mean they're going to get funding or support, but they can get eligibility for information and for planning and for those other sorts of ancillary support services and I think that's a really important point and this also I guess goes into the assessment for funding, both in the community living and initiative in WA.

When I was working for Department of Human Services in Victoria I found that - not for everybody - there were groups of people who actually had the opportunity to go through a planning process and have someone who could spend time with them thinking up creative ideas, brainstorming, getting to know what were their issues. It wasn't necessarily about funding, it was actually about having that type of support, which is a support that still needs to be funded but not necessarily about getting direct funding.

In terms of the assessment for funding, I would support the submission that I know In Control Australia is putting in in terms of there needs to be some form of self-assessment as part of the process for assessment. I have been lucky enough that I haven't had to go through some of the major assessment processes. But as a social worker I have had to give them and sometimes, in reality, you skip a lot of the stuff that's on some of those pages because it's not relevant doing a 20-page document to assess somebody's needs; you have a chat to them, is what actually happens.

I think that the resource allocation system used in the individualised budget system in the UK is a really good example of where funding bands can be used with a points system. I think even at that assessment stage actually having the support people in place that can assist with those sort of processes is really important and it really makes a system work. You would know that from hearing of issues where people miss out on finding out what is available, that sort of thing. So the LACs are actually quite a good model here in WA for that.

Having been through a hospital system myself, I actually wonder about using something like a multi-disciplinary team similar to the aged care assessment team when you're going through that hospital process. Certainly I know there has been research done on people who acquire injuries. Here in WA there's some research - I'm not sure if it's actually available yet - that the Insurance Commission of WA did which looks at that whole issue of people really not knowing when they leave the hospital system what is available for them, or they're waiting to know of which system they're going to be a part. So I think there needs to be that sort of multi-disciplinary approach at that point.

I guess the other thing to note there is that certainly with an acquired disability it can take a year or two before it actually sinks in that you might need support and might need to find out about the systems that are out there. I think that individualised funding is the way to go. I have worked in the Victorian system when they introduced individualised funding and actually worked specifically on the direct payments, when that started there. Here in WA everything is individualised, in terms of it's disaggregated, so everyone knows how much their funding is, and that doesn't necessarily mean everyone gets an individualised service.

I actually think that when Victoria first approached individualised funding they did it in a much more systematic way, in terms of getting a range of management options, and I think that's an important point certainly that needs to be highlighted in terms of the discussion paper from the Productivity Commission, that individualised funding isn't necessarily about that you can't use traditional services, it's about people knowing what support they have got, what the funding is and then choosing a range of management options. So it's not that people who don't want to manage funding would miss out.

In my paper I go through a number of the different options that I think could be used in a system that was more individualised. Certainly when I worked on the direct payments project in Victoria I was the person in the trial that had to go out and do the auditing of all the participants in that project and even at a three-monthly sort of accounting and auditing process it's a lot of work and a lot of resources. I think that's something to be really wary of. One thing I thought that worked very well there was - because people's bank account was with a particular bank and gave viewing rights, not necessarily to do anything but just be able to view the bank accounts of those people who had individualised funding, there was the opportunity there for using technological systems that might be able to keep a track in terms of if people were overspending or underspending to then be able to follow up and why that might be the case. So I think there are mechanisms that can work there so that you don't need onerous accounting processes.

One of the other things that I've raised is indirect support systems. As to how it might all work I'm not sure but ranging issues about - one of the things which has stopped individualised funding working well where it has been in place and hasn't worked well is actually there is lack of the capacity building type supports, so people actually getting trained and educated. A lot of people with disabilities and families are coming from a background of being disadvantaged, poor, powerless, not used to actually making those decisions. So to expect that people might just jump into a system is, I think, a bit silly. There has to be some of those capacity-building things in place.

Another thing which I'd highlight from the direct payments project in Victoria which was really good was actually bringing along mainstream consumer affairs groups to actually talk about consumer rights and knowledge of contracts and things like that, which I think assisted a lot. But I think that's also - talking about availability of information, advocacy and a lot of those - I've called them indirect support systems but that are really important, and that includes the community development work. Again, I think MetroAccess in Victoria is a really great example of community development model. I think the LACs are a good example of community development but I think they both miss sections and that actually they could quite complement each other, if you're looking at different aspects of different systems.

Whether the funding for that would be through the tax that might be what the direct support costs are or whether indirect support costs might actually stay funded through what is currently the funding level through state systems and direct support costs only are part of what a new scheme might be might be one way of looking at it. But certainly there has to be those sorts of supports in terms of advocacy, complaint systems, ombudsmen that are independent.

MS SCOTT: Could you comment on the Victorian system? Would that be all right if I interrupt your testimony for a little bit to - I mean they seem to have a number of safeguards. Do you think they're adequate?

MS JENKINSON: I think there are some issues with some of the safeguards that are in place. The legislation which set up the disability ombudsman, which I think one of the great safeguarding mechanisms they have, limits the complaints. It's a bit ambiguous but there seems to be a limit to the complaints being only through service providers that are registered with the Department of Human Services. So if people are using individualised funding and using a mainstream nursing agency or something then it's unclear about if they had a complaint around that where they might go. I mean obviously they might use normal advocacy services, as anyone else. But I think that that was always a bit of an issue for me in that not being clear. I sort of thought it would be better around a disability ombudsman that's not specifically about disability services. You might say that that might be covered in equal opportunity law but most equal opportunity law and disability discrimination law actually doesn't cover direct disability services.

MS SCOTT: Thank you.

MS JENKINSON: So there's a gap there.

MS SCOTT: Thank you.

MS JENKINSON: I guess just my last two points were just I quite like the fact that one of the things that WA has is the Disability Services Commission is set up as a separate body with a board which includes people with disability and family members that I think that's actually quite a useful governing structure to take note of in terms of the participation and involvement of people with disabilities at all levels, but in particular at that governance level.

In my vision I would like to see that actually the money from insurance models comes into - whether it's a separate bucket behind the scenes but actually that we only have the one system because certainly my work as a case manager in Victoria was very much always hearing about how people wished that they'd had a car accident rather than been born with a disability. I don't know if necessarily this would ameliorate that issue, having a separate scheme that was still separate, you know, where - particularly as my own experience and many of the people with disabilities that I've come across in WA who have had accidents and get payouts, they actually become a little bit isolated from the rest of the disability service system, which has a whole heap of supports that people who have had accidents don't necessarily get access to in terms of the social supports and emotional and - just that information-type support, because it's a different system. It just seems silly to have two things running parallel.

MS SCOTT: Thank you very much. John, would you like to lead off?

MR WALSH: Yes, thanks very much, Samantha. I think you're in a very unusual and perhaps unique position in being a social worker and having worked in both Victoria and Western Australia, which are the two individualised funding states that are most advanced, it seems. My question relates to - there's certainly partly an endorsing issue here in that we've heard from other people today who sort of hang out for the package and if you don't get the package you effectively don't get very much at all but if you do get the package you can then start to purchase services. Given this rationing I'm interested in what the size of the package actually looks like and whether the individualised support packages that are available in Western Australia and/or Victoria are sufficient, too big, not enough. Can you make some comments on that?

MS JENKINSON: I can't make any comment from my own experience in terms of myself but from what I know I think that there's - compared to Victoria I know that there's some very large packages of support here in WA but probably not as broad in terms of how many people are supported. When I worked in Victoria it was when the individualised funding started out. So all new funding was going into that model. I know I worked in southern region and we had, I think, 180 people who got new funding ranging from $5000 a year up to $80,000 a year.

What we found - because one of my roles was actually looking at the plans that came in and approving them or not, which was very difficult, but there were certainly quite a few people who were in that $5000 range that didn't need a lot of support but just needed enough that it didn't become a crisis situation. So I wonder sometimes if they're actually being missed out here. So I thought that was actually a good - I mean and they're the people that probably wouldn't be classified as severe and profound but they still need some level of support. But having that planning process even in itself provided a modicum of support that could assist.

MR WALSH: Okay. Any other lessons learned around how to assess or approve the size of the - do people ask for more than the packages can give, typically?

MS JENKINSON: I think there was a lesson learned in that at first we didn't tell people how much funding they had to plan towards. That didn't work very well. It actually worked better when people knew how much funding they had to plan towards. That didn't necessarily mean that you suddenly got people that didn't need funding asking for funding. What it tended to be more reliant on was actually the facilitator, the person who was supporting them to do the planning process. That was actually the key sort of crux point as to whether people went more creative or not. It was really - it's sort of, I think, quite a highly skilled position but not everyone was as skilled as we would have liked.

MR WALSH: Yes, and in the same vein have you got a view on the self-assessment process in the In Control model in the UK?

MS JENKINSON: What I like about it is it takes into account informal supports but also the willingness of informal supports, from what I know of it. I don't really know a lot about it, only what I've heard and read. But I guess one of the things that I found in Victoria was because the planning process was also the application for funding process, it was - there was sort of a very ad hoc assessment done through intake and response teams which gave people a banding level of funding and then an in-depth planning process. Often people really didn't talk about what their needs were until that in-depth planning process and didn't necessarily feel in control of the initial assessment process because that was being done through an intake and response process, which is very much a sort of gate-keeping role.

So I think the idea of the self-assessment model I guess philosophically has a resonance in terms of it being simple but it also being straight out with the person saying what it is they think they need. My understanding is that usually people under-assess themselves and that it needs to be done sort of in conjunction with a case manager or facilitator or someone like that in terms of if people under-assess, because it was more likely people under-assessed then over-assessed themselves.

MR WALSH: Thank you. It would be really helpful if you could explore those things a little bit if you're going to do a written submission.

MS JENKINSON: Yes, I will be doing a more detailed submission.

MS SCOTT: Thank you. You might be one of the few people that we can get on-the-ground information from, so that would be good. I just wanted to come back to the different elements in that process in Victoria. Intake response, you know, it's almost like, "This is your assessment of needs. Fred, we've assessed your needs as equivalent to $20,000. How do you think that money would be best spent on you?" and then somebody does a plan.

What happens if somebody - you work out the $20,000 on the basis of, I don't know, a bit of speech therapy, attendant care, they need to get out and about, they need to have a break from their family supports and their family supports need a break from them and so on. You work out 20,000 is the thing and then someone goes away and comes back with a model which looks pretty good but doesn't have any speech therapy in it or doesn't have - you know, you made the assessment on this basis and worked out the dollar figure but then when they did their individual plan they came back with a different configuration. Now, was that level of self-direction - was that encouraged, tolerated, desired? Was it, "It's all right if you leave speech therapy out," or would you say to someone, "Gosh, you seem to leave the speech therapy out. Can we just put that back in and cut down the time that you've got for something else?"

MS JENKINSON: I think one of the things that - that probably didn't happen too often but sometimes did where people came with plans that were out there, and I know some were really out there. But what we did - I mean what my role was, actually, was to look at plans prior to them coming to the funding panel and discuss with the facilitator if there were maybe things missing, but also if - checking on their processes if they had really been person-centred and looked at the whole thing.

We were more likely to err in the case of going with what the family or the person themselves had decided. I think that that's - I mean I guess a good example is for myself I would never - I wouldn't waste my time going to physio but I've found that actually doing singing is a really good therapy for me in terms of my breathing control and I do that. So if it was those sorts of things we would actually encourage more of that rather than necessarily looking at specific therapy services or traditional models.

I think one of the things that came up, certainly for me, is that there were areas where because the rules were more fluid in terms of what people could use the funding for. People could use multiple service providers if they wanted to and things like that because the initial system was set up with using a financial intermediary like a bank where the bank held the money. The financial intermediary held the money and invoices went to the financial intermediary who paid them and then sent a statement about how much funding you had left. It meant that people could use two service providers if one of them wasn't meeting their needs or get equipment plus a service, plus a this, plus a that.

We actually found that there were quite a number of times when people were requesting things which haven't normally traditionally been covered in funding that are actually quite legitimate costs in terms of disability support. So we had a lot of people who needed funding support for transport. It's something which in the traditional model had not been funded but it's actually an increase in cost that people were finding it more and more difficult to actually be able to get out in the community and do all the things that we kept telling them they needed to do: be person-centred, get out in the community, have community access, "But sorry, we can't pay for transport." So it was those things which were actually coming up a lot even in some of the like $5000 a year plan. Sometimes it would be - that would be the main thing.

MS SCOTT: Yes.

MS JENKINSON: But it was also because the planning process then helped them to connect to say being a volunteer or other things which didn't need funding. So it was a bit of a gains and losses there, I think.

MS SCOTT: Okay. John, I heard during the break that WA - well, the advice I got was that WA has now discontinued new packages as a result of some problems that seems to have arisen in funding packages. Sam, you can't fill us in on this?

MS JENKINSON: Look, I only know what I've heard and I've heard different stories from different sources.

MS SCOTT: Okay. I'm meeting with the WA officials tomorrow so I might have a chance to learn a little bit more.

MS JENKINSON: Yes.

MS SCOTT: I mean it would have been a few bumps in the road in the Victorian rollout, wouldn't there?

MS JENKINSON: There was. I think what worked - I mean some of the issues I think here were around the support people got for accountability processes. I think there might have been some issues around what people might have been spending money on in terms of family members which is where I think that the Victorian model actually went a little bit more systematically in terms of addressing those sort of issues. Certainly in the direct payments project because we did it as an action research project with a trial group of people who were all willing to do it and who actually developed the policy with us as we went along, a lot of those sort of issues about accountability and what sort of support do people need to know how to be accountable if they've got the money themselves were actually addressed through that stage. I mean I wrote the manual on it, so - but certainly there was a lot more. As I said, we actually invited Consumer Affairs in to talk to people about contracts and about consumer rights. Members of the group who trialed the project, they came up with some tools themselves of spreadsheets and things so they could keep track of funding. Having the remote viewing of the bank accounts actually eliminated a lot of that issue in terms of accountability.

MS SCOTT: It looks very clever. Well, I'm finished with my questions. John, how are you going?

MR WALSH: Look, that was really good, Samantha, and we look forward to your submission.

MS SCOTT: Yes, thank you very much.

MS JENKINSON: Thank you very much.

MS SCOTT: We have another Samantha now and invite you to come forward. Thank you very much for attending this afternoon. Would you like to identify yourself and indicate who you're representing or whether you're speaking on your own behalf.

MS CONNOR: Sure, thank you. My name is Samantha Connor. I'm presenting from the range of my personal experience as a parent of two children with autism. I am a person with a degenerative physical disability and the manager of post-secondary disability services area. My co-presenter is not here because he's currently locked in his home. Darren is a quadriplegic and has had an interesting incident where he has shot water from a drink bottle into the mechanism of his electric door and he'll be trapped for some hours; that's his excuse. I think it's far too clever to not be real. So Darren has given me permission to speak from the range of his experience as well. Darren and I were childhood friends from the age of birth and Darren has an acquired physical disability from when he was shot in the back of the neck when he was 11 years old. Darren was also a rural person. I moved out to the country a little bit later on.

The area that I service as a manager of a disability area is the size of Victoria; so it's the wheat belt of Western Australia. To give you an idea of the length of the distances, two of our campuses are six hours apart. So in order to service all of our students we find it extremely challenging, and obviously there's challenges for students who are attending campuses that are so far away when you're looking at lack of public transport, availability of taxi services and availability of personal care. So the areas that I want to address are eligibility, needs assessment, control of services, early intervention and what should be done in regional and rural communities.

One of the areas that I'm heavily involved in is of parents with autism and the autism spectrum disorder network. So the use of the term "severe and profound disability" as a reference point for eligibility is something that's come up really strongly with all of these parents. So they have really big concerns. The scope of the review is to an approach which provides long-term essential care and support for eligible people with a severe or profound disability. The issue is, for a lot of these parents, about the way that we define disability and the disability not being intrinsic to the individual and defining who we are. So it's not about the medical model of disability, it's about the social model of disability; that disability is an evolving concept. It results from the interaction between people with impairments and attitudinal and environment barriers that hinder their full and effective participation, which is the United Conventions definition. So we're talking about systemic barriers, negative attitudes and exclusion by society being the ultimate factors in defining who is disabled.

It's really, really hard to quantify who should be eligible for the new scheme. I should make you aware that we're doing a consultation at the moment. So we're consulting with people in the prison system as well, which is about a third of my students with disability. Also some people in the wheat belt of Western Australia and regional and remote Western Australia. So it's a little bit challenging at the moment. So people's needs differ really differently, from the evidence that we've collected. Depending on their individual circumstance; their environment; the level of available support, which is a really big thing for people in the country; geographical location; culture; the individual's goals, aspirations; and a host of other variables.

The discussion has been around whether we should discriminate against people with disability by creating another division or hierarchy of disability, or whether we should be including all people. We're really aware of the challenges involved in dollars. So the fears that I've heard articulated amongst many service providers and people with disability and their families is that the government will look at the depth and breadth of the issues and decide that the bucket of money required is just too scary and that they will do nothing or that they will do it in a limited or restricted way, or that they will get it so wrong that people will be worse off than they were in the first place, or the people that need the help the most may not get it and only the loudest voices will be heard and considered.

There's been really big concerns in WA amongst the people that I've spoken to in the wheat belt that a lot of people in regional and remote areas won't be aware of this inquiry and that their voices are the very quiet voices that really need to be heard. The feeling is that the voices that will be the loudest are the people who are struggling through their day-to-day lives to find desperately needed services, the service providers who are aware of the issues within the scope of their experience and location, and the disability advocates. The quiet voices may be the people who may not see this inquiry as being relevant to people with disability. Sometimes some of our students who may have mental illness don't see mental illness as being a disability issue; it's a health issue. So they're the kind of issues that we're hearing about.

People with mild intellectual disability who are partially independent, but when people with mild intellectual disability live in the country they're in a different circumstance. People who live in rural and remote areas, people unconnected with services. That's the type of people that we're trying to find at the moment, is the people who aren't hooked up with services already. People with conditions that are considered severe and profound who may have high support needs, and people who don't fit into a neat category. By effectively shutting out those people who don't fit neatly, we are precluding those people and their families from the opportunity to contribute towards our economy and communities through work and other forms of participation.

I've been getting stories from parents of children with autism and I have about 20 a day, so I can just pick one to share with you. The really big concerns that parents of children with autism spectrum disorders: the diagnostic criteria for disability services is quite varied. Depending on where you are and what services are available - for example, I live an hour and a half out of Perth, which isn't a great distance really and I choose not to access services for my child, but there's another family who accesses services five days a week for their child who has a similar level of impairment and the cost to that family is extraordinary. So you're looking at the travelling time - there aren't the services out, an hour and a half away from the city, and even just being slightly regional really impacts upon a family.

So one of the stories that I received yesterday was from a lady who says, "I have four on the spectrum ranging from 28 to 18, all of whom have been diagnosed and all of who have comorbid disabilities, with three in the moderates to severe range. I think a scheme should include all of our kids. If it doesn't, then change it. Just let us know when and where so we can work as a coordinated team together. In my case, for two of my children I'm fortunate to have brilliant, empathetic, caring case workers who have given their all support not only to children but my family. Off the top of my head, my two youngest will slide through these processes as one has epilepsy controlled, intellectual disability moderate and autism moderate to severe and is attending local TAFE programs for literacy, numeracy and computer skills.

My youngest daughter has autism moderate to severe, intellectual disability, cerebral palsy and epilepsy of such proportions that during one of many a severe seizure at her school she set off the other students and half of the school grounds in raving hysterics. At that point the school politely suggested on days when she was "not too crisp" she would be better off at home. In all honesty I agreed with them as she wears nappies full-time and she needs daily physio. Our psychiatrist estimates my daughter's mental age operating at a three, maybe four-year-old level. Our life is a whirlwind of doctors, specialists, psychiatrists, case workers, et cetera for all of our children. I should mention at this point the government has changed the incontinence scheme. How this will work out will take time, however I'm very glad I stocked up on blueys and mattress protectors prior to this."

There's a really large group of people who have children with conditions like Asperger's Syndrome who wouldn't fit into this category. I have an older child who would be a good example who failed dismally in high school, slid out of year 11 into a $70,000 a year job as a network administrator at a university, failed after two years because he can't live independently. So they're the kinds of issues where people don't fit into neat boxes. In postsecondary institutions quite often you have classes like multi media classes at TAFEs and they're full of children who have autism spectrum disorders, because there's no other place for these guys to go and the workforce can only be filled with so many computer programmers. There's some really interesting stories that have come out of this.

One of these other mums, who has two children with autism, because of the diagnosed lack of severity of the children's disabilities compared to the criteria, only receives $50.30 per week for each child, in the form of care allowance from Centrelink, "Having two children with disabilities means that I need one very competent carer to care for both of them or two carers, which becomes extremely expensive."

Dell also looks after her ageing mother, so she has $150 a week with her Centrelink allowance for the children. She is actually not in the country, but we asked her what kind of benefits would actually assist and what things would help her. She thinks, as Sam was saying, ancillary incentives such as having mortgage rates held at a lower level and those kinds of ancillary benefits would assist; you know, if you have a family who has one income and with their earning capacity they're unable to pay off their homes, that kind of thing, looking at the different ways that we can support people.

There's concerns around the inquiries focus on people with severe and profound disability as measured by frequency of specific and measurable interventions in their lives. If you don't have access to services or you're not aware that you need those services, how do you measure those needs? A large number of our students who disclose that they have an intellectual disability and are incarcerated have access only to mainstream prison services. Similarly, Aboriginal people who live in rural and remote areas and who are disengaged from and cannot access support may be at risk of being shut out by this scheme.

One of the key questions is, "Which groups do you consider to be the most in need of additional support?" The answer that I have got across the board is that there's only one group, which is the human race, there's not any groups of people with disability. There's no doubt that our country has failed to support people with severe and profound disability. We know there is a significant problem for unmet need with respect to the provision of support and assistance for people with disabilities and their families. There's no two identical people, and this leads to issues for people designing a perfect system, because the system has to be based on need and has to be broad, flexible and responsive rather than neatly categorising people, which is hard to do.

The vastness of rural and regional Western Australia adds a further dimension to that issue, and I think one of the speakers today was speaking about the tyranny of distance. In many areas there are no services or few services available for people with disability. In addition, families and individuals have different perspectives on what their care and support should look like. For example, one family who has a child with autism may consider the child's diet inclusion into special school therapies of paramount importance, while another family may not consider those interventions to be beneficial or necessary.

They may not live near a specialist school or their child may be precluded from attending a specialist school because of sensory issues, with transport et cetera. If you're living in an area where you're an hour away from a school bus and your child spends an hour banging their head against a window - that's my family - they may consider it to be important for their child to be included in mainstream schooling. A transformational scheme needs to be broad, flexible and responsive enough to encompass the diversity of disability and people's individual goals and circumstances; otherwise it's not a transformational scheme, it's just a project.

People with conditions such as autism spectrum disorders, people with mental illness, people with degenerative conditions and people with acquired injuries like spinal cord injuries, head injuries or amputees are an example of people who all have changing levels of need and may not be included under the current proposed scheme. The scheme needs to be universally designed with a firm set of principles in place prior to the scheme design taking place or it won't work for many Australians.

A lot of the feedback that we have had is about the set of principles and the importance of having a really strong underlying set of principles. The other feedback from Western Australians is that the things that they feel work in Western Australia work because of those principles that they have in place, and we have heard that over and over again.

MS SCOTT: I wouldn't mind having an example of that, how the principle translates into something that you can eventually hold a government to or a service provider to or whatever, because when we were in Queensland a number of participants said that they could refer to wonderful documents and very lofty sentiments but what it boiled down to was there just weren't enough resources and they were always told that somebody else had a greater need.

MS CONNOR: I think obviously with the scope of what needs to be done it's going to be an ongoing issue. I think that all we can do is strive to attain there. If you strive to attain mediocrity you're probably going to achieve it. It's the principles and the ideas - I don't want to sound like a plug for the Disability Services Commission, because I'm not - especially with the guys that we have, like our local regional manager who is one of those people who firmly believes in inclusion, firmly believes in people with disability having a say and lives those principles every day - and it's about having those people who really do what they mean and that are not just doing it for the sake of doing it.

It's a hard question to answer, especially across the scope of Australia. I'm sure you'll be examining all of the systems and all of their principles and what they have in place to carry them out very carefully. What we need is a comprehensive and holistic needs assessment of all people with disability and a fair allocation of resources. Needs should be determined on an individualised basis. My feelings are that consideration could be given to the use of a points system - and this is off the top of my head, not from the basis of anything other than just my own experience - to assess need so that people can be given the opportunity to make real choices about their care and support and that people with disability and their families are the only real experts on what are their needs.

The can be advised through a transdisciplinary approach about available services and benefits, but self-assessment should be an important part of any needs analysis. Transdisciplinary rather than multidisciplinary where you have a holistic approach I think is really important. Self-assessment doesn't mean putting a person or a family in a place where they tell you how rubbish their lives are - and you've probably heard that as a recurring theme - and how much they need, in response to that statement. That won't empower people with disability and their families to move beyond their current situation. A better approach is to ask people with disability and their family what their current situation is, where they would like to be in five to 10 years and what would help them get there along the way.

Planning is an important and integral part of what we currently do with varying levels of success in WA. I understand how difficult planning is. I have six children between the age of 12 and 24, and if you ask anybody to plan the life of a 17-year-old boy for a period of time, it's a difficult thing to do. I'm mindful of a discussion with our regional manager recently where he was talking about a family of children with Batten's disease - which is a syndrome where children actually don't have a long life expectancy - where he went to plan with the mother, and the mother said, "What's the point?" He said the children lived, unexpectedly, to be 30-something. H said it with this glorious smile on his face. He was so happy to have been able to have been of assistance to that family.

MS SCOTT: Samantha, I'm just conscious we're going to run out of time. We have asked a few questions, but I have got one or two more to ask. We have got your written paper. Would you like to think about maybe two points you want to draw out now as a conclusion. Know that I have read it, because it's highlighted. You don't need to read every word, but maybe just pick another two points you want to talk to.

MS CONNOR: No problems. I agree with Sam and In Control Australia's perspective advocating a funding support system that provides a range of supports for management of funding, planning and purchasing of services. We do have some students who very successfully in the wheat belt manage their own funding. We have a young lady with physical disability who employs some innovative type of solutions where she, for example, doesn't need care all night. She has quite high support needs and she had quite a high package. She employs friends to go and take her shopping or to stay overnight, this kind of thing.

So it's about having that creativity. In areas like the wheat belt where there aren't those services available it's really important for those people to be given that flexibility and creativity. The other thing is the focus on early intervention. Early intervention is really interesting and it's just a bad word sometimes for parents of children with autism, because the early intervention scheme was quite a big one, also the autism schools. So there was quite a lot of backlash for parents of kids with autism. My children were precluded from those programs because they were too old. There's also a lengthy diagnosis process, in which you can be quite a few years on the waiting list. So that's sort of just another point about early intervention, that it's not everything to everyone.

MS SCOTT: We will have to check this out, I'm not a doctor, but a number of people have suggested to us that the plasticity of the brain, people are increasingly coming to the view that interventions can be successful at other stages in life.

MS CONNOR: Just a really quick last point. The things that we hear - and I have just packaged all of the concerns that we have from parents and people with disability, the same frustrations and complaints we have over an over again. "We don't have access to services because of difficulties with access to a timely and accurate diagnosis within our budget restraints." "We don't have access to services because of difficulties with accessible transport and the cost of transport for people with disability, especially if we live in a rural or regional area."

"We might have access to services, but they are often staffed by people who are inadequately trained or in positions which are underpaid, attracting people in the short term and not attracting people who are trained to do a really hard-to-do job." "We don't have access to services because of the cost of disability and the impact upon our lives." "We don't have access to services because there aren't any in the area where I live," especially in regional and remote areas.

"We don't have access to services because we didn't know what was available." "We don't have access to services because we are unsupported in other areas of service provision, for example cost of personal care needs and access to equipment precluding participation and employment or education." "We don't have access to services because the type of service that we require isn't suitable or doesn't exist and we don't have access to innovative, flexible or responsive programs that will fit our needs and enable us to self-advocate, be well-informed or reach our full potential."

MS SCOTT: Thank you very much. We have got many different focuses on this issue. So it's very interesting to have you come along and present today, and I'm very grateful for the written material you've provided. One of things you mentioned on the way through is that there may be people, particularly in remote and rural areas, who may not actually be accessing services. Could you talk a little bit more about that? What is your experience with that? We have already got gaps in our data anyway. Maybe the gap is in fact larger and there's a greater number of people who may respond to the introduction of a scheme by coming forward and asking for services, and we didn't know they were there, we didn't anticipate their demand. Could you talk about that, from your experience?

MS CONNOR: My experience in a service provision or from an education provider is limited to the wheat belt and I think that there's people who are better placed. I know there's a lady named Rhonda Murphy who is doing some consultation for the DDC and for the coalition in the far reaches of Western Australia, and I think there will be some really interesting information that comes out of there. The issues that we quite often have are predominantly transport; transport is always a really big issue. Personal care.

In education, for example, we are fortunate in that one of our campuses has a hoist, but for most people with a physical disability attaining educational services in a facility that isn't equipped to suit their needs it's just not attainable. You always hear the same access stories about heritage-listed areas and people not being able to access education and training, or workplaces, those same issues over and over again.

There's issues around people who have been born in an area and they may be a fourth-generation farmer and they have always lived on the farm, their mums and dads have lived there, and they have a child with a disability and the expectation is that they're going to uproot their entire life and move to Perth. That's just not achievable for those people, because it's their whole identity. So if you took those people, in order to access the services that aren't in that area, down to Perth they really wouldn't function and would probably be less supported in order to access services. So they're the sort of things that we hear all the time.

Just in the education area, we have a place called Moora, which is quite a few hours away from anywhere, and we have had some students with very high support needs who have been enrolled quite happily by our college, but we're very aware that there's a very big compromise because there's no other services available in town. So quite often TAFE and postsecondary institutions are quite often looked at as respite for families, and whether it's going to be beneficial to the individual who has actually enrolled there is something that is not our decision to make but it's one of those things that comes up time and time again. It's about building community capacity and trying to come up with creative solutions in a flexible and responsive way.

MS SCOTT: Thank you. John, do you have some questions for Samantha?

MR WALSH: I have been though your written response as well, it's really comprehensive. So that's really useful.

MS SCOTT: I think you might be finished. So thank you very much. Sorry, just before you go, you mentioned you've had I think about 20 responses. You're going to bundle them altogether, are you?

MS CONNOR: We are. TAFE is actually undergoing a research project with some of the funding available from AFDO. It's quite a difficult thing at the moment, we're trying to capture the wheat belt experience of people with disability but we're also trying to look at people who aren't actually engaged and connected with services already. So you'll see our submission come through just before 16 August.

MS SCOTT: All right, and I wish you well in that. Thank you for coming along today. That's great.

MS SCOTT: If Erik could come forward please. Before we start, could I just have an indication now if there is anyone in the audience who would like to take advantage of an opportunity to speak at the end of Erik's testimony. Is there someone who would like to say something? People are pointing at other people. Is there any one person who might be considering doing it? Yes, we have got one person there, and maybe one other.

Erik, thank you very much for all your very comprehensive written material. I have had a look at that. I don't know if John has had a chance to have a look at it. You're down for 20 minutes, so we might get you to stick to that, and then we might have one, maybe two people coming forward to make a few brief remarks. Erik, could you state your name for the record and indicate whether you are speaking on your behalf or for an organisation, please.

MR LEIPOLDT: Yes, Erik Leipoldt is my name. I present this as an individual presentation. Thank you Mr Walsh and Ms Scott for hearing me today and also for reading my paper, which is quite long, so it's congratulations on doing that. Under the assumption that you have read my paper, I'll just give a brief summary and perhaps you might have some questions for me. I start off with the importance of an overall value system or a set of principles. Some time ago I spoke with a parent of children who have quite severe cognitive impairment and she, on having read some of my material asserting that a value system is important, said to me, "Yes, but it's not important to my children at all, because they haven't got a clue what values are. If I talk to them about values, it doesn't make one ounce of difference to them," but of course it does make a difference to them as they come across people in educational facilities or respite places or when they go into the community when people display behaviours towards them that are definitely based on some sort of values, whether they are overt or not.

So it does matter to have an overall values system and that's true in the life of a person as it is for any scheme like this scheme which I've called - which I think is the correct terminology, the national disability care and support scheme. I think it's important for that values structure to be overt rather than opaque or not overt. I have proposed what I think is the underlying framework of economics is not the best framework to use in dealing with a scheme that is essentially about care and support.

So my first point is that a scheme like this one must be grounded in an overt belief system and I think that should be something contained in the UN convention or also similarly in the World Health Organisation definition of disability, which is about the interaction of attitudes and values, the environment and the impairment in the things that arise from them, constituting the experience of disability.

Secondly, I am suggesting that an alternative framework wherein economics would definitely have a role, because economics is a part of life, but wherein the values expressed in my first point would be the driving force in looking at a scheme. I suppose the adoption of Joan Tronto's framework, which is a framework of care that's been around for about 25 years, well critiqued, there's quite a body of literature on it now and I've set out in my written submission what that framework is about. Essentially it's about recognising a need, taking responsibility for that need, doing so competently and doing it in a way where you're actually responsive to the results of the actions, the caring actions, and in a participative way.

So any scheme like that does need to be grounded, as this scheme would, in any case, in an agency of what fundamental human needs are. Certainly in a scheme that's been articulated as a needs-based scheme I would have thought that an articulation of what needs are is fundamental in order to be effective and to have a measure of efficiency, so you know what you're actually doing benefits people's needs rather than what might be demanded or might be wishes or what anyone else might think that needs are. Together with that there should be an appreciation of the nature and impact of a state of heightened vulnerability that many people with disabilities have, in constructing what that need might be. That goes for an overall values framework as well as an assessment of individual need.

I think, talking about vulnerability, there should definitely be a factoring-in of the likely impacts of climate change, because there's quite a lot written about the likely impacts that are of socioeconomic and environmental nature and certainly on vulnerable people that include people with disability. There are some studies on that that the Disability Services Commission has commissioned, for example. I think there should be an attention to real participation at all levels of a national disability care and support scheme, including in the services or service approaches that it might fund.

There should be an attention to capacity building - we've heard quite a bit about that - of the primary stakeholders towards the most effective way of participating and also in what is essentially the building of community around people and family and carers. We should have an examination of what are the underlying causes of the service system that is said to be dysfunctional, because if you don't know what those underlying causes are, and I would suggest they are more than a shortage of money and being crisis driven, then you're not necessarily going to know what it is that you should do about making it better and deliver quality of service. We need a real change.

I think importantly there should be attention to positive story about disability. In some parts of the preliminaries towards this scheme there have been some examples of what I say are negative expressions of the story of disability. In getting this to happen, in getting the acceptance of the public towards what is going to be something that's going to come out of their pockets, there should be a positive story what - would model what a national disability care and support scheme should be about. Just to take a step back on that, in saying that we should be looking at the causes of - the underlying causes of the dysfunctional service system we're going to be asking taxpayers to get money out of their pockets to do this. They deserve to know, just as primary stakeholders deserve to know, what it is that we're talking about and what attention has been paid to those underlying causes.

There should be an attention to very strong safeguards in a national disability care and support scheme: how the scheme itself is constructed and how services and service approaches that it will fund - how they are safeguarded so that they will be delivering effective things that provide responses to need and will be safeguarded against providing things that could be of a further disabling nature.

There is a mention of a national disability research fund. I think good disability research is incredibly important and there should be a lot of it. But I just would like to caution against the notion that it should be a national disability research institute funded by the NDCSS. I don't think it should not be funded by this scheme but it shouldn't be a separate research institute. It should be something which supports present and emerging research centres, strengthening that so it can have a lot more of that and also preserving a richness and diversity of research in that way.

Last, I think that much has been said about a paradigm shift that this scheme might represent. I think some - has been hyperbole about this scheme but there is definitely a real need for a real change, but it must be based on the values that describe the realities of the lives of people with disabilities within the context of their fundamental needs and vulnerabilities. All that I have described I would hope would contribute towards a genuine paradigm shift.

MS SCOTT: Thank you.

MR LEIPOLDT: Thank you.

MS SCOTT: John, is it all right if I start off with questions?

MR WALSH: Yes, thanks, Patricia.

MS SCOTT: One of the issues that you tackle is - and it's a difficult issue. We covered it a little bit earlier in earlier testimony is the interface with the aged care.

MR LEIPOLDT: Yes.

MS SCOTT: I think heading 13 of your paper. Today when we had Carers WA presenting to us - - -

MR LEIPOLDT: I heard some of that yes.

MS SCOTT: Okay, that's good.

MR LEIPOLDT: Yes.

MS SCOTT: We had that discussion about, "Oh my goodness, how big do you envisage the scheme?" Quite clearly Carers WA envisage it being very broad and not having any age limitation at all so that if someone acquired a disability at age 80 they would be in the scheme and they would be in the scheme for life, just as if someone joined when they were two, 20 or 65. In your analysis you go to the other - I think you support the idea or see some merit in the idea of having a scheme as broad as Carers WA but then you draw back a little bit from that because of potential revenue implications and then pose the other challenging question which is, okay, so then you end up with two schemes, one which is a disability scheme and one which is an aged care scheme. Could you talk to that point, because it really is quite problematic. I haven't worked out which way I want to go. I'm just open to hearing your views on that point.

MR LEIPOLDT: Yes. When I talk about two tiers it's slightly different from - - -

MS SCOTT: No, I'm not confusing it with two tiers.

MR LEIPOLDT: Okay.

MS SCOTT: I'm talking about the fact that you referred to the fact that you could end up - it may depend on the size of revenue obtained from public levy about whether we would end up with a scheme going that brought - - -

MR LEIPOLDT: I get your point.

MS SCOTT: Then you seem to acknowledge implicitly that you could have two schemes. I'd like to talk about what it means having two schemes:

> I suggest that the inquiry pays attention to ways of enculturing both sides of that dividing age line -

so you envisage two schemes. I want you to talk about that issue, please.

MR LEIPOLDT: Yes, thank you. Yes, I think there's an enormous amount of expertise in aged care and some of that in aged care and disability and there's an enormous amount of expertise in what's often been called younger people with disability. Life is not like that, of course. There is no dividing line suddenly between one to the other. There is a merit in having continuity in the services that people get as well from one age group to another. I do think that it's good to preserve that expertise.

The way across that to me would be to somehow ensure that there is an overarching values system that is the same in the aged care area as it is to the disability area in the way that I have suggested, because much of the experience of ageing in discrimination and so forth is quite similar to the experience of disability. I can't see why there would be two different value systems applying to both groups. Certainly aged people with a disability would come under the same values system. So I'm saying that - again, that's the starting point that you'd have two systems but there'd be continuity between the two in having a values system and therefore all the mechanisms that might roll out of that and a dialogue between those two sectors. I don't think that an NDCSS should necessarily - certainly not in the first stage - try and tackle funding that area as well.

MS SCOTT: Okay, thank you. John, do you have some questions for Erik?

MR WALSH: Yes, Erik, thanks for your submission, which I've read as well. I'd like to ask some fairly fundamental questions, I guess, and that is around - the scheme - some of the points in your submission addressed the very difficult questions that we've got to face in the scheme such as capacity building for people with disability, attitudinal change throughout society and a pretty much fundamental change to the service provision system. I'd like you to talk a little bit about - some of this is chicken and egg. I think attitudinal change in society won't be achieved without capacity building of people with disabilities and also without a change in the nature and organisation of service providers. I wonder if you could just talk a little bit about how you see this evolving?

MR LEIPOLDT: Yes. Well, somebody pointed out to me when I came in here before that the principles that used to be part of the Disability Services Act 1986 no longer appear to be there. I think that was a very good framework and the way I suppose that we could have attitudinal change is to have a set of principles or a value framework that everybody adheres to, or tries to, and live up to - which is already contained in the UN convention and in the WHO definition - and by an ongoing and long-term process try and enculture, I've got some difficulty with that word as well, but it's sort of a cultural change, that we need people to think about service in very different ways.

I think that the care framework that I propose is a good practical framework towards that because it force people to think first of all in about - in ways of, "What is the actual need we're trying to meet here?" Then secondly, also importantly, "Whose need is it that we're trying to meet?" So it's not the service's need, it's not the carer's need - that could be important but separate - it's the person with disability that we're looking at. So I think that is a good, practical framework. I suppose that in terms of need we go to the work in the literature on what fundamental human needs are. They are the sorts of things that are all of our - that describe the needs of any human being, really. It's about safety and security and belonging and participation as well and human growth, all those things.

It seems quite complex and maybe it seems like utopia to be able to achieve that, but if you paid attention to practical ways in which to have primary stakeholders participate at every level of this scheme, which goes to the governance of the scheme itself as well as in the services and service approaches that people may be part of themselves - without asking them to become a professional service participator and take over their lives I think that's not what's needed either - then the scheme would be closer to what the lived experience of those people actually is and it's better able to be connected with those things that matter in the day-to-day lives of people with disabilities. In those ways I think that gradually we would get a change of attitudes. It's a matter of having it all written down, having ways of living up to it and having a closeness to the people for whom this is all about.

MR WALSH: I understand what you've described and that all makes sense to me. What you've described is a qualitative description of what people need. Would there be a need to translate that into a quantitative evaluation of what they need?

MR LEIPOLDT: Sorry, I missed that last bit, John, I couldn't hear you properly.

MR WALSH: At any point in time do you need to change the qualitative description of what people need into a quantitative assessment of what they need?

MR LEIPOLDT: Well, I think if you look at safety and security then there are a whole lot of things that you could talk about that would contribute towards that: a wheelchair, if you say that quantitatively; accommodation support, for example, is a quantity, I would say yes and no, I needs to be funded, you need a quantity of money for that - then all those things come into it and I see them as tools towards meeting those fundamental human needs. So a scheme would fund those sorts of things as tools towards achieving those human needs.

MR WALSH: So you would support - in our sort of design of this scheme you would support almost a mapping of qualitative needs to quantitative facilitators and in estimating the resources required that's a legitimate way to go, in your mind?

MR LEIPOLDT: I think it needs to be a combination of quantitative and qualitative because if you look at - for example, that group of people that might now fall out of the eligibility criteria such as people with mild or moderate cognitive or intellectual disability. As I have said in my paper, quite a number of them are found in prisons and do not necessarily need supports there of a quantitative nature. They need supports there of a very qualitative nature.

MR WALSH: Yes, so it's a combination of both. But in principle you don't argue with the description of qualitative need - - -

MR LEIPOLDT: Of course not, no.

MR WALSH: - - - married with a quantitative estimate of what that might require?

MR LEIPOLDT: Yes, I think quantitative estimate is certainly a necessary part of it, yes.

MR WALSH: Thanks, that's good.

MR LEIPOLDT: Yes.

MS SCOTT: Okay, John, well, thank you very much, Erik. I have no further questions. I don't think John has either.

MR LEIPOLDT: Thank you.

MS SCOTT: Thank you very much for attending.

MR LEIPOLDT: Thank you.

MS SCOTT: So now I invite anyone who wishes to come forward to speak to do so. Good afternoon, Greg. Thank you for coming forward. Could you state your name for the record.

MR MADSON: Greg Madson. I'm the president of the Blind Citizens WA.

MS SCOTT: Well, welcome to the table. You'd like to make a statement in relation to the inquiry?

MR MADSON (BCWA): I just would like to talk about what I think people who are blind or visually impaired might use as a scheme or a model. For people who are blind or visually impaired, their major disability is an information disability and that is access to information as far as visual material goes, access to information when it comes to transport, and those sort of things. I can see where at the moment somebody who is blind or visually impaired needs some skills to navigate their community when they firstly become blind or visually impaired. They access the service provider. That service provider might allocate an orientation and mobility trainer, somebody with the qualifications and skills to teach somebody who is blind how to navigate without the use of sight.

Sometimes those resources are quite limited, given that there are not a lot of mobility orientation and mobility trainers here in WA, for example. So someone could wait, say, getting a position or a job where they need to know how to get from their home to this new position - they might need to wait up to two, three, four, five, six weeks to get that person to come out and teach them how to travel that route. With an insurance scheme, if this is the way the model might go, with some funding that you might have through that scheme you might be able to hire that person as you need them. Dip in and out and use them - say, for instance, you got a new job, you hire a orientation and mobility trainer, just like somebody who had a legal requirement would hire a lawyer, in that sort of way, and the same with, say, for assistance with gardening and other issues like that.

Another area for people who are blind or visually impaired, as I said, is access to information. With this age of electronic formats there's a wealth of information that wasn't out there a few years ago. The advances in technology are giving people who are blind or visually impaired - those who are tech savvy, and the younger generation that's going to come through is going to benefit from this the most, I believe - access to personal GPS systems, email in your pocket which might have details on all sorts of information that you need to know. All that technology is great. The problem that some people are facing, given that people who are blind or visually impaired, about 65 per cent or something similar to that - haven't got the figures here but it's an extremely high figure - are unemployed, not because they're not employable, just that the jobs really - the skills of other people haven't evolved to be able to teach people who are blind or visually impaired how to do the jobs.

I've been working at the University of Western Australia for 10 years now and my workmates forget every day that I can't see. So, given opportunity, people can gain employment. Getting back to my point, the technology is there. Where the problem is now is that connectivity, the cost of the connectivity to that information. So the information is there, and this is going to be one of the big frustrations for people who are blind or visually impaired and that is they might have the technology but they just can't afford to pay for the monthly bills that that data is going to cost. So that might be covered in such a scheme as a national insurance scheme; access for people who are blind, access to that information - the only barrier to them is, apart from learning a few new skills, the cost of that information, and the same with orientation and mobility trainers.

What I wouldn't like to see, if the scheme came in, where governments are then considered - let's say 20 years down the track, 10 years down the track, government schemes come in and people with disabilities are seen to have their needs catered for, that governments stop doing those systemic changes that the great advocates of the disability sector have moved them to doing and that is having a universally accessed society so people with disabilities, like everybody else, can access public transports and those sort of systems. I wouldn't like to see the disability sector quarantined off into, "Okay, you're now catered for. You've got your money. You can access taxis or whatever. You don't need to access public transport because you've got the money to be able to do it." I wouldn't like to see governments stepping away from those systemic changes that we're starting to evolve into.

MS SCOTT: Good. I got that. John?

MR WALSH: Thank you.

MS SCOTT: Well, thanks, Greg. Thank you very much.

MS SCOTT: Sam, are you coming back for a second visit?

MS JENKINSON: Thank you. Samantha Jenkinson again. Just two quick things that I've picked up on with Erik's contribution. One was when talking about values and principles, and just wanted to highlight something I came across recently which was talked about, which is part of the point of having values and principles is to be able to measure the integrity gap. So to know when we're not meeting it, you need to have something that you aim towards, and that's where I guess we link into the monitoring frameworks and things like that.

The other thing was around the qualitative stuff moving into quantitative. It's only a starting point and I guess it's one of those things where because sometimes we're often segregated in what we do - whether it's been raised or not I don't know, but Queensland Advocacy Incorporated has done a lot of work as a starting point on human rights monitoring that uses the UN Convention and does try to start and drill down quite practically in terms of monitoring rights, whether rights have been met in the UN Convention, and that might be a way of a starting point of looking at some of those things. I just wanted to mention them before I forgot as well.

MS SCOTT: Thank you very much, Samantha. John, no questions for Samantha?

MR WALSH: Just before you leave, I do. Thanks for that. I'm very big on measuring things. In terms of the integrity gap, I suppose the human rights is one dimension but I'm also interested in other qualitative outcomes; health and safety, self-assessed health status, those sorts of things. Are they things you're interested in?

MS JENKINSON: Look, I really don't know enough about some of those areas. I just know that there has been some work in drilling down the stuff with the human rights monitoring. It was more that that could be a starting point that maybe people haven't thought about because it's related to the Convention and the disability discrimination and not connected it to this.

MS SCOTT: John, while I've got you, one of my people I've been working with on a trade study asked me where was the quantitative evidence of wellbeing before the scheme starts and then once the scheme starts. I said all very good questions but - - -

MS JENKINSON: There's actually been research on wellbeing as well done by someone at Griffith University, I believe.

MS SCOTT: Yes. We found the study that carers of course referred to us about, wellbeing of carers. Have you actually got wellbeing of people with disability?

MS JENKINSON: AFDO had someone come and speak to it at one of their members' meetings about two years ago, but I could probably find out. It was a woman who had done research looking at - she looked at it across a whole heap of different community - but it was around wellbeing and community. I was just hoping to point to something that might already be out there.

MS SCOTT: Yes. Thank you very much.

MS SCOTT: Erik, if you can keep it to two minutes. Return for Erik, John. Thank you for coming back.

MR LEIPOLDT: Erik Leipoldt. I'm pretty sure I put this in my submission as well, but I think that if you pay attention to the processes in delivering the service or a service approach that are commonly known to lead to meet fundamental human needs, that is one way of measuring how well a particular approach might do. There are examples of that actually happening now, notably in citizen advocacy and there are also some approaches that are being used in disability services to pay attention to the processes that are likely to meet those needs, to have evidence for them in place.

MR WALSH: So, Patricia, the message I'm hearing here is effectively an embedded evaluation framework that's across both qualitative and quantitative dimensions.

MS SCOTT: Yes, I think that's right.

MR LEIPOLDT: Yes.

MS SCOTT: I think that's true too.

MR LEIPOLDT: It's an ongoing process.

MR WALSH: Yes, of course.

MS SCOTT: Thank you very much, Erik.

MR LEIPOLDT: Thank you again.

MS SCOTT: So I think I now can draw our hearing to a close. So thank you very much for those people that have stayed to attend to the last minute and we'll be back to Perth again once we've released our draft report with draft recommendations. We don't expect you'll like it all. We haven't even thought what should go into it yet but do hope you might leave some time in your busy schedules, probably around March, April next year. Thank you.

AT 5.12 PM THE INQUIRY WAS ADJOURNED ACCORDINGLY