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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 BRISBANE ON FRIDAY, 16 JULY 2010, AT 9.03 AM

Continued from 15/7/10

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MS SCOTT: Thank you for attending today. My name is Patricia Scott and I'm the presiding commissioner of the inquiry. My fellow commissioners are David Kalisch, who's here at present, and John Walsh, who will be joining us later 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. 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 received around 85 submissions and have released an issues paper in May. We are grateful for the submissions already received and submissions can be downloaded from our web site at www.pc.gov.au.

While we would like to get submissions as early as possible, in view of the concerns raised by some participants the commission has extended the due date for initial submissions to Monday, 16 August 2010. The commission also welcomes second and even further 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. I think this is a point I would like to reinforce today that it is probably more beneficial that you don't read your entire submission in the half hour or 25 minutes allocated but in fact you allow us some time to ask questions, or we could have a conversation and elicit key points. We will be having a draft report available to the public in February for comment and we will invite participation at another round of hearings. It is very important that we hear feedback on our proposals at that stage. That's a very vital stage in the undertaking.

We 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. 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. If you hear something today that you'd like to remark on, we'd welcome a written submission on that. Transcript will be made available from the commission's web site following the hearings. Are there any media representatives here today? No.

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 the evacuation of this building, please follow the instructions of the hotel staff. If you require any assistance please approach Clinton, David or myself. I would now like to welcome Kathy Kendell. Kathy.

MS KENDELL (HCN): Hi.

MS SCOTT: If you just identify yourself and the organisation you're representing?

MS KENDELL (HCN): Yes. My name is Kathy Kendell. I'm representing Health Consumers Network. Health Consumers Network is an unfunded network of volunteers passionate about working towards improvements across the health system. Our network has been operating for about 18 years in Queensland. Over the years we have sometimes become involved in matters which include experiences of people with disabilities and their interface with the health system, often over the lack of access to health care, which we believe mostly stems from the fact of their disability. We have sometimes been asked to act as advocates for these people.

Our main purpose in speaking today is to highlight the need for concerted action to minimise the disparities in access to quality health care and the poor health status experienced by people with disability. It is a major concern to us that people with disability often bear the greatest effects of the rationing and limitations of resources in the health system.

An example of how this occurs is one child we advocated for a number of years ago who was deliberately denied calipers to assist him to walk. It was stated to me by medical personnel at this children's hospital that this child belonged in a wheelchair and that his cerebral palsy would prevent him from achieving much at all. So it was best not to raise the expectations of the child or his family who should be counselled, they said, to accept this. I managed to advocate successfully for his first pair of calipers but there was opposition, delays and many hurdles to pass each time the child grew out of the calipers and needed a new pair. Grown up now, this young man has now successfully worked in a government department for three years. If he had had the full medical care that he required in a timely manner perhaps he would not need the cane he now uses. But without advocacy on his behalf it is almost certain he would have remained in his wheelchair, just as the medical people insisted he would remain.

In the case of another man with acquired brain injury, medical personnel on a number of occasions have pressured the family not to treat when he is brought into the hospital for aspiration pneumonia even though once treatment is given he has a record of good recovery. I could go on with countless examples but it is already accepted in government reports that people with disability die prematurely and often have a number of unrecognised or poorly managed medical conditions and inadequate health promotion and disease prevention.

The National Health and Hospitals Reform Commission report 2009 stated that people with disability faced stark inequalities. There is no single reason to explain why disparities exist in this area. Within the political setting it could be provider bias, stereotyping and organisational barriers. It could be the lack of understanding or awareness and training by medical personnel that could explain why equitable care is not always given. Perhaps it is poor provider-patient communication or the complexity of the diagnosis and lack of research into the health issues of people with disability. But given the inherent increased vulnerability of those with a disability, a new scheme must emphasise the need to make sure that those with disability receive appropriate health care in time for health care to be effective in ensuring a good health outcome.

I cannot emphasise strongly enough how often we observe the system paying lip service only to the right to access health care. That has been articulated in Australia's health rights charters for some 18 years now as a requirement of the former Australian health care agreements, not to mention Australia's ratification of article 12, the right to health, in the Covenant on Economic, Social and Cultural Rights; and article 10, the right to life, and article 25, the right to health, in the Convention on the Rights of Persons with Disabilities.

Again, a couple of years ago when I was involved in this, all health ministers signed off on a new national charter of health rights which once again articulates our right to health care. However, according to the Commonwealth Fund 2010 report, which is an international report, Australia has the worst access to health care for its citizens in all OECD countries alongside only the United States. This disturbing statistic is all the more reason why people with special vulnerabilities need special supports and protections in accessing health care. Australia's ability to fulfil the health rights contained in all of these documents it has is only hindered by its level of commitment to fulfil these rights.

I believe the following recommendations initiated and implemented by a new scheme, which I hope are adopted, will improve access to quality of health care for people with disabilities. Firstly, I believe that we need to initiate - and the scheme could do this - a national network of health services specialising in the health care of people with disability, special support training with doctors and nurses trained to create this network of specialised disability health services. This was recognised in the final report of the National Health and Hospitals Reform Commission, the 2009 report. It already occurs in the Netherlands where there is an established speciality of intellectual disability medicine. These services would be like a consultancy and training resource to mainstream health systems and to enhance the capacity of the system to meet people's needs with disability. The specialised services would facilitate collaboration between local health areas and disability services and undertake research.

Our second recommendation we would like to make is that the scheme should initiate this, but I guess the Commonwealth would do this, but we need to collect data on the health status of people with disability. We cannot improve what we cannot measure and we cannot measure what we don't know or don't understand.

The third recommendation is that all health care planning and in particular those newly-proposed Medicare Locals or the primary health care organisations must ensure the priority of the health needs of people with disability. These health reform measures must take proactive action from the start of their operation to ensure all of their initiatives includes specific consideration and service specifications on how they will meet the needs of people with disability. This will require specific funding. So people can sit on these - they're going to have councils and boards and we want people who know the disability area to be involved with this.

Our fourth recommendation is funding for independent, systemic and individual specialist advocacy programs to support our most vulnerable to access good quality health care and negotiate their way through this fragmented health system. I know of no paid specialist advocates in the health system at the moment. It costs me sometimes between two and five hundred dollars a month of my own personal money over the years to help people access the health system. We really do need special funding for advocacy to occur, and that is just - you know, we do have a few systemic organisations but we have no individual advocacy programs in the health system at the moment.

Our fifth recommendation is consideration of additional MBS item numbers for people with complex disability and their health issues. The Medical Benefits Scheme is currently undergoing a review of its quality framework. We are aware of problems over people trying to access the government's dental scheme that provides coverage for up to 4200 over a two-year period. I've tried to get people with disabilities into that scheme but it's confusing and hard to access for both GPs and dentists who are in or have been reluctant to participate. Also, the enhanced primary care program, it currently pays GPs $240 just to fill out the paperwork but you can only access $250 worth of benefits under that program. That covers only a portion of each of the consultations in that allied health care area. So you get five consultations, the most it will pay is $49 of Medicare benefits. You have to pay the rest of that consultation and the GP gets $240 just for filling out the paperwork. So that's a big waste. GPs tell me that they could just write a referral. They don't need to go through all that paperwork. People with known disabilities don't have to be reprocessed in every aspect of every system that they get money from.

Our sixth recommendation is we need to raise greater public awareness of the needs and issues faced by people with disabilities by using data that we need to collect and research, so that we can act more justly across how we treat these people. The only appropriate framework for the new scheme should be that which is contained in the United Nations Convention on the Rights of Persons with Disabilities. Australia has invited scrutiny of its treatment of people with disabilities through the optional protocol that it ratified. Therefore we should have no objection in using these rights as a framework for any new scheme that we develop. We support a national compensation scheme based on need and not one's disability or how it occurred. This should be funded through a Medicare-like levy on taxes. There should be a system of accountability for this scheme that uses health, wellbeing and human rights indicators as the benchmark for a valuation of outcomes.

I might speak later if you ask me a question about it but the Productivity Commission should consider the need for funding technical support and capacity building measures to enable many of our disability representative organisations - we need to be able to participate more effectively in the development of the scheme itself and its implementation, governance and evaluation. Red tape is currently stifling the Queensland Disability Services and Public Housing departments. This increases human suffering costs and frustration for everyone.

My personal experience with these bodies is that they constantly operate in a crisis mode. Despite all of the principles, policies and legislation, which sounds so wonderful, a number of people with disability are currently being forced to co-tenant in abusive and violent environments due to forced block funding arrangements and a strong avoidance by Disability Services department to allocate individualised funding packages based on actual need and a proper risk management protocol.

There seems to be the widespread joke among hundreds of disability workers that pursuing and receiving funding packages or accommodation support is a game of hoop jumping. Just last week that was said to me over the phone by someone from the Commonwealth Respite and Carelink; "Don't you realise by now this is a game and we are jumping through hoops and this is what everybody just has to do." It's like there's this veil of silence because people are afraid about losing their jobs but there's a culture of acceptance right now where people in the business of providing disability services are prepared to just go along with it, despite all of our wonderful language in our act. So we're going to have to develop a scheme that overcomes this some way and it doesn't allow it to happen.

There should not be multiple schemes where separate silos for services will stifle flexibility, create duplication and inefficiencies, and confuse people or force renegotiations all the time to access to services. The new scheme, we believe, just finally - I'm finished now - there should still be an option for the role of common law claims. Compensation plays an integral role in providing redress and balance on both the individual and social level. Where there is significant fault or negligence which has been attributed to the cause of the impairment, without the opportunity to claim compensation through common law where income or livelihood or enjoyment of life was lost as a result of serious impairment, or caused by fault or negligence, it would be a real injustice that would be difficult to redress, including sending the message to negligent parties that others will pay for their wrongs. So compensation does allow for someone with an acquired injury to make significant life changes and maybe repurchase a more accessible home or a vehicle. So we don't want to take away people's personal rights to be able to seek compensation.

MS SCOTT: Thank you. John Walsh is now available so I think, if you don't mind, we'd like to take a little five minute pause and might get John on the line and I might get some of the people outside in.

MS SCOTT: Your interest in retaining common law rights, I guess I wouldn't mind exploring that a little bit further. Now, I'm not a lawyer, but one of the advantages that some people see with the social insurance model on a no-fault basis is that people don't have to wait for compensation after a lengthy legal case. You clearly are interested in early intervention access. Are you looking at the Victorian model where there's some retained rights or are you looking at - I'm just interested in how you see the two fitting in and if you have a particular model in mind or you'd just like us to think about it.

MS KENDELL (HCN): Well, I'd like you to think about it. I know only a little bit about the Victorian model. I am very interested in early treatment and people not hanging out for a compensation payment, but people at this point in time are required almost to seek compensation and take full 100 per cent of the risk if they lose, and yet if they win, Medicare gets reimbursed. I think that that's a little bit unfair that Medicare doesn't join people. Primarily we're going to have to do something about - if someone has been negligent, why should the whole of society bear the cost of the individual's negligent behaviour. So that is one thing that bothers me. Also the other thing that bothers me is I am aware of some people who have had to rely on the New Zealand compensation scheme and have been most dissatisfied because they can't access the services that they truly need. Someone else is making those decisions on their behalf and that's a pretty scary thing.

So people could still retain the common law right to sue for compensation and not worry about whether it covers their medical costs but their loss of ability to have those additional life supports that may not - I'm worried that people will be locked in and have decisions made for them about what services they want to access. Some people want homeopathic or alternative type of medicines, and yet these decisions are being made for them by people who are - when these schemes are in place, people don't have a lot of free choice. So retaining some ability to receive compensation would give them - so maybe not compensation over costs in the system but to keep that ability to make decisions for themselves.

MS SCOTT: I think I've got it. The system would operate so that immediately you'd be able to receive rehabilitation and medical assistance and carer support, home modifications and so on, but retain some right for, say, loss of income or personal damage or whatever.

MS KENDELL (HCN):   Yes.

MS SCOTT: You want people to have freedom. So within the system you may still have to have some accreditation associated with care. So maybe dolphin therapy wouldn't be available to you, but if people want to spend their own money on dolphin therapy they can do that. I've got that.

MR KALISCH: I've just got one question, Kathy. Just in terms of the nature of the recommendations you outlined, it was quite comprehensive, but I suppose one question: if you had such a comprehensive scheme, do you envisage there being such a great need for advocacy?

MS KENDELL (HCN):   Absolutely. The evidence for that exists right now today. We have, in our legislation and our principles of the act and throughout the system, wonderful lip service being paid. People are not getting - that's not the reality of the system as it's dished out on a daily basis to individuals.

MR KALISCH: Is that the reality because there is such poor funding of the current system, essentially that there's a mismatch between the objectives and the reality? Or is it in a better funded scheme can you imagine that a scheme would be able to provide better service?

MS KENDELL (HCN):   I think that there are people who are so vulnerable that, you know, their needs are not going to be able to be met unless people like advocates who get to know them on a personal basis and understand their needs can help them negotiate through the system. The system will always serve health-literate people, people who have that higher capacity. There will always be those people that are so vulnerable that need that advocacy, that individual advocacy.

MS SCOTT: How do people find you, Kathy? I mean you talked about the advocacy service. We encountered people yesterday who struggled for many years before they found someone who could assist them. I mean, do you have a waiting list? Do people find you easily?

MS KENDELL (HCN): No, we operate pretty much informally. If we have capacity amongst our group members, our network members, then someone will take on somebody, but I've been referred to by politicians, you know, the members of parliament refer people on to me; people in the health area know about our organisation. We certainly get more than we can handle. Most of our work these days is about submissions and working on different projects, sitting on committees, trying to implement better reform agenda; our members are on different national alliances.

MS SCOTT: I guess one of your themes is that the rhetoric exists, the lofty statements exists, it's just the reality - there's such a gap between reality and - - -

MS KENDELL (HCN): Yes, and I - it's just - you know, it's almost unbelievable the difference between what exists in written form and what is happening on the ground for individual people.

MS SCOTT: Thank you very much.

MS KENDELL (HCN): Okay, thank you.

MS SCOTT: Good morning to those that joined us. Very pleased to have you here today. We have had our first witness and we're about to go on to our second witness. If you do have a mobile phone it would be much appreciated if you could turn it to silent `or off. One of the difficulties we have in this setting is just the door creates a lot of noise for our recording service and we do want people's evidence to be available to everyone in Australia who has an interest in this topic. So I'm sorry for any delay outside, just as we ensure that people - we can get their testimony accurately recorded. So I now call to the table Dianne Toohey, Madonna Nicoll and Neal Lakshman, Speaking Up For You.

MS TOOHEY (SUFY): Yes, half of us are sick so we've changed - - -

MS SCOTT: That's okay.

MR KALISCH: Okay, that's all right.

MS SCOTT: All good. Please come forward.

MS TOOHEY (SUFY): So Robyn is going to do - - -

MS SCOTT: All right, that's fine. John has joined us. John Walsh is a commissioner, associate commissioner for this inquiry and he's joining us from Sydney, so he can hear you, so he's fine. So thank you for coming forward. State your name please and the organisation that you're representing. Would you have a short statement you'd like to make? We could just ask you questions

MS O'HARE (SUFY): I have a long statement but Dianne Toohey is here as well.

MS SCOTT: Would you like to come forward?

MS O'HARE (SUFY): If you have short questions you might like to address them to Di?

MS SCOTT: Well, we just need to have it on the transcript, you see, so that's why - - -

MS O'HARE (SUFY): Well, my name is Robyn O'Hare and I work for Speaking Up For You.

MS SCOTT: We have about 30 minutes set aside for your presentation. It's probably best if you could leave some time for us to ask you questions and have a bit of a conversation about some of the things that you're raising.

MS O'HARE (SUFY): Okay. If you'd like to stop me if there's a particular section that you'd like to ask questions about. I would like congratulate the Australian government for undertaking this inquiry into the National Disability Long-Term Care and Support scheme. The national disability strategies 2009 Shut Out report recognised how persons with a disability have often been marginalised and discriminated against in our society. When considering the support options available to people with a disability, it is important that the Productivity Commission be embedded in a human rights perspective. As a signatory to the Convention on the Rights of Persons With Disabilities, Australia has an obligation for support options to be entrenched with human rights principles acknowledging people with a disability as valued citizens as a consequence. This would ensure a new framework for direct care and support for people with a disability as an entitlement which acknowledges people's citizenship and human rights.

Support provided to people with a disability must be portable within Australia to provide flexible lifestyles for people with a disability like any other citizen. How this funding is spent should be flexible and attached to the individual, to be centred on the individual needs of each person with a disability. People with a disability should be supported and encouraged to design and direct their service to ensure the service is relevant, timely and flexible and enables the person to maintain control and direction over their lives.

Human rights principles should be used as a benchmark for analysing, monitoring and evaluating support services and additionally should be seen as an entitlement that will take into account local and cultural differences. People with disability must be empowered under the scheme to have control and direction over their lives, to build on their own innate abilities in a timely and equitable way and to ensure that people with a disability are the primary focus of any programs.

Who should be eligible? The scheme should be an entitlement that is available to all people who have a disability and who require support with daily living needs. This would encompass entitlements by people who were born with disability and who acquire a disability. It must be recognised that many people with a disability have experienced isolation and segregation in group homes, rehabilitation hospitals, mental health facilities and within privately run hostels and as a consequence face additional social barriers that are based on ignorance and fear.

One of the fundamental principles of the Convention on the Rights of Persons with Disabilities is that a person has the right to have their basic needs met. Recognition of the material conditions of persons with a disability must encompass how a large number live in conditions of poverty and that the added burden of having to contribute to their own care and support significantly disadvantages the person. Therefore, people with a disability should not have to pay the additional cost of living with a disability and should be guaranteed lifetime support that recognises the changing needs of people throughout their life.

How could people with a disability have more power to make their own decisions? The state has an obligation under Convention on the Rights of Persons with Disabilities, CRPD, to ensure that people with a disability be actively involved in decision-making processes and programs, including those directly concerning them. The full realisation of this human right would result in a person with a disability or those who know the person best, including family, friends and advocates, making decisions about what services are required, who should provide those services and when to provide services. The effective and efficient allocation of funding should enable people to receive their funds directly, have control over how the funds are spent on support and be given additional support that is required to ensure accountability and financial management of this service. Decisions about the amount of financial support and service entitlements individuals should receive, should be made by an independent panel that will recognise the need to promote, protect and fulfil the human rights of all persons with a disability, including those with more intensive support needs.

Participation of people with a disability in directing their service needs if they choose a specialist disability support service needs to encompass the opportunity to genuinely evaluate service delivery.

MS SCOTT: Can you just explain what you mean by that.

MS TOOHEY (SUFY):   Can I answer?

MS SCOTT: Yes. You might need to state your name for the record.

MS O'HARE (SUFY):   Dianne Toohey.

MS TOOHEY (SUFY):   That when evaluating a service it's actually evaluated on outcomes rather than - at the moment evaluation processes are around a group of standards that don't necessarily look at the outcomes for an individual. So it's about making sure that those outcomes are consistent with the human rights principles.

MS SCOTT: Okay. Thank you.

MS O'HARE (SUFY):   What kind of services are needed? People should have an opportunity to purchase generic services or specialist services depending on their individual need. For some people they may choose to purchase a support worker from a specialist service to assist with meal preparation or may use the funds to buy a meal at a local RSL. The opportunity to dine out with the funds can facilitate social networks that can reduce social isolation and marginalisation.

Providing people with disability with the opportunity to choose generic services to assist with needs facilitates choice and the ability to reduce the cost of meeting some needs to provide a flexible approach to support. Generic services may include a local cleaner, ironing services, RSL club, gardening services et cetera and these services should be able to be purchased with the person's funding entitlements. This encourages community inclusion, is cost effective and gives the person status within their community. Services should be required to take into account the protection and promotion of the CRPD in all policies and programs. This would include ready access to mobility aids, assistive technologies, as well as other forms of assistance.

How could the ways in which services are delivered be improved? Disability can be understood as an interaction between a person's impairment and attitudinal and environmental factors which hinder their full and effective participation in society on an equal basis with other citizens. It is important that the evolving nature of disability be recognised by the inquiry in their consideration of the national disability insurance scheme. Service provider personnel need to embrace values, attitudes and skills that demonstrate their understanding of how services should be delivered in a timely and non-intrusive way so that a person is not subjected to interference with his or her privacy, family or home. Decision-making and coordination of support is performed by the person with the disability where possible and by family members who know the person well.

With respect to the non-interference principle, services must recognise that they are there to provide support with the administration of resources and employment of support staff. People with a disability have a range of service models that include personal assistants necessary to support living in the community and inclusion in the community. Hopefully this would prevent the continued congregation of people in group homes for the convenience of the service provider or funding body.

MS SCOTT: What sort of gathering together of people in a home do you find - some people have suggested to us yesterday that three might be all right and eight might be okay but when it got to 30 it wouldn't be right. Do you have a number in your - - -

MS TOOHEY (SUFY):   I don't think it's a number, I think it's whether there's a genuine relationship with the other person and whether people make that decision or whether - at the moment under the vacancy coordination model it's the service provider who decides who will live with the person, not the person themselves, so it's a denial of basic human rights in choosing where you live and who you live with. So

I don't think there's an optimal number, I think that it has to be a genuine choice and funding has to be individualised so that if you're not happy with that arrangement you can move. At the moment services are block funded and a house is funded, not the individual. So if a person wants to leave, they leave without funding or housing.

MS SCOTT: Thank you.

MS O'HARE (SUFY): How could a new scheme encourage the full participation of people with a disability and their carers in the community and work? If disability care and support is provided as a entitlement acknowledging the CRPD, it is envisaged that people with a disability would receive support in a timely and appropriate way, thus reducing the removal of people with a disability from their local communities. Services would be individual and flexible, thus reducing the need for family members to become carers and consequently enabling families to maintain their role as family. That people with a disability be assisted in a timely way so that their education and employment is not compromised should be a priority.

This is an extremely important aspect of promoting genuine participation and therefore citizenship for people with a disability. The continued congregation of people with a disability in rehabilitation hospitals long after rehabilitation ceases or long-term respite, residential or nursing homes needs to be ceased as a model which is being promoted to minimise costs. The ramifications of this approach are the loss of skills, confidence and hope for a life rather than an existence while waiting for a service response.

In closing we would like to emphasis that a no-fault disability insurance scheme would ensure that funds are available to facilitate support for people with a disability that is an entitlement and not an act of paternalism or charity. The service system allows people with a disability to have control over their service by provision of direct funding; that the scheme recognises the changing nature of disability over a lifetime and makes provision for support which is flexible enough to support people as they age; that people with a disability have the right to independent advocacy to ensure that they are given every opportunity to be empowered and have their human rights acknowledged, promoted and fulfilled.

MS SCOTT: John, do you have any questions.

MR WALSH: No, I don't have any questions, Patricia, at the moment.

MS SCOTT: David.

MR KALISCH: I just have two. In your statement you talked about the evolving nature of disability and that needed to be recognised by the inquiry. I'm just wondering whether you could elaborate a bit more about that.

MS TOOHEY (SUFY): I think it's about recognising that people's needs change and their circumstances change so that someone may be getting some informal support from a family member or something and if that circumstance changes there is a way of making sure that that person is reassessed and that funding is available to provide those needs or that they may want move out of one particular support model to a different one, depending on their life or direction. Changes happen from school to adulthood and so forth.

MR KALISCH: Okay. So it's changes in the person as they go through life, as well as changes in their circumstances around family and friends and community,

MS TOOHEY (SUFY): That's right.

MR KALISCH: The other aspect was around where you talked about people being forced to remain in rehabilitation hospitals or in long-term respite and you suggested that it was to minimise costs. I suppose the other aspect we've heard is that often that takes place, not because of costs reasons, in fact it might actually be more costly to keep them in those circumstances, but because there are few other alternatives.

MS TOOHEY (SUFY): I think it's because we operate from a crisis model of support, so people cannot attract funding or support until they actually get into those situations. So we find mum and dad supporting somebody at home until they either die or they're not able to do it any more and then the person is put into a nursing home or long-term respite and as skills are lost in those places the funding actually is a lot higher when they actually do get funding to move back into the community, so its transitioning from institutional care.

MR KALISCH: Certainly some previous evidence we have heard in other states suggested that people are forced to remain even in acute care hospitals using up a bed at much greater cost than if they were to be provided with suitable - - -

MS TOOHEY (SUFY): So we are working with people who are supposed to be slow-stream rehabilitation. Some people have been there for 10 years and there's no physiotherapy, there's no rehabilitation happening at all but they are seen as having a roof over their head and support so we can't get funding or support for them to move into the community.

MS SCOTT: What was the facility - I don't need to know the name - but what facility did you say they were in?

MS TOOHEY (SUFY): Slow-stream rehabilitation hospital.

MS O'HARE (SUFY): For people with brain injuries.

MS SCOTT: Okay. Maybe others would like to think about this if they're coming forward too, a lot of people have suggested to us that we need to think about an entitlement approach. In your mind, is there something existing in the system now - I don't mean the disability system but somewhere else - that you think we should look to in terms of thinking about how to ensure that that really is an entitlement. The speaker before you made the comment that there is often lofty words but reality is very different. How do you ensure that an entitlement is genuinely is an entitlement?

MS TOOHEY (SUFY): I think once there's a recognition or a definition of who the person is or the particular circumstances around a person that it's not unlike, say, a single parent getting an entitlement for a child, that sort of thing.

MS SCOTT: So like a social security system?

MS TOOHEY (SUFY): Yes.

MR WALSH: Patricia, I do have a question.

MS SCOTT: Yes.

MR WALSH: Dianne, I'm interested in how you think or your ideal model you've described here can be put in place in practice. You seem to be pretty much in favour of inclusion in the community and generic services, provided people have their own funding and entitlements. Do you think generic services are ready for people with disabilities that are able to accommodate them into those services at the moment?

MS TOOHEY (SUFY): I think there has to be a mix of both. I think there has to be some specialist disability services, but it's how those services operate. So there are small pockets of really good service provision that's happening now. One model I can talk about which is called the Collective Action Group, it's only for 10 people, but their funding goes to a service provider and they take the responsibility of making sure all the legal responsibilities are met, like insurances and service agreements and all those things, but the actual person or the family, where the person's not able, employs staff, directs staff, makes out rosters, decide when staff come and work in the house, that sort of thing. So they have a lot of control over how the service operates on the ground.

There are other people that have set up company models of service where they take control of the whole gamut and have the legal responsibilities as well but that's quite a cumbersome model because it's like running a small service, you have to go through standards, you get audited, the whole thing. So unless you have somebody that has those skills, it can be quite difficult.

MR WALSH: So are you envisaging a model where the person with a disability or perhaps a few people with a disability, have a fairly strong relationship with a coordination model and understands their needs and understands their local communities and so on so there's almost an organisational approach to including the people with a disability into society?

MS TOOHEY (SUFY): I think there has to be a range of models. I don't think you can just say one model will suit everybody, but I think that is one model, yes, that could happen.

MS SCOTT: Thank you. I think that's it, John, are we - - -

MS WALSH: Yes, thanks, Patricia.

MS SCOTT: Thank you very much.

MS TOOHEY (SUFY): Thank you.

MS SCOTT: Thank you for coming along, John, and thank you for your paper in advance of talking today. Could you for the record state your name and the organisation you're representing, please.

MR HOMAN (CCDA): My name is John Homan and I'm Amanda's father. I speak for the Capricorn Community Development Association in Rockhampton. At this point I would like to recognise the Darumbal people and elders past and present.

MS SCOTT: We have your piece of paper. Would you like to make just a short statement and then maybe we could ask some questions.

MR HOMAN (CCDA): I would prefer to do a narrative if that's all right and you can happily pull it apart after or during.

MS SCOTT: All right.

MR HOMAN (CCDA): What I have done is some of the research material that I've used which you may not have access to, I've put it on the message stick (hands USB to Ms Scott).

MS SCOTT: Thank you very much.

MR HOMAN (CCDA): I have been at the operational level as a carer and systemic level for many years and I have had an interest in a national disability insurance plan for over 10 years.

MS SCOTT: Yes, I saw in your papers last night that you've - - -

MR HOMAN (CCDA): I've included it, somewhat primitive but I've thought about it a lot and one of the things that I did not find in Bruce Bonyhady's paper or in the issues paper was what to me is critical in the whole shooting match and that is the relationships issue. Quoting Mohamed Yunis, he said at one stage that, "Charity maintains poverty," and this is not about money, this is about relationships, because it maintains unequal relationships. The one thread that goes through the disability issue from its early days, Jane Eyre's time, the industrial revolution, the time of Dickens to this day, is this disrespect for the core relationship and I think that when we talk about a paradigm shift, this is where the shift has to be and that is in the relationships.

Although a lot of things have changed in the disability area, the one thing that we've stayed with virtually is the medical model. We're talking about a social model and normalisation, social role valorisation became very popular from the 80s on but when you look at it closely it's only an extension of the medical model because it still is trying to make people different from what they are and not recognising their differentness and I have a lot of problems with that and I think that is one of the things that is holding us back because in an unequal relationship the person with a disability will largely be a spectator in their own life.

So I think that the crux of the matter is to develop a culture that allows people to be empowered. The present system is largely hierarchal and always has been hierarchal and that suits government departments and because government departments have the money, the service provider tends to follow that model. Hierarchal organisation does not lend itself to creating an environment of empowerment so this is where the paradigm shift has to be and so the relationship between the funder and the client, if we can call it that - because it can be a person or a family - and the service providers needs to radically change and I think that government is not really very quick to do this.

In Western Australia they invented about 20 years ago a local area coordination, and local area coordination started in Albany and spread through the whole state and has since been exported to other places, including Queensland. I don't like the Queensland model very much, but the Western Australian model is excellent because they overcame the problem of a government department not being able to be anything less than hierarchal by isolating the local area coordination from the department by erecting big firewalls. So local area coordination could in actual fact operate on community development principles. The difference between community development people and social workers is that social workers are forever, community development people have an exit strategy, which means that it's their task to equip the person rather than manage them.

So I see the principles of local area coordination as the fundamental relationship between the funder and the person with the disability or the family. That means that responsibility and authority need to be matched. In other words, we turn the pyramid upside down and we say, okay, the interface is the important one and the rest is there to support it. So by matching responsibility and authority, that means that people can have coffee table conversations with the facilitator from the department over what their needs are in a respectful rather than a controlling manner. I think the building of these relationships is critical in all this, that they are trusting and respectful relationships where they speak the same language and where there are (indistinct)

I think that if we can establish that sort of relationship between the funder and the people with the disability, that's a good start, and then we have to look at the relationship between the people with the disability and the service providers. Now, I'm very much in favour, as a hand-up towards empowerment, giving people their own budgets. I've had a very good look at the In Control system in Britain and they have proven the system pretty well. Their major flaw to me is their funding system which goes through local government and that creates a great deal of patchiness and unevenness, but if that was funded on a national scale, I think In Control would be excellent as an option.

MS SCOTT: Do you mind if I interrupt your flow for a second?

MR HOMAN (CCDA): No, go for it.

MS SCOTT: We've been looking at that UK model and you're right, we've actually been surprised by how uneven some of the arrangements are. But also we were surprised by the reletively small proportion of people who take it up and people tell us that if we had something like In Control, there would still be a large usage of people effectively handing over their payments to organisations. Do you think that would be the case here in Australia as well?

MR HOMAN (CCDA): What I read on In Control is that there was a small uptake to begin with but that there was a general trend towards it. Now, there are some people that may never want to have control because they may not feel capable of doing so or for other reasons and consequently it needs to be a choice, not an obligation. But I am inclined to think that once people - I mean, what we don't understand, we kill, and so if you don't understand the system or you don't know people that have familiarity with the system, you tend to say, "Maybe this is not for me." But I think there will be a general trend towards the system. I wouldn't like to guess what percentage would not get into it but I would think that it would be a pretty large percentage that would take it up.

MS SCOTT: Sorry to interrupt a second time, but we were discussing client control funding arrangements with one government department and they cautioned us that it would lead to the demise or loss or organisations because the organisations need this money to - they need to have the surety of having the money. Could you comment on that? How do you think it would operate?

MR HOMAN (CCDA): I think we have to remind ourselves who this is for. If people start voting with their feet, that means that the organisation gets it wrong. By the same token, I've had some discussion with John Pini about what he calls the mixed economy model, where some services may not have the capacity to take on a person because of the patchiness of demand and that they should be supported in the public interest. I had a conversation with my partner about it, who is a community developer, and she suggested that we may also look at whole-of-government approaches, while maybe other departments or organisations have had the capacity to provide those services as required in the neighbourhood, so they're two options.

I think we were getting to the service providers, and I think it will free up a lot of angst in service providers, because I would advocate that service providers get a certain amount of block funding to give some viability, assurance; how that would work, I'm not sure. I'm not an economist, I'm only an engineer. I think it should raise not just competitiveness but also collaboration between service providers, where a number of service providers can provide bits and pieces of services that people want, including generic services. In the generic services, I think that there are doubts whether they would take this on, but I think again it's not just about educating them, it's about mentoring them and I think again it's a matter of them gaining the understanding that people with disabilities are not different, they're just people with their own ambitions of wanting to live an inclusive life and make a contribution.

In the paper that my partner Sandy and I wrote some years ago for the International Conference of Community Engagement, we just found the contributors to a quality life as choices, relationships and being able to make a contribution. That doesn't have to be economic, that can be in many other ways; the pleasure of someone's company at times is a contribution. So I think if we change these relationships that way and have this direct relationship between service provider and the client, rather than the service provider only being accountable to the funder, and a direct relationship between the funder and the client on a respectful basis, that I think will turn the whole thing around and that will address an awful lot of the things that people have complained about for the last X number of years and some of those are recorded in Shut Out and previously in Western Australia 10 years ago. I asked the lady who wrote that, "You've seen Shut Out. Has much changed?" and she said no. I would agree with that.

The other thing that I've been thinking about a lot through bitter experience is that the majority has the power to abuse, and this has been particularly noticeable with minority groups. I mean, we can see it with Murries and we can also see it with disabled people. So the strength in our democracy is in the institutions that protect the minority groups. Now, I have a very serious issue with the checks and balances that are actually operating. Organisations are investigating themselves, you know, massive conflicts of interest, and also that where there is a differential in power, the person with the least power is naturally disadvantaged. So for that reason, I agree with David Hamer who wrote a paper on this that I've quoted from, that in a normal civil case, you have a certain symmetry.

When you have a differential of power, this symmetry disappears because the person with the least power has the most to lose So I believe that to rectify this it's possible to adjust the standards of evidence so that we take in evidence possibly of a lesser standard because I believe that the important thing is, in evidence of probability, that we establish trends. Now, if we look at incidents in isolation, we don't establish the trend. If we look at all the evidence, including rumour, hearsay, unsubstantiated complaints, complaints withdrawn, then a trend may emerge that should help restore the balance in the situation.

David also claims, and I can see that, that the higher the standard of proof required, the bigger the chance that the person that is guilty gets off. When you're looking at very vulnerable people, where maybe a person is dependent on life's functions - on being fed, cleaned, housed and what have you - if there is abuse there, I think that we need to restore a balance so that the chances of this person being disadvantaged by a guilty person getting off needs to be minimised and I think that that can be done by adjusting the standards of proof proportional to the differential in power.

MS SCOTT: I'm not familiar with his work so I'll have to look into it, but is there anywhere where this has been actually instituted in a service form?

MR HOMAN (CCDA): Somewhere on my hard drive I have some evidence of that in Britain and I'll go and look for it again.

MR KALISCH: If you could provide that to us, that would be good.

MR HOMAN (CCDA): On the disc there I did put a paper that I dug out which gives different standards of proof and that goes from beyond reasonable doubt to a smidgen. So that in itself, I think, gives some legitimacy to it.

MS SCOTT: John, is all right if I interrupt your bit?

MR HOMAN (CCDA): Yes. I'm just about at the end of my formal story.

MS SCOTT: This is very interesting because people have suggested to us - we have heard in testimony a number of times people raise the issue of complaints and being powerless, including people actually providing services, parents, people actually in the seat of service, and they've talked about numbered complaint forms; rights of appeal; people have recommended to us the visitor model; public advocacy model that operates in Victoria; that there needs to be referral to appeals mechanisms; and so on. So I think this is the first time someone has suggested that the onus of proof - not quite the onus of proof but the standard of proof - if I've got that right - standard of proof would vary. So this is very interesting. I think we'll investigate this a bit further. Given how widely read you are, John, is there any model in Australia or overseas, besides Britain, where you think other parts of a system provide a good model of protections or checks and balances?

MR HOMAN (CCDA): I think where organisations have oversight over their investigation, that can be helpful. I believe that Endeavour brings people from outside its own organisation on its complaints panel. So I think that at times if there are advocacy organisations, maybe the organisation should be a party to the complaints management. I think they are still basically bandaid solutions. I think that the solution needs to be systemic because - I don't want to hang out my dirty washing, but I lodged two complaints with the CMC and they were referred back to the department, and I never heard anything until I made an inquiry 18 months later. That sort of stuff is not new; it happens all the time. So it's not just the conflict resolution within organisations, it's also with this government. I wrote a piece a long time ago, which I called The Hand That Bites, and how organisations that are funded by government are very loath to complain about governments because they get punished for it - plenty of examples of that.

MS SCOTT: John, I should let you finish your narrative.

MR HOMAN (CCDA):   That was basically my concern, that we need to change the culture and that it's going to be difficult, but that we only can change the culture by isolating the people at the coalface and their backups from the hierarchical culture that exists in organisations and government. Now, Western Australia has proved that that can be done; so it's a proven system. There's no reason why we should believe that we're not as smart as the West Australians. The Queensland system is different because where, in Western Australia, it was completely kept separate from the department and its culture, in Queensland it was attached to the regions, which made it virtually impossible to build the sort of culture that was needed.

In the ACT, I believe, it's run by a non-government organisation and I believe in Scotland it also has got some problems, but I haven't really read up on that. I think the West Australian model as it was enacted is excellent and on the message stick you'll find a piece that was written by Alan Grimsley who introduced local area coordination in Queensland. That was before it was instituted, so it's very much based on conversations with Eddie Bartnik in Western Australia and it's probably one of the best pieces I've seen come out of a department.

MR KALISCH: Just one question in terms of, I suppose, your understanding of your regional environment and the types of services and facilities and infrastructure there is. Can you see this sort of National Disability Insurance Scheme operating well in your region or is it something that is more applicable in an urban environment?

MR HOMAN (CCDA):   I think it will work very well everywhere if we can create this empowering environment. I mean, we can't empower people, but if we can create an environment that is empowering - and if we get into Maslow, most service providers will deliver the first and the second level; institutions only deliver the first; not many deliver at the third level where we acknowledge relationships. In fact there are still plenty of organisations and departments that frown severely on people having relationships with their clients, so we need to break through that. The fourth level of creating an environment of empowerment is rare. I think it does exist.

I mentored a self-directing team for my daughter at one stage and the only rules there were, "Whatever you do has to be demonstrably in Amanda's interest and negotiate with Amanda," and because they were empowered to that extent they were able to empower Amanda. That is the sort of the relationships that we need to get into and you can only create an empowering environment if it's from the top down. I mean, if the management committee or the directors or the CEO are hierarchical it's impossible to create an empowering environment at the coalface. There needs to be people in it..

MS SCOTT: John, you have some questions?

MR WALSH: Yes, I do, Patricia. Thanks very much. My questions are around really almost the opposite of David's question. The way you've described necessities for a system seem to me to be relationships within the organisation, and between the person receiving the services and the organisation, which, in my view, sounds very appealing when it's a relatively small group that we're talking about.

I can see that working quite well in a regional centre .... which was about the unequal status of people with a disability, going back to Jane Eyre and Dickens and so on, and I think that still exists, and many people have told us that still exists, that in the broader community, there's an unequal balance of power and it's an attitudinal inequity, where the broader community is perhaps not yet ready and able to accept a relationship with people with a disability. I think that problem is likely to be more manifest in urban centres than in regional centres. You know, I live in Sydney, a city of 4 million people, and it's very easy for people with disabilities to be lost in the crowd and while they might have a .... very difficult for them to develop relationships in the broader community. Have you thought about that?

MR HOMAN (CCDA): I think there are problems in urban settings that don't exist in the country, and vice versa. I go again back to the Local Area Coordination in Western Australian, which started in Albany, a long way away from Perth, but it's now fully introduced in Perth and surrounding areas as well and has been successful there. So I think that the anonymity in the city can be helpful; it can also be harmful. People have communities that interlink with other communities that interlink with other communities, and that will still happen whether it's the city or in the country.

I think in the country one of the problems there is that everybody knows what everybody else is doing, and that can be a problem. I mean, you don't have to drive up in a marked car that says Blue Nurses or anything like that, you know, you can go there in your own mud-spattered car and they'll still know what's going on. So I think that can be a problem. What I think is a bigger problem in the country, particularly when we're getting away from urban centres, when we're getting out to places like Blackall or Longreach, is that there are no funded services there.

By having a Local Area Coordination type of set-up there, there is an interface then with the funder, it's possible then not to go through a service provider to get a service, because local people can be engaged and the service provider is 200 miles away. So I think that for the country this would be very beneficial. When you get into areas out west where you have a population density of four people per hundred square kilometres, it gets pretty hard.

MR WALSH: My question, John, is more about what happens when the person with a disability needs to or wants to venture outside of their community. So I take your point that there are communities within communities within communities and they all interlink. One of our aspirations is for people with disabilities to be able to interact in the mainstream community. How do you envisage the attitudes of mainstream Australia being able over time to accept with disability as equal citizens?

MR HOMAN (CCDA): I think the critical there is over time. I don't think it will happen immediately or quickly, but I think it's something where we need to lead rather than follow. I think that if we provide the leadership in this and set the examples - I mean, that's the only way we're going to change the world.

MS SCOTT: John, any further questions?

MR WALSH: No. Thanks, Patricia.

MS SCOTT: Thank you very much, John.

MR HOMAN (CCDA): Thank you.

MS SCOTT: Fiona Anderson-Porter is next. We might just take a two-minute break. There is cups of tea and coffee outside, but if you could be back relatively quickly, we'd appreciate that. Just a short break.

MS SCOTT: Good morning, Fiona. Would you like to identify yourself and the organisation you're representing and start with your opening statement, please.

MS ANDERSON-PORTER (AMAH): Good morning. My name is Fiona Anderson. I'm here representing myself and my family. So it's an individual representation. But I also made a written submission on behalf of Australians Mad as Hell, which I co-founded. So although my representations are basically individually based I'll probably refer to information that we gained as part of the Mad as Hell campaign, because there are obviously a lot of overlaps.

The first thing I wanted to do was to thank you for the opportunity to express our views. It isn't something that most parents take lightly, because many parents feel that their views simply go unheard, which was the reason that another mother, Sue O'Reilly, and I set up Mad as Hell, because we wanted to give people an opportunity to express their views in a way that was safe, that they didn't feel there were any repercussions from doing so.

You have received so much fantastic information from listening to people's detailed experiences of their own individual circumstances and, to sort of avoid going over all that again, I guess the focus of my individual presentation today is to try and explain the circumstances and experiences we had as a family - one of our kids has a severe physical disability - when we moved from Sydney to Brisbane. I have said in my written submission that it was like moving to another country, and it really is that ridiculous. From an individual and a family perspective, I have carved it up into three aspects that I wanted to try and refer to today.

The first aspect is the issue of so many different systems not coordinating and integrating, resulting literally in us feeling like we were travelling to another country. I think much of the anxiety that we as a family felt - and I know through Mad as Hell that many other people feel exactly the same way - could be eliminated by stripping down the layers of bureaucracy and admin and treating people with disabilities and their families just the same as everybody else. I will give some specific examples of that in a few minutes.

The second area I wanted to focus on - and this is directly related to an NDIS - is, to enable genuine participation in the whole of ordinary life, that a national disability insurance scheme needs to really interlink with all the other areas and departments and crossovers that people find in their ordinary lives, including when n they have disabilities. For us specifically it has been education, which has been extremely difficult, and the health systems as well, and as our son gets older we're beginning to realise that housing is going to be a major issue as well.

The third issue is obviously, as expressed by so many people, for a national disability insurance scheme, or whatever it ends up as, for it to be understood that it's not just about more money, it's targeted intelligent use of money; and I can give examples there of how we could improve our son's life, which would automatically improve our lives, if the services were targeted to what we need.

From the first perspective of changing the way we treat people with disabilities compared to people who don't have disabilities, when we moved from Sydney to Brisbane, which we did about 18 months ago, we did so because literally we had run out of money in Sydney. We had spent well over $450,000 on top of a pretty average Sydney mortgage only on disability-related services and equipment and therapies and treatment and all the rest of it.

We just couldn't continue to sustain that and an ordinary mortgage on one income; we could have on two incomes, but therein lies the problem, that when you have a child with a serious disability it's almost impossible to earn any kind of reasonable income, because there is no support after school or before school or during school holidays. So it's this vicious circle that many people have referred to.

So because we wanted to try and get some control over our life, not spiral into debt as we got older, we ended up moving. We ended up in Brisbane. There is no difference in services in Brisbane compared with Sydney; we had virtually none in Sydney and there virtually none in Brisbane. What it did mean was that we could sell the Sydney house, so that was the sole reason for moving. So we left family, friends, jobs, the whole thing, just to try and give both our kids, really, a chance at a more controlled life, I guess, where they weren't subject to the problems that we had encountered by financial insecurity from disability issues. When I say "both our kids", only one of them has a disability, but disability affects all of us. When my husband and I are dead it is my daughter who is going to have at least some strong moral and emotional connection with her brother and therefore of course it affects her.

So just to give some brief examples of what it's like to move interstate. When my daughter moved with us, to register her car it wasn't such an issue, she just had to get it checked and then just pay a fee and that was fairly easy. To change her licence from New South Wales to Queensland she just had to go and present the licence, there wasn't a fee; it was just a new licence issued. She had no trouble finding a new doctor. To get into uni she just went through the normal processes. With my son, because he's disabled, the wheelchair accessible van that cost us about 86,000, that was modified to Australian national standards in New South Wales and certified by the RTA - the Roads and Traffic Authority - wasn't automatically certified in Queensland. Nobody could tell me that, either. I spent a week of phone calls trying to work out what to do. That of course involved another fee, involved another cheque, and I've got no idea why when it complied with national standards.

So that's just a little example of how easily you can fix that kind of bureaucracy. My son went to a government school in Sydney. We selected a non-government school in Brisbane and he went from being eligible to receive five hours per day funding in disability support at school to one hour a week. So we think perhaps he lost his disability as we crossed the border. Certainly that's what the education system seems to think. That's silly. It just does not make sense to me that you can be assessed as needing a certain amount in one state, you cross the border - and there was no assessment. It was just, "This is what you're entitled to." So that, again, can be fixed by making an assessment and allocating funds and the funds go with the student, regardless of what school system they're in or where they live.

My son is 15, he can't walk or stand independently, he uses a power wheelchair. He's classified as having a severe disability. He had it in New South Wales and he has it in Queensland, but to get what the Queensland education department refers to as verification that he does indeed have a disability, they wouldn't just look at him or take our word for it, we had to get a specialist report saying, "Yes, your son has a disability," which means that you have to be referred by a general practitioner and it took me two months to find a general practitioner who would take our son on his books because they all know that it just is going to mean a lot of red tape and admin for them.

So even though for a start we had the New South Wales education system documentation to show them, all the other features that go with having a child with a disability just weren't acceptable to the Queensland education system. A lot of the people I spoke to in the system were very empathetic but of course their hands are tied; "These are the rules and that's what you've got to do." That, again, is illogical and that can be fixed very easily. The other issue is the discriminatory aspects that we find with our choice not to use the government education system, apart from the lack of funding, which means - I should explain the lack of funding. An hour's funding a week means that no-one is paid to supply personal care to our son; we provide that at school. We provide the laptop, the software, all the equipment he needs. So if it weren't for us, he wouldn't be getting educated; he'd merely be enrolled at the school.

The other thing is, there is no way of getting him to the school unless we live close enough for him to get himself there, which of course dictates where we live. We can't just decide where we can live within our budget. It has to be a house or an apartment which is on a footpath and the footpath links to the school, and all these variables that go into it. He's not entitled to any kind of government transport because he goes to an independent school. The local buses are not wheelchair accessible. So if I don't use our van to transport him to and from school, he can't get to school. It's that simple and it's that stupid; that is just crazy.

MS SCOTT: Can I just clarify, you're paying for the attendant care at the school?

MS ANDERSON-PORTER (AMAH): My husband works at the school and he supplies it unpaid. If he can't do it, I have to do it, and I don't work at the school. Having eventually found a house that we can make accessible for our son and is close enough to the school for him to get himself there on his own, we have to modify it so that it's wheelchair accessible. That again costs a lot of money. It's not tax deductible. Many things to make a house modified for a wheelchair are not things that we would necessarily do. I don't mean ordinary things like having wider doorways and things like that; that's not an issue. To modify a bathroom and to make it safe and functional for him and for us because we supply all his personal care - we have no support from anyone or any organisation, we need it to meet our needs - it costs money.

On top of that this year we have to pay for a manual wheelchair. He's outgrown his manual wheelchair, he's outgrown his power wheelchair. In Queensland the maximum state funding for a wheelchair, we are told, is $5100. The wheelchair that he needs is going to cost around $18,000, which means we'll make up the shortfall. So we'll be paying for that. We'll have to pay for the new manual wheelchair, which will be about 8000. He needs a new walker, which is about $8000, and we have to modify the house as well. So we're beginning to wonder if it was such a good move to sell up and try and regain some financial security.

So we can do that and we are trying to do that. It would make a lot of sense for a disability support scheme to support us with supplying the services and equipment that our son needs. The whole goal of it is to make his current life as enjoyable as possible. It's not just a therapeutic intervention. He's a 15-year-old kid, he deserves to have as good a life as any other 15-year-old kid. It's also to make our lives better. I think it's really crucial that people understand that, while we're his family, we're not his carers, we are his family, but we are entitled to the same safety and security and working comfort that anybody else would be if they were employed to provide those services to him. It all comes at a cost and the cost is just astronomical for ordinary people.

I think all this ties in very much with what we have found in the Mad as Hell campaign, which is an online, grassroots electoral campaign. We set it up just under four months ago to try and get people to understand that if they want to change the system they personally have to take action, and the action we have asked people to take is to take an online pledge of voting signifying that they'll only vote for a political party if they guarantee to commit to an NDIS and individualised funding. After four months we've received just under 25,000 pledges of voting intent and about 2200 emails, communications, phone calls, which I have provided a sample of in the submission from Mad as Hell, which I think gives a pretty clear idea of the range of issues that are affecting people.

As a mother I'm not surprised by the depth of feeling that people have communicated to us at Mad as Hell but it's horrific that in Australia there can be such terrible anxiety about current lives and future lives. It's 2010 and it is still going on and on. So many people have just participated in inquiries like this for years and years and years and there doesn't appear to be anything changing. So we hope and pray that this will be an absolute catalyst for change. Thank you.

MS SCOTT: David, I think, might lead off.

MR KALISCH: Fiona, the grassroots campaign is an amazing opportunity to get a whole range of ideas. I'm just wondering in terms of the submissions and the information you're receiving from people, is it largely about the difficulties they're facing now or are they also thinking about what could be, and ideas for change and what should be put in place of the existing arrangements?

MS ANDERSON-PORTER (AMAH): It's everything really. We try and make it as solution oriented as possible because I think people who live it are best able to provide ideas of workable solutions. So, yes, there are plenty of examples where people are, for example, extremely concerned about accommodation for their children who are currently teenagers and they're trying to prepare for it. You would know; I know so many submissions have already said that it's just crisis driven and you have to basically be suicidal, give up care of your child, and then they get placed in the system. That's useless; that doesn't meet needs, that doesn't solve any problems. Many parents have come up with ways to help themselves, help their own children; buying land, forming collectives and cooperatives.

The feedback we consistently get at Mad as Hell is that their efforts are stymied by bureaucracy and incorrect assumptions about what meets their individual needs, and what they say is disregarded. So the process just goes on until someone simply cannot care for their child any more. Other areas that parents constantly come up with problems with trying to get their solutions acknowledged is education, obviously, where there appears to be a really strong cultural and mental gulf between mainstream education and some non-mainstream education options; it seems to be perceived in black and white rather than shades of grey. Parents are the ones who have been educating their kids at home and doing the therapy, and doing all the other things that happen, and they can't get what they need. It's either one option or another.

There doesn't seem to be any capacity for parents to have a true partnership with education systems - not just schools but education systems - to explain what works best for their child and how it may change over time. That is the issue; it does change over time. Schools seem to have almost a fixation sometimes with a need for teacher aides with children, which is appropriate, absolutely, for some students - for students with physical disabilities and not those with intellectual disabilities in many cases. An aide is not the right tool; technology is.

Yet the parents are the ones, in many circumstances, who are providing the technology. Definitely in the independent system we are because there's no funding for anything else. Having experienced the government system as well I can say that the basic commercial technology that exists, and I'm talking about laptops and online applications, is not used in schools. It's a battle for really basic things like that. Parents are just staggered that that goes on and on. So they're clear examples I think.

MR KALISCH: So, Fiona, in the proposition that we've been asked to consider around a national disability support arrangement, and obviously an insurance-type scheme is one of the models that we're looking at, are there particular features of any national arrangement that you'd suggest we consider pretty strongly or aspects that you'd suggest that we try and steer against?

MS ANDERSON-PORTER (AMAH):   From the submissions I've read and the questions you've been asking, it seems that most people understand that a structure can be designed to individualise services based on express need. What I haven't really encountered, and this is more of a question than a solution I guess, is how it can overlap, for example, with the education system, and I've said this in my submission. There is no point in providing the opportunity for therapy to enable a child like my son with a severe physical disability to maximise how well he can grow and learn if he's not going to be educated. Sending him to school with an aide is not education. There needs to be a massive overhaul of accountability in education for educating children with a disability.

In the current NAPLAN assessment system there is no provision to identify the supports that children with disabilities have been offered and how that links with their educational outcome. There's no reporting of it. There is no perceived use of universal learning design, which is similar principles to universal building and housing design. It seems in education to be a one size fits all, yet again. If there is some kind of think-tank capacity to involve education for teenagers, students, ongoing, lifelong learning for adults, then I'd love to see something like that. I think it would benefit the whole country, and although it may be targeted at students with disabilities initially, there is no reason why it couldn't have flow-on effects to many other students as well.

MS SCOTT: John?

MR WALSH: Hi, Fiona. I'm interested in your views on how well your son has been able to develop particularly at school and how the children at the new school have been able to accept him and relate to him.

MS ANDERSON-PORTER (AMAH): We moved to a certain location in Brisbane because we selected the school. We interviewed a lot of schools and we chose the school ultimately on how inclusive we thought it was of everyone, of all children and all teachers, parents, the local community. So, in a way, the disability didn't come into it although we knew that in choosing an independent school we would have access to virtually no government funding or support. We knew it would then all come down to us. It was that important to us that we find the right school with the right culture that we were prepared to forgo what we had in Sydney.

In general the school he's at now and in some years at other government schools in Sydney, it's not so much a case of being accepted. It's not such an issue with kids if they're used to seeing other people with disabilities. It seems to be more of an issue for adults than it is for kids. I'll give an example of probably the best aspect of my son's school life so far. He's in year 9 and he's 15. At his current independent school last year they had school cricket try-outs, he loves anything that involves sport and a ball, and he bowled up for the cricket try-outs. Perhaps they just didn't know how to say no, but anyway he ended up on one of the school teams. For him, that meant more than anything else, at any school.

From that, it just bolstered his confidence so much. It completed engaged him with the school very quickly. It gave him solidarity with the other kids: there was something to talk about, he was part of a team, he was just one of the mob, which is what teenagers need. It's what we all need, but teenagers need in particular. It's those little things that are so important, that adults can learn from children. There are many other ways that his actual learning could be enhanced in schools, with much better understanding and use of technology.

MS SCOTT: John, anything further from you?

MR WALSH: No, I don't think so.

MS SCOTT: I am taken aback by your experience, crossing borders. But on the other hand, I had a talk to someone just between the border of New South Wales and the ACT last week and they had almost equally shocking stories about the variations between a few kilometres. When you think about a national disability insurance scheme, what's your view about the likelihood that states will still seek to have their own little imprint on it or that we'll still end up with a WA split from, say, a national model or a South Australian version of a national model. Could you comment on that? Would that be acceptable to you and the people who are working with you on

Mad as Hell?

MS ANDERSON-PORTER (AMAH): We understand the political system in Australia and that it is federally and state based. To us, the point of a national disability insurance scheme, and certainly from the perspective of Mad as Hell, is that we think there should be multi-partisan endorsement of the need for change and that it would be illogical of the states or local government authorities to then take actions that contravene the intentions of a national goal, for example, the registration of the wheelchair-accessible vans situation. I can't see why they would do it. Even from a political point of view, it doesn't make sense, it costs more.

But that is where a system as administratively simple as possible is so crucial. If it's set up at a national level and there are national goals and guidelines to be defined, then they need to be carried out at a local level. One could be more stringent with it. For example, in the UK, where once a person has been assessed as having certain needs there is a legal entitlement for them to be met, if the local borough or local council doesn't meet their needs then they can be sued, and it has happened.

I think it would be unfortunate if Australians had to take those steps. However, people with disabilities and their families have had such a gutful of being treated so badly, it will happen. We already have some generalist kind of principles in the UN convention. If a national disability insurance scheme doesn't work or is made too difficult to operate by state administrations or local administrations, I don't think people will take that lying down.

MR WALSH: Could I just ask a follow-up question to that? Fiona, some of the examples you have given about the difficulties in moving interstate were not really about the disability system. So the registration of your van would have been done in Queensland but through whatever the equivalent of the RTA is, I assume, in Queensland.

MS ANDERSON-PORTER (AMAH): Yes.

MR WALSH: I understand you to be saying that the model needs to include the management of people with disabilities by all government departments.

MS ANDERSON-PORTER (AMAH): It's removing the additional layers that seem to surround anything to do with disability. We didn't have to go through a full check of our other car when we transferred the registration from New South Wales to Queensland, we just got a basic mechanical check, like everybody else does, a roadworthy check. But with the van, because it had been modified, we had to go through exactly the same kind of full check that had already occurred in New South

Wales. If there were different standards operating in every state I could understand the logic behind it. But when the van was certified to comply with national standards, why is it being checked again? It was just another layer. It just doesn't make sense.

MR WALSH: Thanks, Patricia.

MS SCOTT: I think we're done. Thank you very much.

MR KALISCH: Thanks, Fiona.

MS ANDERSON-PORTER (AMAH): Thank you.

MS SCOTT: Welcome, Susan, to our hearings today. Would you please identify yourself, for the record, and indicate if you're representing your family or yourself or an organisation, please.

MS FREEME: Thank you. My name is Susan Freeme. I'm here as a parent and carer of a 19-and-a-half-year-old young man with cerebral palsy, my son, and his name is Alex. I am here to share some of my woeful experiences and to make some suggestions for how the system could be improved for families like ours. Imagine that you're a young person who is different in some way and, due to this difference, you're excluded from accessing certain places, gatherings, life events and rites of passage experienced by other human beings, that your every effort to participate in these events mysteriously eludes you.

The barriers are not obvious. In fact in many cases people will openly tell you that they welcome your participation. But they won't change the way they do things for you, "Sorry." It's only when you or your family digs in their heels and says this is not right and that they're all determined to see this through to its bitter end to make it right that someone will sigh and concede grudging defeat; and even then, obstacles will be thrown at you. There will be areas you physically cannot access, places where you can't even enter the premises, let alone use a toilet; and shops or offices where you clearly are not welcome, due to your physical differences.

A simple thing like walking down the street can be a health hazard, because to many you're invisible; or worse, a target. When your family dares to suggest that you could be destined for a life that may parallel that of other people your own age, they are openly applauded, but no-one helps. No-one smooths the path or says, "How can we make this happen easily?" In fact they are told that, "No-one has done this before," or "Someone tried, but gave up because it was too hard; so you may as well not bother," or words to that effect.

Of course in the context of this commission you know that I'm not referring to the plot of John Grisham novel. I refer to the plight of people with disabilities, their families and their carers here and now in modern-day Australia. We are nowhere near being the enlightened society we imagine ourselves being. In fact we personally have experienced situations which we felt were a clear-cut violation of our son's human rights under the Australia Human Rights Commission's guidelines. I can assure you that there is an uprising stirring now here in Australia amongst our families and others.

Our son has cerebral palsy, spastic quadriplegia and is totally physically dependent. His disability can be described as profound under the ABS core activity restriction guidelines; that is, "a person who is unable to perform self-care, mobility and/or communication tasks and always needs assistance". He mobilises in an electric wheelchair and needs assistance with all aspects of daily living. He cannot toilet or feed himself, answer the door, cook a meal, retrieve a dropped item from the floor, blow his own nose or scratch his own nether regions; that's my job.

He also has a critical vision impairment, rendering him unable to see well enough for all practical intents and purposes, such as navigating a wander to or through the local shopping centre. That said, we are blessed, in that he can speak, communicates his needs and wants clearly, has a great sense of humour and an engaging personality. This has enabled him to complete a mainstream education; participate in social activities such as camps and school formal, and access further studies through TAFE. He is a bit of a foodie, watches all the cooking programs, enjoys eating out, and is currently studying horticulture, in the hopes of growing his own produce.

Alex's ultimate goal is to study sports psychology and we're working towards this now. So not bad for a disabled guy. Therein lies the conundrum, it would seem: because he can speak, apparently his disability is less profound, for funding purposes. I would like to point out here and now that for our son there is an enormous gap between being able to say, "I need to pee" or "eat", and being able to physically accomplish either of those things. Because he can speak, he has said he wants a life independent of us. To that end, he moved into independent accommodation just two weeks ago.

The time, effort and energy expended in making this happen has spanned seven years. It is still not ideal, and we are run ragged trying to source solutions to providing care and carers for him, including scaring up funding from a system that is already sucked dry. The first answer to every single thing that Alex has ever done - and succeeded at - has been, "No." He and we have proven the naysayers wrong in every single instance. If we'd stopped at the first "No", he would never have accessed educational, social, respite and sporting options that he now holds dear. But advocating that strongly - and, yes, aggressively - is tiring, and we're just about worn out with it.

If the health issues such as depression, fatigue, injury and impaired mental health generated by divorce and social isolation experienced by carers were a workplace occurrence we would all be counselled, treated, put on a sickness benefit - which would far outstrip the totally inadequate carer payment - and be given light duties for three to six months before being assessed for a more suitable role. As parents and carers, we continue the very behaviour that has caused our injury, because we have no choice. Our love would keep us there, if nothing else. The very best we can expect is a short break, by sending our loved one off to respite, or temporary intervention in the form of a perfect stranger coming into your family home to take over where you have left off.

Caring for a disabled family member is a bit like having an invisible time-thief in the house. The disabled person has been denied access to an ordinary life, but so has the rest of the family. Our carer role steals our time for socialising, for cooking and cleaning, for spending time with other loved ones and nurturing and meeting the needs of other family members. It steals our capacity for self-maintenance, self-improvement and intimacy. It steals the capacity to be mother and child, turning that relationship into some sort of warped nurse and patient roles. It steals the capacity to spend valuable time with a terminally-ill parent, and that particular grief never leaves you no matter how much time passes.

The word "impromptu" is no longer in our vocabulary. The energy required to manage our day-to-day existence does not just extend to home and personal care duties. There are mountains of forms to complete. Often the same forms are required on multiple and separate occasions for different agencies. We manage issues which require enormous energy, in terms of advocacy and support. There are phone calls to make, emails to be sent, appointments to be made and attended, and consultations held to access equipment and services; then there's therapy - physiotherapy, speech therapy, hydrotherapy; or, for us, physical support in terms of study and assignment commitments.

Our son can think and is highly intelligent and articulate. But, due to the cerebral palsy and accompanying lack of developed fine motor skills, cannot write, and we to date have been unable to influence his teachers or tutors into allowing his work to be submitted into voice format; a battle for another day. In light of this, it then smacks of the ridiculous that families are asked to generate informal supports and a circle of friends to provide what is required for our family member to live independently.

What constitutes "informal support"? Are we talking unpaid care? Who, amongst those we know, would do that when they have their own families and mortgages. If they do have spare time, they're working a second job or nurturing their own families and social networks. What circle of friends? After a few years, we don't have one. We can't be bothered socialising, because we're too exhausted, and no-one invites us anyway, because it's too much hassle to accommodate the person with the disability.

I would like someone to explain to me why, since our son was diagnosed with cerebral palsy at the age of 10 months, we have not received any more than four hours of support a week? Does anyone truly imagine that it only takes four hours out of my week to care for someone who is totally physically dependent? You're kidding, aren't you? That being the case, who could be surprised that families like us eventually relinquish care of their adult disabled children because the system refuses to assist them with support and forces a crisis situation.

How are we supposed to live with ourselves having publicly stated that we are unable and/or unwilling to care for our family member? We are forced to that action because the system only responds to emergency and crisis. The current processes are so mysterious as to be unfathomable to the normal end-user. Processes - including criteria, financial support, other supports and departmental information - need to be made public so that they are user-friendly and not just department-friendly.

Planning and implementation of an independent life for a young person with high-support needs should be a five-year process, commencing as early as possible for the nominated person. Issues to consider include: where will they live; who will provide care; will they access day respite, work or study; will they access the greater community, and how can they be supported to do so safely; and who will manage their affairs now and into the long-term future. These are not issues to be discussed at the eleventh hour when the person with the disability is about to turn 18 and be abandoned by the system.

I can tell you from long, hard experience that these are difficult issues that take years of planning and consultation. We started planning for our son's independent life when he was just 10 years old. I believe that the age of 10 is an appropriate time to commence planning, for a number of reasons. I would like to suggest that if the system can provide funding in a crisis situation in excess of 150,000 per person per year, then funding and early intervention could and should be provided to prevent the crisis ever occurring.

Here are some ways in which I believe that 150,000 per person per year could be better spent. Firstly, it's not just financial constraints that prevent people with a disability from living independently; it's the whole issue, faced by all families when a child of age leaves home, of letting go. This could be a gradual process over many years of visits and stays of respite, finding ways for the young person to engage in their local community so that they are known to others outside the family unit, and teaching the young person where possible to advocate for themselves so that they too can deal with the myriad issues facing one who desires an independent life in a society where this is deliberately made difficult.

If communication issues exist, then advocacy should remain with the family, not an outside agency, unless the family chooses to be relieved of this responsibility. Applications for funding to enact the wishes of the nominee in pursuing their independent life could be lodged by their 16th birthday at the latest, to allow for financial supports to be budgeted for and provided. Surely, two years, as a minimum, is enough for any government body to budget for one person's needs. Funds could be made available to the family no later than 120 days after the person's

18th birthday.

In the 24 months between the application being lodged and activated the family could be assisted to explore their chosen path with support from a permanent key worker. This key worker would also be responsible for assisting the family and setting up the infrastructure for the young person's independence. Depending upon their choices, this could mean applying for community housing. A relaxation of criteria to allow this to happen would be timely and surely beneficial for planning for that department, generating quotations for extensions to the family home - for example, a granny flat or other modifications - finding supports for study, work, special interest and social opportunities.

They would also need the tools of life, which we all require, such as bank accounts, passports - if for no other reason than to facilitate ID requirements; an 18-plus card, at the appropriate moment; taxi subsidy card, or other transport facilitation; and an ATM card. Of course they will already have their Extraordinary Person card, which, with just a swipe, negates the need for ever filling out another form for service, equipment or financial support. Well, okay, I made that up; but it's not a bad idea. Their own email address and perhaps a PO box or separate letter box would further engender the first feelings of independence. This could all be achieved with a standard checklist which the key worker would assist the family to enact.

Another huge advance would be the establishment of special interest respite programs. Why should the same bunch of people be herded together for the government's convenience due to the nature of their physical, intellectual or social limitations, all doing the same thing when all they have in common is their disability? My son has three peers who we met when our children were diagnosed at around the same age and accessed services together at the Cerebral Palsy League. Our children, whilst united by the disability as very young children, could not have more widely differing interests as young adults. One has a burning passion for sport, one for Beatles memorabilia, one for wheelchair dancing and one who doesn't care too much what's going on as long as his brothers are there.

Why not band together a bunch of like-minded individuals pursuing a common interest as occurs in the real world. This is not as far-fetched as it might first appear. There are already organisations and service providers who generate these opportunities however they, too, are limited by lack of funding. Organisations such as Sporting Wheelies and Disabled, Riding for the Disabled and Crossroads could all work towards reducing the demand for day respite by providing genuine and ongoing opportunities for young people with disabilities to live full and interesting lives. The ultimate goal would be to generate paid work or small business opportunities which would then be utilised to improve quality of life for those with disabilities and their families.

Finally, there needs to be a consistent qualification for support workers and good incentives put in place to attract entry into the industry. Contracts which provide free training and attractive remuneration in return for a commitment to two to three years minimum to the industry and preferably to a person or family, would see workers and families bond and work together more coherently to provide care solutions for the nominated recipient of support. Sourcing suitable carers or a suitable pool of carers which does not rely upon the family to continue to provide unpaid care, unless they choose to do so, must be a key element in alleviating one of the greater causes of stress to families like ours.

It needs to be said that had something along these lines been in place when planning an independent life for our own son, he would probably now be living in a purpose-built granny flat at home, with us there to provide companionship and a roster of carers in place. As it stands, even we, as loving parents who have planned ahead, have found ourselves in a situation where moving our son from the family home into separate accommodation was the only way of ensuring that my care-related injuries could be attended to before they worsened and became life-limiting for me. How would we cope if I, too, became disabled by nature of my carer role?

Parental carers need to be recognised as professionals in their field. No-one knows our kids as well as we do and no-one can plan better for them than we can. Our decisions need to be respected and more information and consultation to families is required in a more timely fashion. Parental carers need to be remunerated in line with their professional experience. The Carer Payment is an embarrassment to the government. Many of us are forced to abandon promising and lucrative fields in other fields to become full-time carers. Our experience is the equivalent of a long and difficult masters or doctorate and should be recognised as such. Much of the stress we face is financially generated and if we are expected to approach care of our disabled family member in an informed, full-time capacity, then we should be remunerated accordingly.

Raising a child with high support needs could well be compared to running a small business. Certainly the same elements exist: financial accountability; long hours; time management and staff management issues; workers compensation issues; hard physical labour; day shift and night shift, frequently both and concurrently over decades; menu planning and meal preparation; applications for funding; attending meetings and holding consultations with medical professionals, educational professionals and in some cases advocating aggressively with politicians, ministerial aides and other senior public servants. Show me another job in the world where just one person performs all these roles.

I reckon I'm worth about $150,000 a year just in the services I provide to my son; never mind the unpaid assistance and advice I provide to other families, some of whom are perfect strangers who approach me due to my own dealings with the system. Time and time again I hear and have read in many other submissions to the Commission that people feel they have fallen through the crack of disability funding. We, too, have found this. Despite our son's severe and lifelong disability, we receive very little help. We don't fit the criteria. Well, where is this criteria? Who dictates and administrates it and how is it humanly possible in this enlightened day and age that a person with our son's physical limitations is not automatically funded to live a full and productive life - as full and productive a life as possible. There should not ever be a crack for anyone to fall into.

Families are currently wholly financially responsible for alterations to the family home, the family vehicle and for the shortfall in providing all medical aids, in-home support and equipment. Our investment over the 19 years of our son's life would be in excess of $750,000 and we are one of the fortunate families who had that to invest. What happens to other families, many of whom are single parents - as I was for a time before meeting my current husband - who are struggling just to pay their rent and put food on the table. At the very least all of these things should attract tax relief with funding available for those that cannot afford the enormous initial outlay without support. Another submission has mentioned interest-free loans and I think that would be a good start.

The great thing is that if families were funded sufficiently to manage their own affairs, including equipment, care and modifications to the home and vehicle, the moneys would quickly be returned to the government coffers by way of job creation. More jobs in the areas of support work, building, vehicle modification, education, therapies of all kinds and types, can only be a good thing for Australians with a disability. We've all heard of the Stolen Generation; well, we're the "hidden generation" and I have it on good authority that many of us will remain hidden no longer. We are fed up with being at the bottom of a pile that sees greater political and economic value in saving the planet than in caring for the disadvantaged and weaker members of society. A civilised society should build, invest in infrastructure, manage environment affairs and encourage participation in the arts and sport at all levels, but a civilised society does not do so at the expense of its weakest and most defenceless citizens. Thank you.

MS SCOTT: John, would you like to ask Susan any questions?

MR WALSH: Susan, thanks. I could ask many questions. In your submission you said that you thought your total investment to date was $750,000. I'm assuming that's out-of-pocket expenses, not including the cost of your care - cost of your labour?

MS FREEME: That's correct.

MR WALSH: So that's roughly $40,000 a year, do you think?

MS FREEME: That sounds about right, John, yes.

MR WALSH: I just wanted that for the record. My other question relates to you mentioned that the ideal situation for your son would be a self-contained granny flat where you were available as a carer of last resort, if you like, with him leading a relatively independent life. Failing that, for people who don't have such a supportive family as you obviously have, we've had people put forward ideas of clustered housing with full-time carers in existence or a block of units with a live-in support worker as well as their own individual care workers. Have you given any thought to those sorts of models?

MS FREEME: John, we have, and in fact my husband and I were very involved at one point with the Wesley Mission. We'd held a meeting with representatives from Youngcare to ascertain whether our son would fit their criteria; he didn't, and they referred us to the Wesley Mission as a possible partner for a joint venture of our own. Now, we spent three years in negotiation with the Wesley Mission and in fact held a meeting with the Wesley Mission and Senator Bill Shorten and it's just never come to fruition. I think the wheels of the corporate world turn ever slowly and in the end our own son's needs had to come first and we moved forward with our plan B. We believe the Wesley Mission is still pursuing exactly the idea that you suggest; an apartment complex of 10 with a number of young people with similar levels of support needs and funded as a group situation. I don't believe that to be an ideal situation for our son. I think he's a lot more savvy than that. He's a lot more regular and needs to be out in the world experiencing life as other 19 and 20-year-old young people do, and I think that's the most important issue for him. Yes, that was certainly a model that we considered and looked at for quite some time before deciding it wasn't for us.

MR WALSH: Thank you.

MS SCOTT: So what is the outcome of seven years of activity? I took it from your testimony right at the start that your son now has moved out.

MS FREEME: Yes, our son has moved out. He has now been there two and a half weeks. He was offered a wheelchair accessible, purpose-built apartment by Community Housing. Having said that, we were initially told by Community Housing that he was not eligible because he resided in the family home and we had to make a very strong case for the fact that as a young adult in a wheelchair our family home was no longer suitable and in fact he was causing damage to the home and injuring himself, and potentially injuring his younger sister, who's 10, by remaining in the family home in an environment that in fact is not purpose-built. The family home has been modified to the greatest extent that it possibly could be and we could no longer modify it any more to accommodate him. So our only other option was to move the entire family and we didn't think that that was a viable option. His little sister is entitled to have stability in her life and we felt that maintaining the family home was an important issue for her.

MS SCOTT: Thank you for that. Now that he's moved out, and he's only been there a relatively short time, what level of assistance is the government or any other service providing him?

MS FREEME: That's a tale with a sting. We do have emergency and crisis funding in place at the moment. This only came about because my husband and I are very persistent and aggressive in our lobbying. We do not take no for an answer because we do not believe for a moment that there shouldn't be something already in place for this situation. So we in fact negotiated at the normal levels with Disability Services; we got nowhere. I spent three weeks with a phone glued to each ear and Disability Services telling me who to ring next, and it was people like Blue Care and UniCare and Spiritus and all of those sorts of people.

After three weeks, I kid you not, I got a phone call from Spiritus telling me that what I really needed to do was apply for a package with Disability Services. I burst into tears and I said, "We've already done that. We did that two years ago and Disability Services told us to come to you." I felt like I'd had my foot nailed to the floor for three weeks and I was jumping round in circles. It was just an utter farce. So from there we emailed Senator Shorten again because we've maintained contact with him and kept him abreast of our progress. We emailed Annastacia Palaszczuk's office on several occasions and fairly aggressively. We emailed Premier Anna Bligh and received no response.

Ultimately we threatened to engage the services of a human rights lawyer, and only then did some very senior members of Disability Services come and hold a meeting with us to offer us some options that we felt were viable. I have to say, we were deadly serious about that; we were absolutely confident that we had a case and we were quite happy to engage the services of a human rights lawyer to act on our behalf or on our son's behalf.

MS SCOTT: Your son is now in receipt of emergency crisis funding for what would be a permanent parameter?

MS FREEME: As I understand it the situation is reviewed every three months.

I've been told that that is a formality and that that arrangement will remain in place for as long as it's required. So that's my understanding of the situation. Whether someone else changes the rules somewhere down the track is something that remains to be seen. I find that untenable as well. That creates a level of stress in our family life forever, virtually, that shouldn't be there. We should be able to sleep at night and Alex should feel comfortable in his own abode that nobody is going to come along one day and go, "You know what, that emergency and crisis funding is no longer available." Whilst it's a good bandaid, it is just bandaid.

MR WALSH: Susan, can you describe what the support looks like and who it's provided for, and what's the network and coordination and so on?

MS FREEME: Yes, certainly, John. We've been told that Alex can access 65 hours per week of carer support plus overnight stays. Now, that is by no means 24-7 support and I personally will be filling in the gaps. So I'll now be shuttling back and forth between home and Alex's place to fill in those gaps, and that's okay, I can live with that in the short term but you might not like my response to that in five years. That's being funded, as I say, by Disability Services emergency and crisis funding. It's coming through a service provider and they will administrate those funds and source the carers for us.

MR KALISCH: Susan, you talked about the role that a key worker could play. I'm just wondering whether you can just expand on that because it seemed to be quite integral to the type of model and assistance that you thought should be in place?

MS FREEME: I think that's so important. Over Alex's lifetime we've dealt with so many different so-called professionals that it makes my head spin. It sometimes appears that just when you're making a little bit of progress that person transfers to another area or is offered a promotion or leaves that area of expertise, and you're right back at square one and you have to tell your story all over again. That wears thin, not just because it's a little bit annoying to have to repeat yourself, but it's actually very, very stressful to have to continually repeat all of the things that your disabled child cannot do. I just about weep every time I look at a Centrelink form. I almost can't do; I honestly almost can't do it. I have to work myself up to it and have a couple of wines and have a big cry, and only then can I tackle it because it's just depressing. I think that's so unnecessary. How many times do you need to tell the story before there's no more need to tell the story again?

So I think a key worker is, as you said, integral to that process and that key worker should, where possible, have that family for that period of time, at least between the commencement of high school and the age of 18. I think over that period of six years all of those things can be put in place. I accept that not every family wants to plan for their young, disabled family member to live away from home or independently, but what I've been trying to say to some of the families I know is you can't have no plan at all because therein lies a path to marital breakdown, mental stress and fatigue and there's even been sad cases - I read some of the other submissions - where one parent committed suicide. Now, I think most of us are a bit stronger than that but I don't think that negates the fact that that can and does happen.

So have a plan. Even if your plan is to not have a plan, you still have to sit down and think about, "Okay, my young person is not going to live independently, but what can I do so that when they're 25, 35, 45 and 55 if, God willing, I'm still here - how can I engineer it so that I am not still my young person's primary carer." It's insane to have these poor, elderly carers who are still caring for 45 and 50-year-old family members who have severe disabilities. That's absolutely and utterly ridiculous. So, yes, I do think planning is the key and I do think that having the consistency of a key worker who can manage those affairs for that entire period of time, or at least with minimal changeover of staff, is absolutely essential to the success of that type of project.

MS SCOTT: John, any further questions?

MR WALSH: Just one more quick one, Susan. You mentioned in your testament that you've had endless interactions with therapists and medical professionals and others. I'd like you to just talk about the extent to which medical professionals and health professionals and others - can you just describe your experience with ....

MS FREEME: I lost you at the end there, John, but I - - -

MS SCOTT: Yes, John, we got up to the stage where "your experience with" and the next - - -

MR WALSH: Yes, I'd like you to just talk about the extent to which medical professionals and health professionals have assisted or impeded your life?

MS FREEME: Yes, look, we have had a love-hate relationship with all of Alex's medical and health care professionals. Again it has often been a case of them making recommendations which they just assumed we would accept and take up and run with, and I often say, "Well, no, we don't think that's right for Alex." Again, a problem with changeover of staff, through the Cerebral Palsy League I think we have had something like nine speech therapists, 11 occupational therapists and perhaps three physiotherapists over his lifetime. Quite frankly, most of them, although not incompetent, were mostly graduates, because they're the only ones who are willing to accept the very minimal salary packages offered by these type of service providers, and mostly I was leading them and they were not really that much help to us.

If I had listened to every single thing that these young therapists recommended over Alex's lifetime he would have been trussed up like a turkey and not have achieved anything. I'm serious. He would have had a halo and wrist splints and AFOs and a brace on his torso and God knows what, and there were times when in consultation with our son we simply said, "No," and, "We will bear the consequences of our decision somewhere down the track." I think there's far too much made of recommendations and pressure on the family to accept everything that the medical and health professionals recommend as gospel and not enough credit given to families who are able to make a decision for themselves or individuals who can do that as well. So, yes, it has been a love-hate affair.

MR WALSH: Thank you.

MS SCOTT: Susan, you're obviously following the work of the commission carefully, reading submissions and so on. Would you end up categorising yourself as a supporter of a national insurance scheme?

MS FREEME: Yes, I would. I'm a little bit nervous about that idea, because we don't yet know what form that will take. I would hate it to become another white elephant, where families like us are forced to fill out more forms and join the queue and be on a waiting list and so on, because in fact being on a waiting list for things like essential equipment, like perhaps a wheelchair, for our son has meant that one of his feet has actually become a little bit deformed because of the position it was held in his old wheelchair, which he was in for far longer than he should have been.

He was probably in that old wheelchair for two years past where he should have been and his right foot now sits in a very unnatural position just by nature of having been in that wheelchair for too long. I think two years is an unacceptable length of time to wait for an essential piece of equipment. We're not talking about buying a new car, for God's sake. So yes, I think that the national disability insurance scheme is a wonderful idea in essence but there would need to be a strong commitment to ensuring that families can access what they need immediately or with the minimum of waiting time.

MS SCOTT: Thank you very much.

MS FREEME: Thank you. My pleasure.

MS SCOTT: Okay, John, we're going to try and replace this Polycom, but we'll continue with this one for the moment. Mary, welcome to the table again. Good to have you back here today. I have just asked Mary if we could have a little bit more than usual opportunity to ask questions, because there's quite a bit of material in her submission into which I'd like to be able to just dig a little bit deeper. Mary, if you could identify yourself for the record and the capacity in which you are appearing here today and then make an opening statement, please.

MS WALSH: I'm appearing as an advocate, I have been an advocate, but also a parent. I will continue to say I am parent-advocate, because even though we no longer have our son we certainly will always be his parents. Our son had a very rare disorder when he was born, back in the 60s, and we were just told to institutionalise him, and that was it, "Get on with your lives," he wouldn't live past two. He lived to be 40, passed away six years ago, and in that time we had to fight for every single service that we had. He was not even entitled to an education.

Relating to the carer issues of primary care, I had been out there battling I guess for about 40 years, because he was that age when he passed away. The thing is that I am now paying a price for that physical care. In addition, I also was the primary carer of my mother for 40 years as well, and she has just passed away, at 100. My husband, who is now 75, had a heart attack last year, and so I am not his carer. I applaud the fact that I look around here and see so many young parents and so many young people, because so much of where we are at - and it's not perfect - has been done by a lot of people who, as my grandchildren tell me, are crusties. So that's where I come from.

I was the founder of Australian Parent Advocacy. My advocacy is not funded, never has been. Australian Parent Advocacy was never funded, because we simply believed that funding put us at the behest of government, and the government policies were not providing what families or our children wanted. So over a year we built up that network, and in fact I don't think there would be an organisation anywhere in Australia about which I couldn't say, "Oh, yes, I know them," or so on and so forth.

Over that period of time I have been an adviser and an advocate and I have been in a lot of positions where we have come up with policies, schemes, and I don't know how many of these inquiries I haven't addressed. I thank the commissioners for making it available, because I really believe that the time has come where we have to do something. The younger parents who aren't taking what we took - and they shouldn't - will demand that this right be met. I'd like to have rose-coloured glasses and say that all will go well. However, what I will do, so that we can have questions, is I will just make a couple of comments in relation to some of the things today.

I have provided a full submission to the commissioners. Some of those pages remain confidential, because there are a lot of case studies in there. However, I will relate a case study just right here and now, because I think it's relevant, of a case that I was involved in where the mother was 87. I have known this family a long, long time. One of the issues that I am going to be introducing is premature ageing, because it hasn't been looked at. In this particular situation this young man - he is now in his 50s - his behaviour became so difficult he could no longer live at home.

He had been in residential care for probably 20, 30 years. Even though we tried different service providers, his behaviour was putting him at risk and the service providers and other clients were at risk. You won't believe the end result. He went back to his mother, at that age, because no-one in the region could provide a service. I became involved as an advocate, and I had always been an advocate for them. The best we could do was have him transported an hour and a half away to try out some emergency crisis housing. There is no crisis housing in, particularly, much of Queensland.

Some of our crisis housing is motel rooms. It's an absolute disgrace. In that mother's situation she became a prisoner. She could not go out of her room, because he became violent. The neighbours were going to take out a domestic violence order. He escaped one day and went to the place next door where they were erecting a building, he was physically hurt and they had to take him to hospital because he fell off something and cut his arm. Those sorts of things are absolutely disgraceful. We have now addressed that situation, but it should never have happened. We still are fighting for some crisis housing, particularly in Bundaberg, which has some of the highest incidence of disability in the whole of Queensland, and about third in Australia.

MS SCOTT: Can I just check, Mary, how recent was this incident?

MS WALSH: That would have been 18 months ago. We have now resolved that, but that family should not have had to go through that. I won't take up any more time. What I will do is just go through the summary of issues that form the basis of the paper and then just some broad comments, and then I'm happy to answer any questions.

Regional Australia, policymakers know nothing about it. Carers, the various types, that's a very important issue. If there are any foster carers here I don't wish to get them offside, but governments pay more attention to foster carers and they get better benefits than primary carers do, because if you as a family can cope you'll be made to cope till you fall over. Family carers have no legal rights. Not-for-profit service provision is actually at a time of the shrinking charity dollar. There is a lack of uniform portable guardianship legislation, and that could run over to various state entitlements.

I will make a comment here. As a 2020 summiteer to Canberra, representing regional Australia, there were two primary issues that came out of that. There were a lot of others issues as well, but this one was, "Let's get rid of the states," and the other one, a more practical one, was, "There needs to be some national legislation that covers entitlements like education, that covers registration" - like, we have a situation where a truck will go over the border and it then has to change, all that sort of stuff. So they were the two. So that does tie in with the entitlement situation.

Early intervention, a must. Service provision, a business, the paper war and administrative run-around, risks of applying successful overseas models, because there are differences with the Australian psyche and the Australian size. The siloing of services of current funding models - and there is a diagram in there and it's in a public document, I don't think it's marked confidential, it shouldn't be - it actually does show that a person has to access nine different types of services. I could actually sit down and work out extra services within those services, and I'm sure most of us could.

Informal networks, they're unknown and they're unlinked, but they do exist. Australia has a strong set of community linkages and support systems which no-one has ever tried to actually link up, because I think there's a control mechanism there as well. I think while they keep us divided, they control us. But that's a way to me that would actually solve a lot of the problems. Multi-agency competition, disability and entitlement, not charity. Disability and premature ageing, a case study, that's open, that's on the line. Assessment tools and inappropriately-trained assessors, and I have had some experience with that. Integrated, existing federal agency data, which again is a minefield. Centrelink. I don't think there has been a word said here to which I can't relate.

If I use the word "versus", don't get me wrong, it's not like that, it's just simply that there are differences. So lifelong disability versus mental illness and the fact that psychiatric is an illness and not a lifelong disability places it in a different department. It's health, the other is disability, and there's lots of differences there. Social inclusion, some of the experiences have been that some of the social inclusion is taken by ideological purists within the bureaucracy, and unfortunately sometimes not necessarily just the bureaucracy, has led to a lot of inequities. Poorly targeted information and education. The transitional life phases, which become a time of crisis for people who have a disability.

Premature ageing, a subset of disability, I don't believe it's a subset of natural ageing, and my son's situation is explained in there. Family relinquishment, it's an inhuman process, I have been through it in the last 18 months with families of two adolescents; and I went through it with my own son, as an individual, that's the only way I could get the money to give him a package. There's a difference between child and adult, because with the adult situation families lose guardianship once the child turns 18, and in my circumstances we applied for guardianship of our son - a very rare disorder - and we were knocked back.

So I then threatened to take them on again and I was prepared to go to the Supreme Court. So I demanded another hearing, because under the Guardianship Act you cannot be reheard, they cannot change the decision, you have actually make a full application and go through it all again. But I did that and said that if we missed out this time - but I also involved the media. In fact in some of these things that I have been involved in I have involved the media, for which I was criticised because I was "using our son to gain, for God's sake, a public profile". The reasons for the increasing incidence of disability.

Then just the ones that that have come up yesterday and today, flexibility versus accountability, training versus value, the problems that arise with legislation that says one single service provider cannot be involved in the total care. Also, from the broad perspective, the problem with any national scheme is always going to be, as it will be with the health one that's now being proposed where it's going to be 60-40, that coming from a low base - which this one may have to come from originally because there's no build-up of funds initially - then you're always going to have state providing the services, and I do not know a successful way of getting the state imprimatur off some of those things - like, the issue of education came up before - because, unfortunately, there is always this political will and political whatever it is.

But there is a problem. It has to be done, but we have to devise a way to do it. In my submission I have detailed my experiences and the time it may take us. I also have had 11 years experience as an elected councillor. I was also a member of an Australian local government task force and very involved in developing a framework for women in local government. I really strongly believe that the linkages between state, federal and local are not strong enough and that's because they all try to do their own thing. But I still believe that that's an area of great inefficiency, when we talk about regional Australia.

Every region and territory in Australia has a local government. So what happens is you go and build these things, Centrelink or the federal government comes into town and we have got a Medicare office and a Centrelink office, now we're going to set up a Carelink office and it's going to be a separate building with a separate staff. There's another national service, I can't remember the name of it, but it's useless. There seems to be this tokenistic way of putting service provision and hierarchies in place so that you can say, "Yes, but we are addressing that," "We have a committee doing this," and "Yes, that service is there." Some of those services are useless, I'm sorry.

The other one is a strong plea that we do not go to - and this will upset some people - total individualised funding. There needs to be a mixture when you're talking particularly regional Australia, because you've got people who have to access extreme distances to get a service, for example in the Bundaberg area. As I said, I did 11 years on there as a councillor and helped develop their social plan, which led to the development of a network, that I can go into, aside from this, in more detail. But those networks do work.

The issue for people with physical disability and mental competency and how we can actually make life better for them is that perhaps some of the family modifications, if government has a flexibility issue or an accountability issue about, "We should not be giving you money to modify your house," so on and so forth, perhaps there's a way around that - and I am an accountant by profession - by providing some tax deductibility for some of those issues that relate to certain individuals. Now, there will also be cases where some of the people who are providing that care are not in a position to pay tax - trust me - because they've just spent their whole life and all their money providing services for their disadvantaged children and adults. So I think that the tax deductibility issue has to be looked at.

Also where we have young carers - and I've dealt with some of those as well - then perhaps some of the work that they do - and again we have to go back to regional Australia where we don't all have universities and some of our kids actually have to travel to go to university. The parents may have no income or they may have a business which on paper makes an income but their kids are not entitled to the Youth Allowance that gets them there, so they have to apply under independence. Those hours of work experience have now been increased, so some of those people are in fact carers of young people with a disability. So why don't we make some of that care a work-related time.

So instead of going to university after they've done 18 months - my grand-daughter says it's 18 months - why can't we say, "Okay, some of those hours" - and maybe you have to do a ratio, I don't know - "actually become work," because, as we all know, it's hard work. Then they'll get there earlier. Then the system will be forced to kick in because the kids are actually doing it tough. The other one that hasn't cropped up much but it needs to be mentioned is families with multi-disability. I instanced a case yesterday, and it will be on the record, of a family who have three - 50, 52, 54 - but I also have a family who have four children, three of whom are autistic in various degrees and the husband has gone.

There is not the extended of family support that there should be because some people, for whatever reasons - career options, whatever - they no longer live near family support. In fact I've got three children and two of those live away from home because that's where their careers have taken them. So there are many, many families now that the old, stable unit with the support is not there. I think I've said enough. I'm happy to take any questions.

MS SCOTT: Mary, thank you very much for coming back two days in a row and appearing in front of us. I found your submission evoked a few questions. We've spoken to one jurisdiction about relinquishment, but relatively briefly and it's something that your submission does cover. I'm particularly interested in - although I'm sure it's harrowing to talk about - the recent cases that you've been involved with on relinquishment. One of the stories we heard from one of the jurisdictions, we asked a question about just how frequently it occurs and they explained that it was relatively frequent and it was now accounting for a large proportion of respite facilities. I'm not familiar with Queensland's experience. If you could tell us something about how frequently you think relinquishment is occurring and under what circumstances. You're obviously giving examples here of how difficult it is. Could you just talk about that briefly if you're able to?

MS WALSH: Yes. I obviously can't make it too specific. This is the public record and one of those case studies, again, is the parental - I have permission for these to be used but I don't have it in writing and I'm sure they don't realise it will be on the net. So perhaps if I can just talk about my own situation first, which was I was in a position where my son needed one-to-one care. As I said, when he passed away at 40 he was the oldest living Australian with that clinically diagnosed disorder, which was Williams syndrome. There are now 327 people with that in Australia, but we had nowhere to go. We just trailblazed everything.

So that was difficult because at the time that there was an issue with his health, he had been sick, my mum had been sick and my husband had his first heart attack. I had to come to Brisbane and I had to stay here because of my husband's health. It was crisis and I couldn't get any assistance. Not only could I not get assistance for my mum when she came out of hospital to be showered, I had to fly my niece and my two nephews down from Alice Springs to actually be there to live with her because we couldn't leave her on her own. She didn't haven't an up-to-date ACAT assessment. She had been living at home; she lived at home until she was nearly 97.

So that lack of care there meant that I was in crisis. My son was in crisis. Because of everything that was going on around him, he wasn't able to emotionally deal with it and he got into a situation where he was in legal trouble. I still couldn't get any help. I said, "I need a one-to-one package." The only thing that I could do to absolve responsibility and ensure that he got assistance was to physically write to the

Premier and say that I no longer accepted responsibility for my son's care and, what's more, I no longer accepted responsibility for any harm that may come because of his behaviour on any member of any service that he was attending or the community in general. I got a one-to-one package.

That one-to-one package was too inflexible. It gave him the best quality of life that he had had in two years, because it was towards the end of his life sadly. The issue was that it was a one-to-one package for an individual and I said, "My son doesn't need one-on-one care everywhere he goes. Can't he share that package? That is, if you're going to take him fishing - his behaviour is not that erratic when you're fishing - couldn't you take someone with him?" "No." It was just him and the one-to-one support for those two years. That was because, "Sorry, but we can't split that. It's been allocated to him and he's the only person entitled." Now, if I move to the relinquishment issue for children. That's a relinquishment for adults because we had guardianship and that made it easier. Had we not had guardianship we'd have had no control at all.

MS SCOTT: I'm just a little bit curious; why weren't you actually the guardian anyway?

MS WALSH: The law says that once they turn 18 you've got no say in lifestyle. I was very heavily involved in the introduction of legislation in 1998 to bring in the enduring powers. He had an operation and I didn't have the power to sign his form. I sat beside his bed for six weeks because no-one could interpret what his needs were. He nearly died three times and he had three operations in 13 days. I was not legally entitled to sign that paper. He couldn't give me an enduring power of attorney because he didn't have the legal competency and we didn't have enduring powers anyway.

That experience we fought and I wasn't the only person involved. All of these groups that are here speaking today, we all worked together to get that. So we got enduring power. We got the Enduring Powers of Attorney Act which gave us health attorney status and brought in the Advance Health Directive. That's why you can't automatically get guardianship. We've had people who have come perhaps with guardianship from another state to live here; those guardianship laws don't apply. "Because they got them in there; you can't have them here," which is the same sort of issue. So having no guardianship as an adult creates that issue.

Now, if we move to the children, to the adolescents. I have mentioned and I'm sure you would be familiar with it, the crises that develop at every stage of transition. I've dealt with a mother who took home from hospital a child who was destined to live a month. With her love and support the child lived to be nine months. Where do you put them? Where do they go? She had other children. So they're not supposed to be in respite. Respite - centre-based respite - is supposedly short term. How do you send someone who's one month old - where do you put them? They say, "Well, you take them home and we'll provide the support." Sadly, they didn't provide the support. That's a very young one.

So we were given the option of institutionalisation, which I wouldn't accept and many people didn't - then they've got no options. They have to rely on a system where that child had no entitlement, no rights. That child came into this world, no rights, nothing. Using that example and working very closely with that mother, we managed to get a service for zero to eight in our region, and that's all covered in that other paper. So there are all those stages. She still had rights because the child wasn't 18, but how do you exercise them if there's no money and no service?

Moving on to the others where we had families who lived 30 minutes out of the city, there's another one that I will instance broadly. So let's look at it from a parent position and a grandparent position. From a parental position, a child who is profoundly disabled - intellectually disabled, tube fed, wheelchair, non-verbal, no capacity to do anything other than lay on the floor or be in a wheelchair if they're being taken out and whose only means of communication may be screaming and the level of scream is what tells you what needs to be done, and many of you would be familiar with that - if you look at that sort of situation. In both these cases they were boys and both of these mothers are small people. There were other children. In one case this child was the youngest and the other children left home, couldn't get out of home fast enough and, what's more, "We're not coming back." It's not just the disabled child, it's the disabled family. There were heavy medical needs as well, often trips to Brisbane for specialist care. No support. The family had to provide that support.

For a service provider, the system to provide that entitlement, they calculate that it has to be done in the most cost-effective way, which is by car. All they will pay for will be the cost of petrol. Then you've got to pay the overnight accommodation, which is $30. You're not going to get accommodation for $30. Because of the level of needs - incontinent - all of those issues, the family couldn't afford to have anyone do it other than the mother. That's a safety issue as well. As the children grow older they obviously do get heavier. There's the lifting. These were only very small mothers; they couldn't physically do that. They were getting up two and three times a night. In the end they absolutely couldn't do anything. We tried everything. In consultation, the only way out was to actually relinquish the child.

Now, service provision, yes, they had been going to day services and live-in services in residential care, which were excellent, but because they were not children who had been - can I use the word "abandoned", because that's the word they use -

abandoned, then they were putting in insufficient supports for the family to cope. It's not until the family actually says, "I'm not going to get the help I need unless I fall over." In one case there had been a marriage breakdown but the marriage breakdown had been with older children. The thing is that you are expected to care. It doesn't matter how badly you fall over, you'll get propped up for a little while. Then suddenly all those supports go out. It is extremely difficult. To go through the process in Queensland, as it is at the moment, is that, first of all, you have to basically take the child somewhere - a service, a politician's office - leave them there and walk away.

The minute you do that, of course, the system kicks in and then you start to get people pressuring you, pressuring you as a family; "We'll give you this." I won't go into all of that because that is just too horrendous on those families. So everything that's been tried has not worked. This is the only thing that's going to work. So what happens is you actually relinquish your child and then, because the child is abandoned under the law, we then look for foster carers. We've been able to prove that no level of foster care can actually help these people. "Is it possible to shift them out of town? Can we put them somewhere in the system that will help?" "No. There is nothing there." Now, I would have to give full credit to some of the departmental people with whom we worked because you then have to see how the systems kick in.

You've relinquished the child, so you're formally served with papers. In that case you have to sign all this documentation; it's dreadful. Those parents feel so guilty but this is the only way that they can get what they need. In both cases with which I dealt, and they were both young, adolescent males, they had trialled residential care and they had some funds from the department, and that had been very positive. In fact their lives improved because of that. The case was, we've got a service provider that's prepared to provide the care, but that can only happen for a limited number of days. So what happens after that is the state steps in. So we had to get it all sorted out before then. They move then from a different system of funding; because they're children they're under a different department.

So what we had to deal with was how we in fact tried to keep the best possible influence of those parents in their lives. It was very successfully - very, very, well done, but I wouldn't want this to send a signal that, "Let's just go and put our children in front of the department and make them listen to us." I could not speak highly enough of some of the public servants and the people in the system with whom we had to deal. Under normal circumstances I would not have been allowed in to a hearing where they actually formally handed over care because they're closed hearings. In this situation I was allowed in. When you go to court there's two hearings. You go to court and the mum and dad sit in the front. I was allowed in but it was up to the magistrate to choose whether or not I was allowed in. I happened to know her; that's an advantage of living in a region. She said, "I know Mrs Walsh, but you sit behind."

So you sit there like a guilty criminal. You have to sign this paperwork that says you basically relinquish your child. They're not entitled to any packages, for want of a better term, because the packages under one department actually state they have to spend so much time in care and so the package had to come out of another department. It's just that you're made to feel like a criminal.

Pleased to relate that in both of those cases they are now in excellent care. The Department of Child Safety actually has been excellent. There's actually two court appearances, and the second court appearance is you actually have to have a meeting of everyone involved in the delivery of care to that disabled child, because they're a child and not an adult, and the different departments differ with different things. So they were excellent. In one case one of the mothers said, "I didn't know that this amount of support was out there." They didn't live right in town, they lived half an hour's travel away.

It's all confidential, but it's just said that you have to get to crisis and threaten; threaten, and in actual fact do it. It's just inhuman, absolutely inhuman. As a guardian or as a parent, you should have more control over what you can do to provide care for someone who is as disabled as those two children. Those two children are very happy. They're living with peers, because even though they are disabled, and significantly disabled, honestly, their eyes tell it all, and their smile, and it's worth fighting for. But we can't have everybody just relinquish. Sorry, I get a bit emotional on that one.

MS SCOTT: Thank you for telling us that, because it's very hard for us to get that information from anyone else. So thank you very much. John or David, are there questions you'd like to ask of Mary?

MS WALSH: No, I'm okay, Patricia, thanks.

MS SCOTT: Mary, given such a heavy topic - - -

MS WALSH: That's okay, they're all heavy topics. I could sit here for two days.

MR KALISCH: I just have one question, Mary. In your submission that you provided us - thank you - you talked about multi-agency competition and sort of put it in terms of it being a concern. I suppose one of the other aspects that we have heard from people is actually where there isn't an alternative they feel trapped with one agency. So for them to some extent multi-agency competition was seen as a positive rather than a negative.

MS WALSH: It is both. I'm putting my financial hat on here. Particularly when you start going to regional Queensland, you may not have multi-agency. The thing is that if you look at history of Queensland and why we had institutions in Brisbane, it's the distance. Queensland and Western Australia, being the most decentralised states, have significant differences. When I was involved as the national president of Australian Parent Advocacy I was familiar with all of those. Sorry, I have lost track of your question.

MR KALISCH: Just whether sort of having an option to go to an alternative provider was a positive or a negative.

MS WALSH: Yes. It's a positive in many ways, but also our legislation doesn't allow a provider to have whole-of-life care. So the legislation has a little quirk in it.

MR KALISCH: So that's the current legislation in Queensland.

MS WALSH: Yes, that actually says that you can't have control over all aspects of one person's life, and neither you should. There was a move to try and have that watered down. But I think the principle still is that total service provision from one agency is not always the best outcome. Getting back to the specific question, in much of regional Australia you don't any options. Even if the service is not what you think it should be, what entitlement do you have? It's this service or nothing.

MR KALISCH: But if you had a system which had much better funding, could you envisage that there could be sort of options and choices?

MS WALSH: Yes, I do, and I really think that not all of those options and choices actually need to be government-funded services, and that's the point I make in the involvement, that there are services that are there that no-one knows about. If there was a little bit better networking and a little bit more assistance. Families move home, house, everything because they can't get a service they want in regional Queensland. Mind you, this is not just for people with disability, it can also happen in cases of extreme illness. I had a grandson who had leukaemia and they had to move from western Queensland and now live in Brisbane.

MS SCOTT: Mary, I looked at where my notes are about asking questions. I think actually I can say we have covered it, so that's good. Thank you very much. Very good.

MS WALSH: You're welcome.

MS SCOTT: It's our lunch break now. We'd like to resume at 1.30, so if you'd like to be back here at 1.30, please. Thank you very much.

(Luncheon adjournment)

MS SCOTT: Good afternoon, thank you for coming back or thank you for appearing for the first time. We've now recommenced taking evidence and I invite Geoff Rowe to come forward, please.

MS TILLMANNS (CPL): He's actually downstairs at the moment.

MR SWARTZ (CPL): We have the Cerebral Palsy League here.

MS TILLMANNS (CPL): We can go.

MS SCOTT: Thank you. Thank you for coming along. Would you like to identify yourself and then make an opening statement.

MS TILLMANNS (CPL): Great. Good afternoon, I'm Angela Tillmanns, the CEO of the Cerebral Palsy League here in Queensland. Today I'm joined by Daniel Swartz, who is a young man with a physical disability who lives in Redcliffe on the northern shores of Moreton Bay. He receives support services at home and in the community from the Cerebral Palsy League and we'll be starting our presentation with Daniel who's going to tell us a little bit about what life is like under the current scheme.

MR SWARTZ (CPL): What life is like is very, very - no good for me because I get not very good support. Like, people look after me so it's really very hard for me to make that decision. Yes, that's it.

MS TILLMANNS (CPL): In our discussions with Daniel he's highlighted the lack of flexibility and choice that he has in how he organises and lives his life. Also the lack of certainty for him to be able to have any long-term life planning and most importantly the lack of opportunity to contribute to society and the community, you know, to be able to have a job and make that contribution. At one stage I remember Daniel telling me that he thought he was one of the lucky ones because at least he did get funded support and there was so many of his mates out there that didn't.

I suppose from my point of view in 2008 Australia was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities and last year the optimal protocol was also signed. But for may people in Queensland these rights remain out of their reach. People with disability have a right to a life, just the same as everyone else, to have a home of their own, family and friends and meaningful work, education, connection to the community and, most importantly, freedom of choice, just like everyone else in Australia. Yet people with disability continue to struggle to obtain those supports that help make these things a reality.

Daniel's issues of lack of flexibility, certainty and most importantly lack of opportunity are all outcomes of Australians with a disability having no entitlement to the support they need to make their place and live their lives in their own communities, just like every other Australian. Consequently, they are living unacceptably as second-class citizens in one of the wealthiest and most advanced countries in the world. Due to their lack of power in our society this plight usually flies under the radar of the general taxpaying community who presume all is well until they come into contact with someone with a disability or their family has someone who has been affected and they discover that the current system for funding and accessing disability support services is broken, and I think the commission has already recognised that fact.

The current system is based on continual rationing of financial resources and presents a view that Australians with a disability are simply a drain on the public purse. We see evidence every day that this is just not the case. We have many of our clients who are making a very active contribution to our society. Daniel is a talented musician and artist who does make money from those activities and gives back an enormous amount.

Entitlement to lifelong disability support is just not the right thing to do for this country, it's the only sensible thing to do as an investment in Australia's social and economic future. It also ensures that all Australians get a fair go. Key features of a new system would be the universality of its eligibility criteria and the range of benefits to the individual with a disability through the appropriate funding of essential services, no matter where they live in Australia. The new system would ideally finance independent living, therapy, personal care and community access, planning to facilitate independence, maximise potential and support people through the major transitions of their life.

For us aids, technology and equipment and home modifications are very important to our clients. So is training, development and access to work to build social and financial independence. I suppose once again in effect having true inclusion into Australian society. This will require implementation of a system that supports early intervention as a top priority, especially in the areas of therapy, education and independent living. We also need to make sure that we balance out the other side of the equation. It's fine to invest in people with a disability, that is a given, I think, but also we need to make sure we're investing into the broader community to make sure that we're building capacity in our schools and our workplaces and in the broader community so that they welcome people with a physical disability, in our case, but in society with all disabilities.

We of course have given some thought to about how this could be financed. Models already exist in Australia. There are fully funded no-fault insurance schemes that meet the needs of people injured in the workplace in other states. Any new system for people with a disability would need to sit alongside and complement other entitlement models, such as the ones that we have for health, education and adequate income support. We believe a new system could be funded through a levy on all taxpayers, similar to that of the Medicare levy. This would give taxpayers clarity on where their money is being spent and confidence that people with a disability are being adequately supported and that everyone in Australia is getting a fair go. This would also bring comfort to the taxpaying community, as disability can strike any individual or their family at any times.

To achieve Daniel's aims of flexibility, certainty and opportunity, the purchasing power must sit with the individual person with the disability or their representative. The purchasing system must encourage full market forces just for other services in the community. There must be adequate choice and open competition across suppliers. Any mainstream community or specialist provider could provide the services to meet the needs of the individual or family wherever possible with the person buying services from the broader community, just as we all do. But the bottom line is that individuals need that flexibility to buy what they need at a competitive price and quality to maximise their social and financial independence.

So who do we think should be covered and for how long, which are also quite difficult questions. We think there needs to be a two-tiered system: one for adults who have been assessed as having severe and profound core activity restrictions for as long as there is an assessed need for assistance with core activities of daily living and inclusion into the community. But we think that there is a special case for children. By children, I am referring to people between the ages of zero to 18. We think early investment in children who have a mild or moderate disability is vital to enabling the child to reach their potential, and as such they should be considered as a special cohort in the eligibility criteria. This investment would in turn reduce downstream public outlays and increase Australia's productivity and future social and economic health. This reduction would not only be in the disability spend but in all other areas such as health and criminal justice. So there is a whole-of-an-economy look at this investment. We also believe that national consistency and portability across states is important and therefore we support a national assessment process.

However, it is important to remember that most people with a disability are assessed by a number of government agencies on a fairly regular basis. Perhaps they're the most over-assessed people in our community. So for this reason we recommend where individuals and families have existing government based assessments that we give some credence to that process to reduce duplication to the individual as well as to government. In conclusion, we're asking for a system that will deliver flexibility, certainty and opportunity. Consideration of this new system brings hope that one day in Australia we will be able to deliver a fair go to all citizens.

MS SCOTT: I have got a few questions, but does anyone else want to jump in before me? No. Angela, thank you for that. I have got about three or four questions and I'll try and make them brief. I just want to check on your eligibility criteria. I know our terms of reference use the phrase "severe and profound", and there has been some commentary about that. The issues paper opted for those "in greatest need", as we thought that might be a better phrase. You have divided eligibility by age and have "severe and "profound" at the top. Could you just talk a little bit more about that. Is it because you think about the affordability or the acceptability in the system?

MS TILLMANNS (CPL): It is an affordability issue. I suppose we wanted to make the point that early investment in children makes a huge difference, especially with physical disability, which is where our specialty lies. If we can give detailed and intense therapy to young children, that has a huge payback to the community and the economy, and that is not happening currently. Putting it in the realms of possibility and reality, that was our reasons for having that two-tiered approach and limiting it at that adult level.

MS SCOTT: But if, for example, there was a means to go further, you would propose - - -

MS TILLMANNS (CPL): We would be very enthusiastic about that, yes.

MS SCOTT: On the issue of person-centred care and so on, a number of service providers are worried that that would affect the viability of their organisations. You don't seem to be as concerned. Why would that be the case, do you think?

MS TILLMANNS (CPL): I think probably because we already have a number of clients who openly choose to use our service. Our vision is very much around supporting our clients to become active members of the community, and it's that achievement of vision that drives us. It's not about keeping our service in business. We would only want clients to choose our service if it was going to meet their needs to become more independent and to link them into the community, and if we can't compete on that basis we shouldn't be delivering the service.

MS SCOTT: So just to be absolutely clear, you wouldn't seek the retention of block funding?

MS TILLMANNS (CPL): There are advantages in a whole range of different funding models and I think those ranges are good. If we were to move to a purely individual-based funding model, we would be comfortable with that, yes, as long as that funding is based on the true costs of the service that's to be provided. One of the advantages of block funding is that at the moment we do not receive 100 per cent funding for the service that is to be delivered. So block funding affords you flexibility to move that around. If it was 100 per cent funding for the service being provided, individual funding, from our perspective, works quite well, because most of our clients have a physical disability and manage their own funding packages now, and have individual funding.

MS SCOTT: Thank you. I have got some more, but I don't want to monopolise. John?

MR WALSH: Yes, Patricia, can I jump in. Just following up that question of yours. Angela, in a new world where there was I guess a combination of individualised and block funding and all sorts of funding models, have you given any thought to how your organisation might need to change at all?

MS TILLMANNS (CPL): Absolutely, and positioning ourselves for that now, because I think, regardless of what happens, what we support and we are seeing is that people with disability are taking much greater control over the support that they want, they need and how they want that delivered, and we actively encourage that and we are positioning our organisation to be competitive in that marketplace. We're doing that through training of our staff and marketing our services and fully costing our services to our clients so that they understand exactly what it is that they're buying and what quality that they are buying.

MR WALSH: Thank you. I have a question for Daniel too, if that's all right, Patricia.

MR SWARTZ (CPL): Yes, that's fine.

MR WALSH: We have heard a lot, Daniel, about the preferred accommodation models and suggestions of cluster housing and groups of self-contained units with a live-in residential - almost caretaker of last resort, with support coming in. Have you got a preferred model of accommodation in your own mind?

MR SWARTZ (CPL): I would like to, but I don't know what you mean?

MS TILLMANNS (CPL): How would you like to live, if you could live in any way; like, live by yourself in a house, live in a house with others? What would you like?

MR SWARTZ (CPL): I would like to live on my own, if that's possible.

MR WALSH: Thank you, Daniel.

MR KALISCH: I have a question, if I can, Daniel. What sort of services would help you become more independent, or what services help you be independent?

MR SWARTZ (CPL): Like, disability. I need help on this one.

MS TILLMANNS (CPL): Yes, that's okay. So what type of services could people provide that would help you? Things like doing your shopping, housework, getting ready to go to work of a morning.

MR SWARTZ (CPL): You mean Cascade?

MS TILLMANNS (CPL): Yes, Cascade can be one of them.

MR SWARTZ (CPL): Yes, I go to Cascade Place.

MS TILLMANNS (CPL): Which is a day service.

MR SWARTZ (CPL): Which is a day service I go to, and they're pretty good.

MS TILLMANNS (CPL): That's around skill development for adults. That leads to greater financial independence, whether that be through creative endeavours, such as Daniel is involved in the music and art program. Textiles.

MR SWARTZ (CPL): Rope. That's another day service.

MS TILLMANNS (CPL): I think what Daniel has alluded to us before is sometimes you feel locked into a program, especially on weekends. You've got a support person - and correct me if I'm wrong - who is locked in to being there for so many hours of a day.

MR SWARTZ (CPL): I like to get out.

MS TILLMANNS (CPL): Because he's in a home with a number of people, the bare minimum is done of a weekend. It's like get in there, fix meals, personal care, get out. Daniel is saying, "Well, you know, it would be great if sometimes I could all of a sudden say, 'Gee, I'd like to go to the footy this afternoon,'" but because that hasn't actually been planned in advance and thought through about "how do we shift that roster around?" that can't happen. Where most of us make those decisions, "Nothing in the fridge, let's go out tonight for dinner," someone with a disability doesn't have that flexibility.

MR SWARTZ (CPL): Yes, that's correct.

MS SCOTT: You get stuck in on the weekends?

MR SWARTZ (CPL): Yes, I get stuck in, mostly on a Sunday because I've got one client in the house and there's only one staff provided, if you know what I mean. I would like to have another staff member so I can go out a bit more.

MS SCOTT: Where would you go, Daniel, if you had the chance?

MR SWARTZ (CPL): To the beach or go fishing if I had that chance.

MS SCOTT: Angela, of the services you nominated, you haven't got down advocacy services and I'm just conscious that a couple of people who have presented evidence over the last day and a bit have stressed the importance of advocacy services. Would you agree or do you think that a new better system it wouldn't be necessary?

MS TILLMANNS (CPL): There's probably a transition stage there. By the way in which this country has supported people with disabilities to date has meant that they have not got strong advocacy skills, but I think through hearings such as these and the attention that this is starting to get in the media that there is a quiet confidence growing there, and I think we will start to see for many clients self-advocacy emerging, but there probably is a need in that transition phase. I mean, we're noticing, just as we do in the general population, our younger clients are as mad as hell - to use a statement that there's a group out there called - and they're not going to put up with it any more. I can see as our younger generation are coming through they're champing at the bit to get out there and self-advocate.

MR KALISCH: So are you seeing a generational change?

MS TILLMANNS (CPL): Yes, very much so.

MR KALISCH: Daniel, you've got certain aspirations and desires. Are you making that known to your service providers and to the community?

MR SWARTZ (CPL): Yes, I am.

MS TILLMANNS (CPL): I think the advent of technology assists that. We have many clients that now communicate with us that are 10, 11 years of age, very adeptly on their computers.

MS SCOTT: Fair enough. Angela, have you turned your mind to how service delivery - you've talked about the individual packages and you've mentioned block funding and no-fault insurance schemes and so on, but have you thought about who would actually do the distribution of funds, who would actually best be placed - - -

MS TILLMANNS (CPL): We're probably thinking that would be a national system but that would be administered by states so that we would have national criteria so it wouldn't matter if someone moved across state boundaries, but it probably does need to be administered, I think, probably by a government agency and that would be state governments.

MS SCOTT: One last question and maybe you want to think about this one, you made the point that people have to go through the assessment wringer over and over and over again and it's well noted and people have told us. But if a new scheme is introduced and new services and new capabilities and new funding is available so Daniel has access to a larger package, for example, would you see a need for at least an initial assessment in that case given that it's almost like a brand new old opening up to some people, especially people who have only have ever received very minimal support in the past.

MS TILLMANNS (CPL): There is quite a lot of detailed assessments that are made but there are records within government departments that I think we could - there would be a cohort of people that were obvious recipients. But I would be confident that in talking to our clients that if it meant they have to go through another assessment process to access that new world, they would do that and they would be keen to do that to get to that new world. But it would be a shame for us not to see if there's some way that we can minimise that workload for everyone involved.

MS SCOTT: John?

MR WALSH: Yes, just on that, Angela, do you have any view on particular assessment methodologies or instruments that might be appropriate?

MS TILLMANNS (CPL): That's probably beyond my scope of expertise. We can certainly include that in our written submission though.

MR WALSH: That would be useful. Thank you.

MS TILLMANNS (CPL): I can draw on the expertise within the organisation.

MR KALISCH: I just have one more question. You've talked about the links and, I suppose, complementarity to health care arrangements and education and other things and I'm going to suggest if you don't necessarily want to answer it now, to actually just mention something in your submission about how those systems might also need to be adjusted or reformed alongside a national disability support scheme.

MS TILLMANNS (CPL): We have already got some of that in our submission so it's probably good if we do expand on that in there. I suppose the big one for us is education. We're constantly seeing kids falling through the cracks there and so we have paid particular attention to that and also with health.

MR KALISCH: So you have got some examples that actually work?

MS TILLMANNS (CPL): We've got some that do work and we've got a lot where it doesn't. But, yes, we can certainly highlight both.

MR KALISCH: We're certainly interested in, I suppose, what are some that - - -

MS TILLMANNS (CPL): That's working. Yes, absolutely.

MS SCOTT: All right, John?

MR WALSH: Yes, thank you, Patricia.

MS SCOTT: Thank you, Daniel. Thank you, Angela.

MS TILLMANNS (CPL): That's great.

MS SCOTT: Good afternoon, Geoff. Would you like to state the organisation you represent and your full name, please.

MR ROWE (EF): Yes. My name is Geoff Rowe. I represent the Endeavour Foundation.

MS SCOTT: Are you comfortable to make an opening statement?

MR ROWE (EF): Yes, that's fine. Thanks for the opportunity. Endeavour will be lodging a formal submission to the commission before the closing date. Today, I guess I wanted to talk about a few things that are in front of mind for us at the moment and certainly don't want to spend much time on telling you the system is broken, I think you're well and truly aware of that. I did want to make a couple of comments in relation to the current system though and one of those is that we know that people with a disability are over-represented in the criminal justice system, in the child protection system, in the health system, in the aged care system, that people with a disability are more likely to come from a single-parent family. To me suggests or reinforces the fact that the disability system is broken and the fact that other systems are having to pick up, often at a more expensive or a greater cost, the needs of people with a disability and tend to, at the end of the day, respond to them far less appropriately than they would be if they were supported in a well-designed and well-funded system.

For Endeavour I guess there are a couple of issues that didn't appear to jump out of the report that are jumping at us at the moment and both of those are largely around the issue of people who are ageing. Endeavour at the moment supports about 80 people over the age of 65 years, about 200 people between the age of 60 and 65 and that number between 50 and 59 increases to something like 750 people. So we're talking, all up, more than a thousand people over the age 50. So I guess we're seeing what we're describing as a bit of tsunami that's arriving in terms of people with a disability are living longer. Heard Mary talk earlier about the issue of premature ageing and that's something for us that's absolutely alive and well, that we're finding clients who are in their mid 40s who are experiencing early onset dementia and other ageing-related issues. I guess for that cohort of people they're too young to access the aged care system. The disability system doesn't quite know what to do with them. So that's something I would like the commission to consider as they prepare their report.

Associated with that is Endeavour, as you may be aware, is a significant employer of people with a disability. We employ 1836, to be precise, people with a disability across Queensland and New South Wales in Australian Disability Enterprises. At the moment we've probably got 13 per cent of people that are working in those employment services who are wanting to retire but cannot retire because there are no options, as in their employment service meets their needs for daytime support for social interaction. The current system where employment services are funded by the Commonwealth, support services are funded by the state, there's no interest in the state picking up that cohort of people. So we've got a whole lot of people who are, on one hand, not experiencing the sort of life that they want to experience because they're stuck at work and often doing less menial activities because of loss of abilities and loss of functions.

We're also plugging the system up and the disability employment system is such that there are a limited number of funded places and we know that there are lot of young people who are looking at getting into employment, who want to be productive members of society and who cannot get in because there are not the vacancies or there's not the flow-through of people that would happen in the normal employment system.

MS SCOTT: Would you have figures for that employment - - -

MR ROWE (EF):   Absolutely happy to provide figures.

MS SCOTT: The figures indicated that people wish to retire but are unable, so the fact that they then stay in your services, what that means in terms of denying opportunities for a younger cohort to come into your service.

MR ROWE (EF):   Yes. I suppose it also begs the question about the linkages with the other inquiry conducted at the moment by the commission, Caring for Older Australians, and that's certainly one of the inquiries that we're also wanting to put a submission in about. I heard you ask the question of Angela about whether as a disability provider we're preparing for perhaps a new system. For me, in an ideal world organisations like Endeavour wouldn't exist; that people with a disability would have their needs met by mainstream services. That's an ideal world and we're some way off that but I think one of the principles we should be looking at with the new scheme is that as far as possible you should be seeking to access the mainstream and use the mainstream. Let's not look at employing disability support workers when someone really needs a cleaner. That addresses some of your workforce issues, for example.

In looking at the new scheme, one of the considerations that Endeavour has done has been around the economic impact and I suppose I touched on that in terms of talking about people being over-represented in different systems. At the moment we're seeing a whole lot of carers who really want to work, who want to contribute to the Australian economy, who can't. We're seeing a lot of people with a disability who want to work, who want to contribute to the Australian economy, who can't. We also know that by spending money in disability support and care it's an industry that is very salary focused; that probably 80 per cent of the money spent goes directly into wages. So it's a significant job creation program.

So while it's a social justice issue that we have a good disability system, it's also a very sensible economic argument to have a good disability system because in an environment where we're asking people to retire later, where we're looking at immigration to fill employment vacancies, we have a whole lot of people who are there who want to work, who can't work because of inadequacies of the current system.

Endeavour supports a single universal approach to assessment of eligibility. Clearly there would need to be some sort of transition and even if the new disability care and support system developed its own, there should be some linkage with the social security system, et cetera, to look at some sort of commonality, some sort of streamlining, so that if someone goes through one system that they don't have to then go and jump through another set of systems as well.

MS SCOTT: Can I just get you to pause there for a second. There are approximately 750,000 people currently on disability support pension. Are you envisaging those people actually being eligible for this scheme? I mean, I think the way the government had been framing it as severe and profound or (indistinct) those in highest need; possibly the groups are distinct.

MR ROWE (EF): While I know some people are certainly supporting the severe and profound, I guess it would be my argument - and I'm talking from Endeavour's perspective where we're supporting people primarily with an intellectual disability - often we find that for people at the lower end of the disability spectrum a very small amount of support can make a huge amount of difference in terms of them being independent in their living, in their employment, in their community participation and in their personal success in their lives. Angela talked about a two-tier system in terms of adults and children; I'd probably talk about a two-tier system or even a three-tier system in terms of a high, medium, low support needs and looking at that sort of level of intervention.

Certainly when I talk about people being in the criminal justice system, we're not talking about people with severe and profound disabilities, because they can't, but I heard a figure in Melbourne on Monday where the figure was quoted that 50 per cent of people within the Victorian criminal justice system have a diagnosis of an intellectual disability. That's a great, very expensive way of providing support. I guess our experience is that with a small level of support, which is maybe an occasional drop-in, maybe it's once or twice a year, it makes a huge difference. So we would be arguing that a fair and a just system and a system that is economically smart would make that investment across the board.

In terms of what would the system look like - and I certainly read the sections where you talked about the user pays contributing - I think "entitlement" is one of the words that we want to see attached to the new system along with universality, equity, self-determination and individual need. If we look at our health and education systems you can expect, as an Australian citizen, to receive a core level of support through those systems and then you have a capacity to buy above that. Perhaps that's a model that needs to be explored. The Medicare levy is probably the obvious one but, again, I would encourage the commission, in tabling their support for it, not to be presented as a big, fat, new tax, but rather an economic, wise investment because there will be tax savings in other systems where people with a disability aren't necessarily accessing.

The final comment I wanted to make was in relation to service costings. Endeavour has recently, over the last 18 months, has moved to output-based funding with the Queensland government and we receive about $55 million a year in funding from the Queensland government. We're the first agents in Queensland to make that transition so we've done a lot of work over the last 18 months around unit cost, cost of service, et cetera, which has taken considerable time and energy. If any of that work and some of the financial modelling that's been developed can assist, we're certainly happy to put that on the table.

MS SCOTT: I think we'd be very interested in that. We have to, as part of our approach, actually cost the scheme, so having costings of outgoings or deliverables would be very useful. John, any questions?

MR WALSH: Yes, I've got a couple. First one, Geoff, is one of your statements was that, "In an ideal world an organisation like Endeavour wouldn't exist," and I suppose the question that I have coming out of that is, at the moment we have Australian Disability Enterprises and I suppose I'm interested in the transition from that sort of situation to a more mainstream situation. The specific question is how many of your people do you think, with help, might be able to work in open employment or, alternatively, is the model that over time your organisation employs more and more people without a disability so that over time your organisation becomes a more mainstream employer and the people with disabilities be regarded as non-supported employment, if you like. Do you have any ideas of the transition of that model?

MR ROWE (EF):   That's a good question, John. I guess in terms of how many people can transit to mainstream, probably a lot more there. At the moment there are penalties in place or "penalties" associated with people having to give up their place in an ADE to try mainstream employment, so there's no safety net there, so people tend to stick what is safe and what they're comfortable with. I think your suggestion in terms of agencies like Endeavour just becoming employers and running businesses, I think that's quite reasonable. The move from the federal government in recent years about paying real wages for real work and real jobs - Endeavour nowadays is, I think, in the scheme of things on the national companies about 253 or something in terms of largest companies in Australia and about 57th in Queensland. We are a major employer and some of the products that people see on the shelves in supermarkets are produced by Endeavour. Not branded Endeavour, Gumption, one of those cleaning products that you see and it's been around for ever.

Lots of scope, lots of opportunities and I think even the last couple of years with the GFC we've had to reinvent our businesses. The playing field hasn't been level and if you didn't have a social bent you wouldn't run some of the businesses that we run, you'd buy a big machine. But I think there would be agencies out there that, with a level of support, would be happy to employ people with a disability and run a business and not be a disability service provider. Indeed, within Endeavour I think we've had to do a fair bit of work in the last 12 months to try and bring what we call our disability services and business services areas together because they've operated so much in isolation that one's been about employment and employment outcomes for people, the other has been about providing support to people with a disability.

MR WALSH: My other question is a quick one. You mentioned that you'd like to work on costs.

MR ROWE (EF): Yes.

MR WALSH: That's very interesting. When you put in your information on that, Geoff, would you be able to talk a little bit about the relationship between outputs and outcomes. One of my concerns around the input-output model is that again it's a service model and it doesn't really measure people. I'd be interested in your discussions around that.

MR ROWE (EF): Certainly the output model is a bit of a crude and a blunt instrument but making a transition from input to outcome is a huge leap, so the Queensland government has decided to do it in steps or bite-size pieces. Certainly I think even the step to output in the first instance is proving difficult for some people but, yes, I'm happy to talk to that.

MR KALISCH: Just following up on the question that John asked you about on disability employment services a little bit more, to what extent do you as an organisation have conversations with families around what's the best option for kids coming into the service in terms of is day service an appropriate option for them or is disability employment service or open employment? To what extent do you try and have that conversation with families to encourage them to think broader about options.

MR ROWE (EF): I think we do try and encourage people to think more broadly and I'm sure you've heard the figure quote in the last couple of days, but in Queensland the disability spend represents about two-thirds of the national per capita spend. You've heard a lot of unmet need, to some extent it's almost any port in a storm. Families are looking for something for their son or daughter that will meet their needs or vaguely meet their needs. Certainly there are people in our day services who want to work but there aren't spots in either the ADE - for Endeavour we only operate one open employment service and that's in Toowoomba. We can probably improve our linkages with the broader mainstream employment service network but - - -

MR KALISCH: I would certainly be interested in your written submission about further information about some of those other funding arrangements or other rules that you are bound to operate by can actually provide some disadvantages or preclude people.

MR ROWE (EF): Certainly there has been historically - you've probably heard about the Post School Options program or Post School Services scheme that operates in Queensland and it's been very much focused about people who don't have vocational aims and objectives and if anything, people are punished or risk losing their funding if they aspire to contributing, which is again one of those problems with that Commonwealth/state separation of functions and funding in terms of disability services. Neither wants to pay for the other's domain.

MS SCOTT: We see across Australian figures quite a variety in funding levels for disability services. This doesn't seem to have had much difference in terms of seeing people rise to a higher level in terms of their funding levels. Why don't you think those figures that you just gave - two-thirds of other states - why don't you find that a powerful figure in terms of being able to get more funding?

MR ROWE (EF): It is a powerful figure and indeed I sat at the recent budget breakfast that was hosted by QCOSS with the minister for disability services who leaned across the table and said to me, "Your boss is being mean to me." When the state budget was released we went to the media and said, "Nice to see you're focusing on early intervention. Nice to see that disability services got some funding but you haven't addressed the real issue," and the real issue is if you live in Queensland you're a second-class citizen and you have a disability. Indeed, our media stuff said, "If you've got a disability, don't come and live in Queensland." We've been taking that to the marketplace and we will continue to take that to the marketplace because in my mind it's a no-brainer. How can you argue that someone in Queensland is not worth the level of spend as someone in New South Wales.

Interestingly government here is struggling with the concept that while we're two-thirds of the national per capita spend, in terms of service delivery and the individuals who are funding, the cost of service is higher than that of other states. So, you know, I'm watching people in the department saying, "We need to be spending less on our services." The issue is that we're focusing on the crisis, the critical, the high support needs, we're not spending money on early intervention, we're not spending money on family support. If you're then bringing another 2000 people into the system but spending a thousand dollars a head, suddenly the average spend comes down to a lower figure.

MS SCOTT: Given that you offer services in New South Wales and Queensland, would you be comfortable to include in your submission the features of those two systems that you consider warrant replication in a national model or features of those two systems that you would never suggest replication and then also indicate something about the red tape and efficiency of those systems. Would you be comfortable doing that?

MR ROWE (EF): Red tape is something dear to my heart. Indeed, on the red tape issue you might be aware that in Queensland there are large statewide bodies and peak bodies who have got together and negotiated a compact with the Queensland government and recently there has been the National Compact. One of the key things that we're arguing within the Queensland system is for that red tape reduction and indeed, the cost of compliance is one that's getting higher and higher, and the intent is absolutely good, fine and admirable, but the cost to the service provider of complying with a quality system, with a criminal history checking system, with a restricted practice system, with a workplace health and safety system, blah blah blah, is very high and I guess that's where I would argue that we need a single national scheme so that we're not ending up with multiple compliance systems.

I would hope that over time that the current funding arrangements either are absorbed in or grandfathered to a point where we're not going to have something for a national disability scheme, a quality system that looks like X, one for the state system that looks like Y and we spend all our money on compliance rather than services.

MS SCOTT: Would you be able to give figures on, for example, overheads in New South Wales, your organisation, versus overheads in Queensland. We're trying to look for areas where - clearly a new scheme would come at a considerable cost and people point to efficiencies and I guess it's hard to get a handle on what, if any, of the efficiencies would exist and your organisation must have some insight into that because you operate over two systems.

MR ROWE (EF): Yes, I'm happy to.

MR KALISCH: I just want to take you back to one of the points you made fairly early on about recognising the commission's also to work on caring for older Australians, a study that a number of our colleagues are working on. Just in terms of the dimension of providing good services to people who are ageing or the aged, what role you see for, say, the residential aged care services or community-based aged care provision as opposed to disability services providing ongoing support for people as they age.

MR ROWE (EF): I guess one of the terms that our new CEO has brought to the organisation is that Endeavour is an organisation that aspires to support people to have an ordinary life. I think it's a very powerful term. We're not asking for anything different than the rest of the community. That ordinary stuff means that they should be able to - people with a disability should be able to access the same sorts of supports and systems as the rest of the community. So when they need residential aged care because they are old, they are frail, they have high medical support needs, that's an appropriate option. If they want to age in place, because they don't have the high medical support needs, et cetera, there should be systems there.

Certainly I think - you know, and you talked earlier about the changing expectations of that younger generation. I guess it has been interesting working in the field for a number of years, working in agencies that support both children and adults to see that very different expectation. I guess my experience has been in time gone by where we've tried to support people with a disability to access an aged care day program - there are two issues there. One of the issues is about whether the staff have the necessary skills to provide their support. But for me the bigger issue is that often older people are not very welcoming of people with a disability because they've never had to interact with a person with a disability before, because as they grew up people with a disability were removed from the community, weren't part of the community.

I look at my son's generation who has kids with a disability in his school. So when he gets into aged care, God forbid, if there's someone with a disability it won't be a big deal. So I think there are two barriers there. Certainly the one that we can influence in the short term is about - and as I said, we're pedalling fast at the moment on the aged care issue and talking to a number of aged care providers about how do we work together to support the needs of our client group within their system. That means providing training to their staff. It means for us providing support staff to come in and to do the things that the disability sector does better.

MS SCOTT: But just to clarify, it's not Endeavour's intention to find itself in that role of provider of day services for an older group of people with disabilities, to find yourself providing, effectively, aged care - - -

MR ROWE (EF): We've already found ourselves there, not by desire but by default. I think again in that ideal world - I'll stop using that term but in that world somewhere future that people with a disability should have access to the mainstream systems, that would be the principle that we operate on. But in the absence of that we find ourselves providing it.

I'll go off on a slight tangent. One of the things I saw many years ago was this wonderful photo when I worked at the Cerebral Palsy League of a whole range of white buses that were sitting in a football field and they were just full of it. It was from the early 60s and it was - you know, the League provided transport. Their organisation now is probably 10 times bigger or 20 times bigger but you'd probably only find a 20th of the number of vehicles if you tried to pull them out in the one paddock at the moment. That's because the mainstream - the transport system, the public transport system, has started addressing the needs of people with a disability. I think that same sort of principle that we should be moving toward wherever there is something that could be provided and supported by the mainstream, that's where we need to be aspiring to.

So in terms of the aged care I think that's a really hard one. I know some of the things that we're putting in our submission is a question about well, do you just look at a care system and forget whether someone is ageing or someone has a disability or someone has something else; that it's about saying what does this people need to live a normal life, an ordinary life, will be supported in employment or be able to work or be able to whatever.

MR KALISCH: I suppose just taking that up a little bit further, Geoff, does that sort of point to a range of options being available that meet people's aspirations and - - -

MR ROWE (EF): Yes, one might - - -

MR KALISCH: - - - won't sort of pigeonhole this is the way - if you're over 65 this is the way we treat - - -

MR ROWE (EF): Yes, look, a colleague I worked with in years gone by who I have a great respect for, she used the term, "We need to have a menu of options". That one size fits all doesn't work because we're all individuals. It's the same with disability housing. You asked the question of Daniel before regarding where he would like to live. I mean, if you went around this room and ask people, "Where do you currently live," we would describe very different situations. It's about choice.

It's about choice but it's also about circumstance in terms of whether we can afford to live on a canal or own an island in the Whitsundays. That's maybe not an ordinary life, that's maybe an ideal life. But the ordinary life means some people here will live in units, some people will live alone, some people will share with others.

MS SCOTT: John, how are we going? We think we're finished.

MR WALSH: No, I've got one more question, if that's okay.

MS SCOTT: Yes, sure.

MR WALSH: You mentioned earlier that - in talking about your live-in scheme, that some of your members might only do the drop-in occasionally to provide the support they needed.

MR ROWE (EF):   Yes.

MR WALSH: I'm just interested in what that might look like in the Internet world. My question really, in blunt terms, is people with an acquired intellectual disability, that is that - electronic services or access to the Internet and they were set up in a such a way that those sorts of things are provided to them, would that - - -

MR ROWE (EF):   Absolutely. Look, that's one of the things we've started talking about. Our new CEO has a long background in IT. So I guess he's certainly challenging us to look at different ways of doing business. I think it's a meeting that we have - there may be issues around touch screens versus log on and what have you but we've started talking about that even in terms of where you're talking about people with perhaps not a mild but a moderate level of disability in terms of rather than having a staff person there overnight that there is a capacity for them to - you know, out on the fridge there's a computer screen they can go whack and the support worker in a house five streets away can respond to them. Yes, look, absolutely.

MR WALSH: Thank you.

MS SCOTT: Yes, it's been good. Thank you very much Geoff.

MR ROWE (EF):   Thank you.

MS SCOTT: We look forward to getting your submission.

MR ROWE (EF):   Thank you.

MS SCOTT: Thank you. We just might have a short five-minute break. I think some people might appreciate that. We will start then with John Catania and Margaret Ward please. So five minutes and that will be - five minutes.

MS SCOTT: Would you like to state your full name and the organisation you represent and then maybe you both could commence with an opening statement.

MS WARD (BSG): I'm Margaret Ward. I'm representing the Blue Skies Scenario, which is a group of loosely affiliated people who have wanted to describe a positive vision for people with disabilities and develop a plan for not only government but for Australian society generally to fulfil in order that people with disability can have a truly inclusive and participative life. I have with me John Catania.

MR CATANIA (BSG): Hello. My name is John Catania. I am working with Marg on the Blue Skies team and I'm also here as a concerned citizen with a disability.

MS WARD (BSG): Thank you for this opportunity. I come with the experience of parenting a woman with a disability for 30 years, who unfortunately died last year. I have also worked as a bureaucrat and I have worked in the service system. Our family has been supported by a small parent-run organisation called Homes West. I also developed the policy and operational - the operations for a cash payment system for over 200 families through Mamre Association. Now, I raise those because I understand yesterday there was some interest in one - cash payments and how they worked. So I can talk to you on that, if you wish.

MS SCOTT: Thank you.

MS WARD (BSG): But before that I'd like to name what we see as a way forward, that there are in fact five elements that we want to focus on, on a future disability care and support system. I name these five because I think these - if these are taken seriously then we will be able to address the notion of blow-out. I know that this is of concern to the commission. So I'd like to focus on this.

The first is a specialised service system that can provide a service in the person's established community and provide the system at the right time in the right place by the right people in the right way. We've talked about that in a number of ways and that's a little bit trite. However, we can talk in more detail about that.

The second important element of a disability care and support system is that there is intentional work done in building capacity in communities. There is great capacity in communities. I know this personally, that communities can do extraordinary things. They can do ordinary things as well but when there is intentional strategies to assist communities to welcome people with disability, some amazing opportunities come about that can never be provided by a formal service system.

Thirdly is that there needs to be an intentional strategy to build the capacity of people with disability and families to envision what's possible and to plan for their life and to build a good life for themselves. Currently we have a turnover of around 20 per cent in the service system and I think that's conservative. So within five years you have lost your knowledge, you have lost your skill base. So it is a continuously bottomless pit. But families don't turn over to the same extent. So if one invests in families learning to envision, to plan, to network, to build networks of support, to think about what's possible and to skill up doing those things then you have made a very good investment because those families will be there for 50, 60 years. I'm not talking about one level of a family, I'm talking about a three-generational strategy. That is, parents, siblings and then the children of siblings or the three generations. It takes three generations of a family to really safeguard and to work around a person with disability through their life.

The fourth is a capacity for research and development. What is possible is changing all the time, and I know this personally. If what I had envisaged for my daughter in 1980 when she was a babe in arms, if I thought that was the life she was going to have and I could see what actually happened for her in the next 30 years, I would not have believed it. I put that into the hands of the people that thought about new ideas, who trialed new things, who demonstrated, who broke the mould. So when we don't invest in that area we are only making enemies for ourselves. So it's terribly important that we put energy into research and development.

The last one is safeguarding strategies. We will make another mouse trap, there is no doubt. But what we've got to do is make sure that the damage of the next mouse trap is less severe, that we have strong, independent advocacy who will blow the whistle when things are starting to go wobbly. We need systemic separation of the policy-makers, the funders and the providers so that we limit the conflict of interest that happen, that we see happen in Queensland where we have the funder, policy-maker and the service provider all in one department.

MS SCOTT: Do you mind if I interrupt you there?

MS WARD (BSG): Yes.

MS SCOTT: Why does the funder need to be different from the policy-maker?

MS WARD (BSG): Because if you want a policy-maker to think creatively and broadly to imagine what is possible, then they need to be separate from the strictures of the funding. Now, clearly funding will need to be considered but if the funding is the driver then you are not going to think as creatively.

MS SCOTT: Okay.

MS WARD (BSG): We've seen the best strategies - or the best outcomes I've seen come from when the policy separates from the funders. That doesn't mean they don't talk, and they have to negotiate, but you need to have separate systems to work those three and then they come together to make it happen.

Also that there is a simple, transparent accountability measures for services and users. Now, I did refer before that I had worked on a cash payment system, so I'm pretty clear about the possibilities there. I also have done five - prepared a service for five audits and I do have some thoughts about that too. There is some advantages in audits but I think that we are over-audited right at this moment.

So I name those - just to summarise, I name those five things that I think if we go straight into a disability care and support strategy without those other elements then we are more likely to have a blow-out. If we do look very carefully and creatively about how families can be empowered and learn skills to build informal networks, then - and that communities can do their bit, that we're always thinking about the future and that we're safeguarding through independent advocacy then we are less likely to make another mouse trap as damaging as the one is now. So that's it, and I'm open to questions.

MS SCOTT: Well, I was going to start with the workforce one. You may not have heard from yesterday but we asked a couple of people - or they raised with us the issue of accredited care, certificates III and IV versus people with values or a disposition or an interest. I'm interested in that because if there is an expanded service offering where are the workers going to come from, Margaret? Where are the people going to appear from? Where are the services going to bring up - - -

MS WARD (BSG): I'm very hopeful about this. I'm hopeful because this is my experience for the 11 years that my daughter was in her own home and we had a team of six people with an average turnover of 20 per cent. No matter what I did I couldn't change that figure. I think it is a natural attrition.

The first is they must be paid properly and paid well. The second is that - now, you bear with me for being flippant but this was a rule - not a rule but a rule of thumb that Homes West came to by default. We never employed anyone with a certificate III. We never employed anyone that had worked for a large service system that had been inculcated with institutionalised behaviour. If an applicant walked in the door I checked for two things that you cannot train: one is values and one is attitude. You cannot train people in values and you cannot train people in their attitude to work. Then I could train the rest. I could train hoisting, PEG feeding, turning, keeping a house clean, cooking. I can train - as the family member who wanted the level of service that was required I could do that and do that fine. Not only that, I had inculcated in the other staff the values or the standard of support that we wanted and they were able to train the new staff member. So the family had or the household a culture of service that was individualised around this one person.

I had women doing doctorates in palm oil, I had business students, I had one woman who was illiterate with a mental illness who was one of the best carers. I had the most extraordinary array from so many countries in the world. It was such a rich, wonderful household of live, wonderful young women who made that house rock. One, because they were there with aligned attitude and values to the family and to my daughter. So I have no problem. We will have a problem if we require accreditation. We will have a problem if they've got to go through broad-based training. Families who are empowered, and I'm clearly an empowered family member - but it's not hard because every family knows, every person with disability knows what they need. All they need is strategies to interpret that and pass that information over.

So I'm very hopeful about the future. The staff are out there. They lined up. People knocked on the door wanting to work because they had heard about this family, this household. Yes, so I won't go on.

MS SCOTT: Okay.

MS WARD (BSG): So, you know, look at it in another way.

MS SCOTT: John, do you have a different view?

MR CATANIA (BSG): No, absolutely I couldn't agree more. I think the thing that is really important is to work with the person with a disability and their families and their informal support networks, really harnessing all of that support around identifying what that individual's strengths are, what their aspirations are and their goals, whatever that may be. Really it's just a matter, I think, of facilitating the best strategy to make that happen. That doesn't have to be through any formalised networks, I don't think.

I think the current system - one of the things for me personally and in speaking to other people, other friends of mine with disabilities, we all seem to say the same thing, that the current system makes us - we feel this kind of barrier in terms of ideology and values. We feel that - I certainly do at times feel this kind of lack of understanding about what my circumstances are in my life, the way that I actually go about living my life to achieve the things that I want to achieve. I think it's important that the current system works with those people that know the individual intimately so that they can really feel like their goals, their aspirations, their dreams and their vision for their own future is aligned with those people that know them best.

MS SCOTT: Okay, good, thank you. John, David?

MR WALSH: I guess I'm interested in the views of both of you about how many of these people there are out there. I mean we've got a lot of people with disabilities and is it feasible to build a scheme around the people with the right values and the right attitudes alone?

MS WARD (BSG): Yes, I do. I primarily - and the people in Homes West, which is where my experience came from and from Mamre Association is students who could manage the flexibility and who had the smarts, they're very smart people, they learn quickly and they're open to new ideas and open to learning things in a new way. So we did mainly use students. However, the families who had older family members in their 50s, used people who were around that age group as well so there was a match. If you let go that they have to be trained, if you let go that it has to be full-time work, if you let go that they're of a certain type of person, then there isn't a problem. I had such an extraordinary range of people, and I really came to the position that I was continually surprised who was out there.

We did have difficulties getting staff around Christmas, but I had a technique of always having a Hindu or a Buddhist on the team, they love to work over Christmas. It's having a team that is mixed, a team that has got a variety of skills and strengths and, yes, suits that person. I think that the sky is the limit really, once we let go our assumptions about what a worker should be.

MR WALSH: I have just got more question, Patricia. Margaret, have you had any industrial issues with unions saying, "This is not kosher, you can't do this."

MS WARD (BSG): It's all absolutely kosher. There's nothing in the unions that says they have to have certificate III. We absolutely comply. We pay them according to the award, that is absolutely a non-negotiable, you stick to the award. So we don't have any issues with the union.

MR KALISCH: Margaret, I understand where you're coming from, in terms of workforce values and attitudes, and how critical that is. I suppose the other thing that the commission is being made aware of, and is aware of from some of our other workers, is that the health sector is looking for workers with the right attitudes, the right values, the right skills. Aged care services are also looking for increasing numbers of people, other community services, the education sector, retail, mining, et cetera. Need I go on?

The aspect that we are somewhat concerned about is about workforce availability, in broad terms, particularly if the scheme was to be better funded so people could get better services and with large numbers of services actually being delivered by individuals. Are you still confident that there will be workers in, say, 20 years time if we have a better funded system?

MS WARD (BSG): Clearly you have a broader picture of workforce pressures. I think one of the things that has made it work for, say, Homes West and Mamre is that the service is individualised. Certainly in Homes West a family never shares their workers with another service. Only 10 people are supported, but there are over 60 workers, so it is all part-time work. I think there's only one full-time employee in the service. We do focus on people who want a bit of work here, and they're doing other things. We focus on people in the local community, because that travel for that short work can be onerous if you're doing a little bit of work here and a little bit of work there.   We focus on local people.

The third is that you don't rely on the service system to hold the knowledge, to hold the skills around the quality of the service. You rely on people that are going to be there in the long term. You rely on families to hold the knowledge, to hold the vision, to keep the standards and to monitor the quality. I think that's a problem in larger systems where there isn't family involvement, there aren't friends and people coming in and out, and so the worker has a much larger responsibility to I guess hold a lot more knowledge about the person than the Homes West system.

The other thing about the Homes West system is that it's so flexible around the individual that people like to work there. Their lives can work in it and there's a lot of capacity to negotiate, you know, for students if they need time off to do their study, or whatever; the service system, when you've got your rosters and things you'll find that people will drop out when they can't stick to those rosters or are penalised. I give that information humbly, I do not know the bigger picture.

MR KALISCH: That gives me a better sense of the flexibility of working arrangements that can be quite attractive.

MS SCOTT: Could we take two things in order: one, cash payments, maybe your quick observations on that; and accommodation, people's choice of accommodation. Both of your views on those two topics, quickly, please.

MR CATANIA (BSG): In terms of accommodation, it's never a one-size-fits-all scenario and I think it should always be based on the needs of the individual, the emotional needs of the individual and the capacity of the individual. I think that is always different from individual to individual. Some people may benefit from continuing to live in their own homes, some people may benefit from community living. I just think that needs to be identified with the individual and that need needs to be respected and every support needs to be given to provide for that.

MS SCOTT: Okay. Margaret?

MS WARD (BSG): Around accommodation, I'm always fascinated by the word "accommodation", because we only use it for people with disability and older people. If we talked about homes, if we talked about where we want to live, how we want to live, I think we might get some different answers. I used to work for the housing department and we used to say, "Only nuns and hippies lived in unrelated groups, and they did it badly." So when a group of families came and said, "Our sons and daughters want to live together in a group home," I was always suspicious, for that reason.

I'm very clear from my reading in this area that people grouped together when they have no relationship is a service construct. It's about meeting the needs of the service rather than meeting the needs of the people. One doesn't overcome loneliness when you share your toothbrush glass. You overcome loneliness by having real relationships and by having a lover, by having a truly emotionally rich life. Research has found that that doesn't happen typically in group homes. You have got me on a subject here.

If people want to live with other people, that's fine by me, I'm not going to stop that. But I do question, when those people don't know each other and it's actually the service that has chosen them. How they live is fine, I don't mind. A good service can provide a service in a tent or in a castle. The type of building is fine, you know, whatever. But what I do worry about is when we get this message that people get companionship and overcome loneliness because they live in a group home, it's typically not true.

MR CATANIA (BSG): Can I speak to that issue as well. From my own perspective, I have had some people look at my life and my so-called independence and I get a lot of questions about the fact that I live with my family. I think the general socially accepted view is that people live with the family, they move out of home, they get married, they have kids; they move on in their life. That doesn't happen for everyone.

I think, as Margaret pointed out, it's having a stable environment in which relationships are paramount, and those relationships, in my case in particular, are with my family. That has provided me with the ability to engage with the world in employment. It has provided me with transport options. I have got really wonderful networks of friends that also help facilitate that. I can go out to movies, to book clubs, to a whole range of social and recreational pursuits. For me personally, I would not have that without the relationships of those that know what my needs are most intimately.

MS SCOTT: Thank you.

MS WARD (BSG): Mamre Association I don't think is presenting but it is - - -

MR KALISCH: They did.

MS WARD (BSG): They did.

MS SCOTT: Pave the Way and Mamre presented together. I'm sorry, I don't have the list in front of me, but - - -

MS WARD (BSG): Yes, no, that's all right. Mamre runs a family support program. About 14 years ago they started to offer family cash payments rather than to provide a direct service. Families loved it. They were only small amounts of money, and over time that amount of money grew. A couple of years ago I came in to review the program and to update it, according to the new tax laws, et cetera. I worked with the Australian Taxation Office to develop a very simple cash payment system that was accountable not only to Disability Services Queensland but to Mamre, the family, to the worker and to the Tax Office. Everyone had an interest.

Those guidelines or the how-to book is on the Mamre web site. It's a little booklet on how to do it. It hasn't been done before in Australia, so we had to get a private ruling from the Tax Office. It is I think quite elegant, in that families learn it very quickly and it works like a charm really. When we started we had 50 per cent of families getting cash payments, now I think we're up to 80 per cent of the families are using cash payments. A key element is that the family and Mamre agree on a plan, and that plan is done every six months. So what are they going to do in the six months with this money?

In that plan, interestingly enough, is how are they going to develop their informal supports first and then their formal supports. So it's a very interesting priority. First, let's see what is naturally there before you need to rush out and spend money, or you may spend a little bit of money to develop those informal supports and then see what you need for your formal supports. That plan is reviewed every six months. The family has got a budget, the payments are made when the family sends in their receipts. So if the family does not send in their receipts for the last payment they do not get the next payment.

MS SCOTT: So they don't actually hold the cash themselves, then?

MS WARD (BSG): Yes, they do, but they're paid every four weeks.

MS SCOTT: I see. Right.

MS WARD (BSG): Okay, so they get a six-month allocation. We do four-weekly payments. I think we can loosen that up, I actually think we could do three-monthly payments.

MS SCOTT: Why not six-monthly?

MS WARD (BSG): Sure, but we have held it tight because we wanted it to work, absolutely work. Families are fine. All that means is that we have a higher admin load. We were way out there in policy land and we did not want to blow this, so we held it in very tight so that we could track every dollar.

MS SCOTT: I understand.

MR KALISCH: What was the maximum amount that was provided to a family, say, over six months?

MS WARD (BSG): One family had a budget of $120,000 a year, that was the highest, down to $4000 average, $2000 to $4000, yes, little amounts.

MS SCOTT: John, do you have a comment or a view on this?

MR WALSH: No. But if there are further details on this, Margaret, I'd be very interested.

MS WARD (BSG): Yes, it's on the Mamre web site and under Family Managed Funds the handbook is there. But you could contact Mamre at any time and they would send you the handbook.

MS SCOTT: People have raised the ATO ruling issue with us. So it's interesting that you've solved the problem so early in time. Now, the other John, do you have a comment on this?

MR CATANIA (BSG): On funding?

MS SCOTT: On cash funding.

MR CATANIA (BSG): On cash funding. Well, I certainly believe that again one size doesn't fit everyone's circumstances. Individualised funding based on express need can be a really meaningful way for a person to build on their life. It needs to be, I think, flexible, according to the future needs that are expressed. There was a theme that was touched on about mainstream services, that is kind of a goal that I see, that we break down that idea of disability services. I think it's important that mainstream services encourage and welcome and support people with disabilities to use their services and there needs to be that kind of transition that works in a very integrated way between mainstream services and people with disabilities.

MS SCOTT: Thank you for your testimony. I think we have finished, haven't we? John, we're finished?

MR WALSH: Yes.

MS SCOTT: Thank you.

MR KALISCH: Thank you very much.

MS SCOTT: A couple of people haven't arrived yet. So we'll have another break.

MS SCOTT: Welcome to the table, Kevin Cocks. Kevin, could you state your organisation and would you like to make an opening statement?

MR COCKS (QAI): Thank you. I'm the director of Queensland Advocacy Inc. QAI was established in 1987 as an independent community-based organisation that conducted systems advocacy and more recently we're providing individual legal advocacy for people who are in guardianship, particularly restricted practices regimes, and assisting people appear before the mental health review tribunals. QAI welcomes the opportunity to present our preliminary responses to the Productivity Commission's issues paper for comment on the design implications for a national disability insurance scheme or a similar scheme. I would also like to acknowledge a lot of our comments are based from working collaboratively with a number of advocacy organisations and people with disability organisations around Australia recently.

Firstly, we're very encouraged by the recognition of the Productivity Commission of the central relevance of the Convention on the Rights of Persons with Disabilities for the design of NDIS or any other scheme. We're very fully supportive of a scheme that is a national scheme which is based on entitlement for all who are eligible; properly funded; based on equity for all who are eligible; based on self-determination; committed to the empowerment of people with disabilities; it's portable; a national scheme; and it's responsive to changing circumstances of an individual.

We also believe a strong independent advocacy support program is separately funded to support and protect the rights and interests of vulnerable people with disabilities eligible under the scheme, that we recognise a need to include groups from the start that might fall through gaps: refugees and new migrants waiting for residency and citizenship papers; people with disabilities living in rural, remote areas of Australia; indigenous people with disabilities, particularly in those areas; people with disabilities in correctional services systems, health and aged care institutions. We also include people with mental health issues and people with ageing-related disabilities.

MS SCOTT: Would you like us to ask questions as we go?

MR COCKS (QAI): If you like, yes.

MS SCOTT: Questions, David or John?

MR KALISCH: One of the things that you've talked about was the national scheme properly funded and portable and that provided better services. Can you envisage the day when advocacy services won't be required?

MR COCKS (QAI): That would be a great day if advocacy services weren't required because we would have realised what I think we all hold hope to and that's a truly civil society when that is measured by the most vulnerable people not being vulnerable any more.

MR KALISCH: I'm not sure whether you were here earlier but there's been some talk about individualised funding and personalised funding. Do you see that as a possible option within the scheme as well?

MR COCKS (QAI): Yes. I think that's got to be central to the scheme. I have a five- or six-page preliminary submission - that's why I didn't read it all. We certainly see that for a long time people have called for a paradigm shift where we move from being passive subjects of pity and charity to one where we are subjects with rights and we have empowerment and entitlement. Central to that paradigm shift, people have to be funded individually or through direct payments such as the UK scheme and other schemes around the world, recognising that not all people will or want to have direct funding. Individualised funding we do not have in Australia except for some individuals who receive that direct payment type of approach; in the early days, in 1987 I think, around 10 or 11 people under the pilot attendant care scheme.

At best we have individual focus service provision where an individual may have a name and a number of dollars attached, and then it varies to the degree that they actually have control of those dollars. So when I talk about individualised funding, that means it is clearly the individual's dollars and they will either be able to self-manage it or be involved to the degree that they wish to or be supported through supported decision-making. The principle of all supported decision-making is that everyone can make decisions with support and it's clearly that those decisions are based on the person's best interests and fundamental needs. Along with that cross-filtering, that they're being empowered and included in society in a way that everyone else is.

MS SCOTT: I was going to ask a couple of questions about other protections in the new system. What's your view about Office of Public Advocate as opposed to just funding advocacy groups such as your own, a visitor program, complaints mechanisms like appeals, would you have a view on those issues?

MR COCKS (QAI): Yes, I think there should be a number of complaint and resolution mechanisms but very differently to the ones we experience today. They must be independent of any service provision or potentially funding mechanisms and we do talk about a governance approach here which I can come to, but there should be an administrative review body that looks at all funding and any decisions that are made under a model that disseminates and manages the distribution of any such resources. Community visitor programs to date have had a various rate of history and success. I think the most powerful form of advocacy is advocacy that is provided with people that is paid and that is the citizen advocacy model.

But until we overcome the structural discrimination that exists in our society, then public advocates won't do that. Public advocates, as the way that I understand them, are there to assist where people have assisted decision-making requirements. But the role of independent community based advocacy is critical, important and it's clearly highlighted the role that NGO, disabled peoples' organisations which they would fit under in the text of the convention, I think is a role for a number of advocacy-type safeguards.

MS SCOTT: What about if there's a move to individualise cash packages and people are able to vote with their purchasing power, for people who are under those packages, do you think there should still be the capacity for independent review of service provision for those people because effectively they've got choice, as now they have less choice about what milk they purchase?

MR COCKS (QAI): What we're talking about is a semi-regulated market concept here, aren't we?

MS SCOTT: Yes, I think so.

MR COCKS (QAI): One would envisage in any marketplace there are consumer protection mechanisms and there may be enough already existing without us creating other ones where those consumer protection mechanisms should be addressing the issues of people with disabilities. 10 years ago QAI was exposing a range of issues of highly vulnerable people living in the for-profit hostel industry system here in Queensland. When we approached the ACCC about those issues, their response is, "That's a matter for Disability." So statutory authorities such as the ACCC right through to state-run consumer protection mechanisms need to be able to come to terms with the issues that they are there in a marketplace to protect people with disabilities as well.

So I see one of the advantages of having such a scheme is we actually significantly reduce the duplication of protection mechanisms and administration mechanisms that currently exist within the administration of disability of services throughout the state and Commonwealth level today.

MS SCOTT: Thank you. John, should we have Kevin go on to his other topics or would you like to ask a question?

MR WALSH: No, let Kevin go on, Patricia.

MR COCKS (QAI): I'll just finish my opening statement, I forgot to turn over the page. Within the disability sector we're fairly au fait with a lot of the social and public policy issues. Where we are a little bit lacking in expertise is around the economic debate. So when people hear about an insurance model, they're very fearful that insurance is based on managing risk and in this context we have witnessed the covert push for the elimination of risk and financial hardship of having disability in many schemes. You may all recall in the HIH collapse there was a significant move by the insurance moguls to reduce their limitations or liability in payouts to people. What we've witnessed since is because people weren't properly compensated the state has had to intervene and add or supplement because those insurance payouts become short-lived.

We have also witnessed the non-supply of lifesaving medical interventions, ie, antibiotics or organ transplants, where people who have had a disability and needed an organ transplant but were actively discriminated because their life was viewed as not valuable enough and assumptions that impairment is a social cost and the burden too heavy for the Australian economy and society to bear. So I think there is a real issue in addressing some of the perception matters around the term "a disability insurance scheme".

Overseas models and trends. We believe that a hypothecated tax levy is required to systematically address the ad hoc, indiscriminate and crisis-driven approach to receiving support that exists today to function in daily life. Perhaps some of the countries such as Germany, New Zealand and Scandinavian countries are examples of those but I think we can learn from them. One of the things Australia has done well is often we have been the last to do things, but when we do take up transport standards or the built environment, we've learnt from our predecessors and made significant improvements to them. I think that would need to happen to make this a comprehensive and robust scheme to really ensure entitlement for all those who need assistance with their daily life. Again, individualise funding and direct payments as per the UK government's right to control initiative, and that's our latest evolution of individualised funding and payments which I'm sure you're well aware of.

Under the heading of a New System Design and who should be the focus of the scheme, we believe we should use an inclusive definition as set out in the UN Convention, the CRPD. Article 4 of the CRPD requires that state parties need to take into account the protection and fulfilment of the human rights of all persons with disabilities in all programs and policies. We support eligibility for disability support based on needs and shaped by the impact of a person's impairment, on their capacity to undertake normal activities of daily living. Possibility that a tiered eligibility structure could range - needs to be developed under a new scheme. For example, three tiers of eligibility could range from low support needs, medium support needs or high support needs as per the German model.

In Control has facilitated the emergence of individualised budgets with the various local authorities in England, in the UK. There have been various techniques used to try to best understand the person's needs and how that links to public funds. Basically the main mechanism is called the resource allocation system. At its heart it provides a framework for translating needs, levels of support - sorry, translating levels of support need with available funding, in turn - levels of support needed turning through a simple to use assessment tool. QAI suggests that the Productivity Commission and staff have further engagement with disability organisations and other allies to examine a more detailed and comprehensive framework around self-assessment and needs.

What should a new scheme cover? We believe the need to address the interface and interrelationship between systemic and structural barriers to inclusion of people with disabilities in Australia and their individualised and personalised support arrangements must be taken into account through the Productivity Commission's inquiry. Investment in making our community and their services universally accessible and inclusive will lead to a reduction in the level of funding need in personal budgets for support and equipment. I think this leads into the economic analysis as well.

Historically in an economic analysis we've seen in the transport risk statement and the built environment risk statement those economic analyses have been based upon cost and deficit. There has been no valuing of wasted time. By that I mean if you've got to wait for two hours for a taxi or you've got to go 587 yards to get into a building when everyone else walks five, then there is a valuing on the waste of that time and the loss of productivity. So what we would argue, that when we come into - we look at the benefits or investment in people. That language is also more in the genre that is advocated for through the UN convention as opposed to the medical model, which is around deficit and burden and costly.

A definition of disability support needs to be broad to take into account the diversity of support needs according to the individual context: cultural diversity, geographic remoteness, allowing for changing needs due to changing circumstances across the life span and have a capacity to respond in a crisis situation. By that I mean quite often people have strong and natural supports within their family and neighbourhoods and friends but sometimes if a crisis occurs those supports may not be there available. That's where some immediate support, additional support - access to. So - - -

MS SCOTT: Can I cut your flow - presentation?

MR COCKS (QAI): Yes.

MS SCOTT: Yes, all right. Kevin, in relation to Queensland, in such a centralised population there must be quite a few people who - in their town who have very limited choice in terms of services, very limited. Given your organisation's role, what's the approach that you think we should have in relation to provider of last resort or access or special arrangements? I mean, people choose to live in these places and they may already live there, their family may be there, their support network may be there but there may be very few services available. Does your organisation have a view on that?

MR COCKS (QAI): Well, yes, and from a personal view I can recount as well. When I had my accident I was living in country rural Queensland in a place called Doolbi.

MS SCOTT: Yes.

MR COCKS (QAI): I was raised in St George, so - and there weren't many services, if any. In some ways I think that allows for some creative and innovative responses to occur. I think that's where - what this offers great hope to actually reform the way that our current human service structures are developed and limited, because coming from the country there's a bit of an attitude that whatever it takes will do it. When I went - after I was released from the spinal injury unit there was no money for modification for my home. I either went to an aged care nursing home or my family supported me. So because I had my accident and I was embedded in the community, the local community made appropriate modifications and I was able to live with the support of my family. But all my footballing mates wanted to have a roster to support me, I mean, doing things like having a social life but it wasn't formalised. It was, "Hey, you're coming to this," or that. So I think it allows for natural relationships to continue to evolve but it allows for creative and innovative ways to be supported. So I see this as not much as about service provision, it's about support. People don't want to be serviced, people want to be supported.

It also then - also irrespective of whether you mange your funds directly or are supported to manage them you actually could be seen as a small business employer, because in your community you are creating employment opportunities. So straightaway you're starting to begin that paradigm shift of being seen as a burden to our society to somebody who is contributing to our local community.

MS SCOTT: Yes, that's good. John, do you want to chip in here?

MR WALSH: I've just got a general question around advocacy. In relation to the area where - we're dealing with people who have a need for support in decision-making or have very little decision-making ability. There's a lot of talk around making decisions, about what's in the best interests of the person with a disability, making a decision about what's in the best interests of the person with a disability.

MR COCKS (QAI):   Who makes that decision?

MR WALSH: Yes.

MR COCKS (QAI):   Well, I think there's probably a number of answers to that, John. Clearly under our guardianship legislation - is a good place to start from. Family members are automatically seen as informal guardians. Unless somebody contests that, that's often the way it remains. Yes, we know that in some circumstances families don't make good decisions. That's why we have guardianship legislation to step in there or if a person has no family that an adult guardian is appointed. But I think it's an important thing that the person - the first principle is that the person - it should be assumed that the person can make decisions or can be involved in the decision-making.

I think we need - that's where some scrutiny needs and that's where advocacy comes in, whereas sometimes we've seen in service provision where, for example, say, I've heard a person who may have obesity and diabetes and a lot of health conditions, workers say, "That is their right to order pizza three times a day, five days a week." That's certainly not in the best interests and so that's where an advocacy role comes in, to demonstrate to try to get a balance. Sure, if the person does like a pizza - we all like to indulge in those prohibitive luxuries, whether it's chocolate, pizza or too much alcohol, but it's about getting the balance right. If the person's rights are being exploited or their health and wellbeing isn't being looked after in those circumstances that's where a role of advocates often come in, or other places where it may not be to do with their health but just with their relationships.

We have heard excuses of using workplace health and safety for not taking a person to a family reunion because there were barbecues there and gas bottles and it could have been dangerous to the worker; the gas bottles could explode. So there are these often excuses that really are nothing more decisions that are made for the convenience of the workers in the service and so that's where the clear role for advocacy lies at an individual level, but also at a systemic level where we see things in legislation such as restrictive practices and other legislation where a number of unintended consequences arise out of that. Where people are structurally marginalised and excluded from society we need systemic advocacy to continue to address those situations.

MS SCOTT: Can I just jump in here. In terms of restrictive practices is there a regime in Australia or overseas that you think the commission should look at in terms of best practice, in terms of reporting or oversight?

MR COCKS (QAI): I'm not sure if there is. I know where it has been in existence in England and America for a number of years there is now a movement growing to eradicate restrictive practices from the legislation because it hasn't achieved what it was intended to. I believe, by having an NDIS or such scheme we will significantly reduce the need for restrictive practices if there ever was one, because I believe 90 per cent of the people who are under restrictive practices are there because of environmental factors, because they've experienced neglect and abuse from their early childhood days or living in such abnormal situations that what is an appropriate behaviour is not even being fostered or mentored for them, or people being forced to live with other people who have quite significant and severe behaviours as well and where there may be quite a lot of violence between people, yet continue to forced to live in those situations. So my belief is that if such a comprehensive scheme came now for future generations we would not be able to sustain or justify a restrictive practices regime.

MR KALISCH: I've just got one question about, I suppose, the nature in which we might need to balance administrative costs, self-assessment and individualisations. Is that something that you've thought about? I mean, is self-assessment a way of trying to deal with sort of keeping admin costs to a - - -

MR COCKS (QAI): Yes, self-assessment, as is evidence that's coming out of the UK and others that it does minimise - and in my personal experience people with disabilities in families often underestimate what they need. There's an anecdotal line that give a person with a disability or a family one dollar and they'll turn it into 10, and of course there's no scientific evidence to suggest that. I've always seen that people are very conscious of the short supply of money and really only ask for the limited amount. Where there also isn't any hard evidence, but anecdotal I think we'd see, once we start to cap the amount of money that's being distributed, we see a lot of waste and misuse of that money, and particularly if I can extrapolate to government agencies or even non-government organisations, if you get $1,000,000 and you haven't spent it by the end of May there's a mad rush to spend it because you won't get another $1,000,000 next year.

That's just, I suppose, a very unscientific piece of evidence. But when a family or a person with disability lives with disability all their lives they can assess quite quickly what do they actually need. The way our programs and policies are structured today are not always located into people's what I call fundamental needs - and for me that is about having my hygiene needs met, getting in and out of bed and whatever, that other stuff that I need to function in daily life. I might have to go and get community access and so that has a set of criteria which really don't fit what I want, and so you see where I'm going with this. I think from what we've seen in England that self-assessment tools are a very empowering way to be involved but also a pretty responsible way of assessing it, and reduction of that red tape and administration.

MS SCOTT: John, how are we going?

MR WALSH: Yes, thank you, Kevin. That was helpful.

MS SCOTT: Kevin, I think we might start wrapping up now. Have you any last comments you'd like to make?

MR COCKS (QAI):   Just on governance and administration?

MS SCOTT: Yes.

MR COCKS (QAI):   We believe that a creation of an independent body to govern and administer funds is required. This body could be a statutory authority. This body would be responsible for the governance of a new disability support scheme. Key features of the body would include a board with a majority of people with disabilities who are representative of key constituencies, the board having oversight of the UNCRPD implementation as part of its brief; the board making decisions about funding distribution; the government to fund this body independently and separately and the government also to be a stakeholder in this body; that one of the roles would be research and development to promote cultural and paradigm shifts in disability support; the body being underpinned by specific legislation reporting against CRPD-based performance measures which would significantly flow into the reports that the Australia Government are required to produce; and the body would need to be reviewed regularly by an appropriate administrative review body.

We also believe that a new scheme for funding disability support cannot be expected to address all the issues that impact on people with disabilities. Ongoing structural reform work to address systemic barriers and remove discrimination needs to be properly funded and is not the direct task of a national disability scheme, and by that I mean transport, health, education, the built environment. Those government agencies have that obligation under the CRPD to protect people's human rights and to develop policies that progress and fulfil people's human rights in those ways.

MS SCOTT: Thank you very much.

MR COCKS (QAI):   Thank you for the opportunity.

MS SCOTT: Good afternoon. Would you like to identify yourself for the transcript and indicate the organisation to which you belong or are representing, and would you like to make an opening statement?

MS VICARY (QDN): I'm Fran Vicary and this is Josey McMahon. We're representing Queenslanders with Disability Network. I am the manager and Josey is the treasurer on the management committee. Our opening statement: QDN or Queenslanders with Disability Network is a network of, for and with people with disability with over 700 members across Queensland. Through connections with this membership QDN has a deep understanding of the impact of disability on people with disability and through talking with those people. We strongly support the establishment of a care and disability care and support scheme that would fund the support needs of people with disability throughout their lives.

With regard to entitlement, QDN believes that a disability care and support scheme must establish and fund support for people with disability as an entitlement. So regardless of the kind of diagnosis or how you acquire your diagnosis, if you require some form of care or assistance to be independent or to live in the community, then you should be entitled to get that. We also acknowledge people's citizenship, their right to participate in society and to contribute to a meaningful employment or other community involvement. Within this framework there will be a need for generic services such as housing, education, transport and health care. People with disabilities require access to use these services like any other Australian and currently this form of access is not fully available.

Now, any funding should be portable. That is, that people with disabilities should be able to live anywhere in Australia and move between states and territories. For example, if you've got funding in Queensland you can't, if you get a job in another state, move to that state because you can't get any support. Once you move you keep your funding for one year if you're lucky. After that you go back to the bottom of the list in the state to which you move to - as I understand it from a conversation with our disability services.

MS SCOTT: We also had evidence given in the last day about that, about people looking at job opportunities and not being able to take them up because they weren't offered support they required in another state.

MS VICARY (QDN): Yes, that's right. So some of the principles of an entitlement-based support system which QDN believes are really important, is that there's adequate support to live an ordinary life as an entitled citizen of Australia and there's an equitable response across Australia. So it's a state-based versus a kind of federal system.

MS SCOTT: Are you looking for national standards and state delivery or are you looking for national standards and a national delivery?

MS VICARY (QDN): We're looking for national standards and a national delivery because that takes away the vagrancies between state delivery and how states report to standards.

MS SCOTT: Thank you.

MS VICARY (QDN): A system that focuses on building people's abilities rather than managing their differences. The current location system, you have to portray yourself as severely destitute and about to be imprisoned or homeless or entering into a nursing home before you will get any kind of support, even basic personal care support. A system that also focuses on social inclusion and participation like any other citizen. So you can't just be present in community and be cared for behind locked doors, you actually need to be supportively moved around community and to have community access, to be known and, no, we do not support disability ghettos where a lot of people live together. We always look at a social housing model where there's a mix of people from different economic backgrounds, different cultures, different abilities, different employment situations, different genders, that kind of thing.

Also the empowerment to direct their lives. So people with disabilities, while they're supported if the person can't do it themselves, that primarily the person needs to be empowered to direct their supports to say, "Only this," "Only that," and to have that happen. When people get what they need to live a decent life, they do not ask for outlandish, extravagant things. People just want to be able to get up in the morning and to do the tasks of daily living independently or with assistance.

It needs to be timely; so when you need the support. At different ages your support needs change. If you're living at home you need, like anyone else, as a teenager or early 20s or late 20s, the social scale for leaving home goes up. People with disabilities need to be able to choose and to plan for when they will leave home to live independently or to live with friends in that sharing model that we see in the 20s and 30s, and then to move into a home of their own. So what is socially acceptable for the rest of the general population is what people with disabilities need.

As well as the principles, another thing which is vitally important is access to equipment, because even if people had the support they need they can't live an inclusive life unless they have the equipment. Currently equipment is funded on a state-by-state funding model, mostly through Health, this funding is not 100 per cent of the equipment, so you only get a percentage and you have to make up for it with a gap payment. A lot of people can't afford this gap payment. Some of the principles that we think around the question of equipment, I have done some research work with some occupational therapists at the University of Queensland and at Deakin University and we're writing a collaborative paper on this topic.

Some of our principles are the best combination of equipment, personal care and environmental design to meet needs in every area of life. Access to sufficient funding to pay for good quality, long-lasting equipment, having needs looked at holistically so that each piece of equipment works well and does not interfere with other equipment, because sometimes you might get given, say, a new wheelchair, which you desperately need because the old one is dying and is mechanically unsound, but you find with the footrest on that new wheelchair you can't actually get to the table to reach your dinner, so there needs to be a holistic approach.

MS SCOTT: Can I just ask about that? Would you support the idea that the scheme would fund good quality equipment but people would have the option if they wished to upgrade that to something better, by making a personal contribution, or don't you favour that?

MS VICARY (QDN):   If it was a genuine upgrade. It's hard to kind of fully respond without knowing what the genuine upgrade could be, because often the basic minimum is quite extensive and the top of the line. Like, power wheelchairs can cost between $7000 and $15,000 and more, up to about $35,000, depending on the level of automation that you need in the reclining or the raising of the foot rest or that kind of thing, and if you need that you need that.

It's also about having equipment across the lifespan, because for many children as they grow or people as they need change, this is not met. Accessing the support to get the equipment right, to do that matching, and able to access resources when they're needed and being actively involved in the decision-making process. In Queensland you cannot apply for equipment yourself, you have to apply to an occupational therapist or an assistive technology prescriber and then they talk to Queensland Health. You cannot have a direct line of communication with Queensland Health.

Should you jump that line of communication they kind of splutter and tell you, "No, we have to talk to your therapist," then you can persist. But, again, you should not have to, you should not have to fight to be able to talk to the person who is making a decision on the equipment that you'll be using. So it's all about having that person involved and being at the centre of the prescription process. Equipment not only means mobility aids, it means technology in the home, for instance environmental design and environmental controls for people who need climate control; it's light switches that are voice-activated, it's those very high end technologies which are not a luxury, they're a necessity.

The new system will require fresh thinking. This will be about looking at working together to avoid a blow-out in cost and working towards a fair and effective service system. There will need to be a capacity-building strategy to assist communities to include people with disabilities and welcome their participation. This is why we say about not grouping people in the one community, because you reach a level of full capacity where no more people can welcomed, and then you move from an inclusive community to a system of exclusion, where the people are clustered together and they're avoided, because they're different.

People with disabilities need to envisage what is possible and to plan for the future and to build a good life for themselves and to maintain that when they need support. Like, that might look like whenever something happens in your life - say, you're moving in with a partner or you're moving out from a partner, you actually need to be able to go to someone in the system, tell them what is happening, tell them how your needs are changing and know with some certainty that there will be at least some accommodation really to the bare minimum that you won't end up in a nursing home because you are getting a divorce. This is what is happening to a lot of people currently.

Behind this, there needs to be a specialised service system that is responsive to needs. If you've got very complex needs you need to be able to go to a specialist, a service provider or a provider who will be able to work with you to accommodate your needs and know where you're coming from and what you're looking for so that you won't have to tell your life story 300 times. Just to be given the wrong shoe, so that you can't walk, and then you can't transfer, you know.

People who have very complex needs need to know that it's a complex system which is interlocking like a puzzle or like a net which is woven together, that has different pieces that fit together, that do different things, that actually work to meet their needs, because currently we try to squish the person into this system that we have and often some of their needs or their basic, fundamental human rights get cut off because the system is not able to respond and is not flexible. Within this and underpinning this there needs to be a capacity for research and development to identify the way forward first for social change and as society changes as people's needs change, as demographic trends change.

Also there needs to be safeguarding strategies, including individual advocacy and administrative appeals mechanisms and some more transparent accountability measures, for both services and service users. Independent advocacy is the most independent safeguard. People need to speak up. They need to be supported and they need to be supported by advocates who are not from their service, who are not paid by their service, who have no vested financial interest in keeping them within a service which is not responding their needs. This is what we're seeing a lot with services that are funded to do advocacy. That is not true advocacy. It's not independent. The service has a vested interest in keeping the person within their service. They are dollars involved and if the person leaves the dollars leave.

So in summary, we believe that a disability care and support scheme should facilitate people with disability defining and directing their services so they receive the right amount of service with the right equipment by the right people in the right way at the right time and it's how they want it, not how the system thinks they should receive it.

MS SCOTT: John, have you got any questions for Fran?

MR WALSH: Thanks very much, Fran. Yes, I'm just interested, Fran, in do you have any views on the extent to which technology can reduce costs through reducing support needs?

MS VICARY (QDN): Technology can be a safety issue and John, because I don't want to speak from a global or systemic - I'll give a few examples from my own life. I use technology to make myself safer and to possibly reduce the cost of care. I have a mobile phone and wherever I go if I'm even home alone, if I - I take that phone to bed. Now, if I need to I can ring a support worker and they come over. That's like a one in a hundred chance. I think in the last 10 years I've made those kind of calls about three times. That is a simple, everyday use of technology which keeps me safe and - you know, what if you get a flat tyre? You can use your mobile phone to ring the RACV, they'll come and fix your tyre. So it's a simple thing.

There's also technology where the need just to buy a shower chair or something to enable people to shower safely, can reduce falls, can reduce carer injuries, because the person can transfer onto the shower chair that meets their needs. Then they can shower safely; so those levels of technology, There's also a level of technology to work. People need certain technologies to work. They need special software such as voice recognition software, that kind of thing, so yes.

MR KALISCH: I just have one question about some of the - one of the aspects that you talked about in terms of what should be in the new system and the new framework. There was certainly a lot of perspectives here that we've heard from others, so it was actually quite confirming and reaffirming that this is a shared view. But I'm just wondering about how a scheme could go about trying to encourage people with disability to have a fresh vision of their potential. Is that an aspect that should be worked on a bit more?

MS VICARY (QDN): Yes. That's an aspect that really needs to be worked on, hey

Jose?

MS McMAHON (QDN): Yes, I think so, because I think often I think in Queensland - certainly I think people often will see people's deficiencies rather than their abilities. People have very little vision for their lives.

MR KALISCH: We've certainly had from past hearings some very uplifting and enlightening perspectives that we've heard from parents and families and people who are friends of people with disabilities.

MS McMAHON (QDN): Yes, I think it's - you know, often it will be the parents or the family or some people with disability themselves, but if it's actually left to the service system then there won't be that vision.

MR KALISCH: Okay.

MS VICARY (QDN): Because we see all the time people with the same disability as I have and the same support needs that I have - other members born at a different time in history, later in history, cannot get support to live individually. That is absolutely horrific to know that a small window opened, some people got support and now people who are coming along with the same support needs cannot get the assistance. Also when that window did open people with really high support needs or really complex needs missed out and got left behind in institutions.

MR KALISCH: Okay, thank you.

MS SCOTT: John, any further questions for Josey or Fran?

MR WALSH: No thanks, Patricia, no.

MS SCOTT: Well, thank you very much, both of you.

MR KALISCH: Thank you.

MS McMAHON (QDN): Thank you.

MS SCOTT: We're up to our last group, Lisa Bridle and Mark Riemers.

MS BRIDLE (QPPD): We have Phil Tomkinson.

MS SCOTT: Phil as well, okay, great, thank you. You can make an opening statement.

MS BRIDLE (QPPD): Yes.

MS SCOTT: Thank you. Will you leave us enough time to ask some questions?

MR REIMERS (QPPD): Yes.

MS BRIDLE (QPPD): Sure. How long for the statement, 10, 15? Okay.

MS SCOTT: Sometimes people use all the half hour.

MS BRIDLE (QPPD): Okay.

MR REIMERS (QPPD): We plan on being very quick.

MS BRIDLE (QPPD): Do you want us to start or you want to sit down first?

MS SCOTT: Welcome to the table. Could you please state your name and the organisation you represent?

MS BRIDLE (QPPD): Sure. My name is Lisa Bridle. I'm the president for Queensland Parents for People with a Disability and with me I have Phil Tomkinson, who's a member and a past president of QPPD, and Mark Riemers, who is our director. We basically want to cover seven points. We are going to try and move through that fairly quickly. Phil and Mark are going to cover two points each and I'll cover the final three.

But QPPD is a funded family and systems advocacy organisation with about 300 paid family members. I guess it has been an incorporated organisation for over 20 years but I guess it came together as a concerned group of parents in the early 80s. Its mission is to defend justice and rights of people with a disability, to challenge exclusionary systems and I guess to insist that our family members with disability get to live lives where they can contribute in their communities the same way as other citizens. I'll pass over.

MR REIMERS (QPPD): In terms of the scheme and how it's being looked at, QPPD's mission has always been about inclusion and participation and we welcomed the federal government's social inclusion agenda and we believe that whatever happens as a result of this, it should sit within a social inclusion framework that assesses how services are delivered within that framework. So when specialist services are needed that do remove people for periods of time or for specific reasons or for specific supports, then that needs to be looked at in the framework of social inclusion and what they're doing to still have some outcomes for people in terms of being part of mainstream society and connection with society rather than just removed and excluded and ignored.

We also believe and are really glad that Australia is now signatory to the United Nations declaration of the Rights of People with Disabilities and to the optional protocol and we believe that any activities or outcomes from this scheme should also be assessed against the standards that are set in terms of human rights because we believe that has a lot of implications for housing, employment, education and how those services are delivered to people. Currently, people with disabilities are often excluded from the very basic things of having their own home, having an employment, having an education. Work opportunity and options are seen as add-ons that you may be lucky to get rather than entitlements. So we liked the entitlement nature of some of the proposals for all people with disability.

We particularly were grateful for the definitions of disability in the paper regarding both disability determined on the basis of disability and impairment; however, the membership of QPPD strongly believes that the focus on severe and profound disability is not necessarily the best way to go because often people with mild or moderate disabilities functionally have very large impairments that preclude them from being socially included and participating. So we believe that combination together of disability impairment is a much better way to go, rather than simply looking at severe or profound disability.

In relation to the application of those principles to the scheme, members were very concerned about the determining of eligibility. There have been many instances over the years of people being assessed, reassessed, annually assessed, going through hoops yet again, and yet again, and yet again. Particularly when the disability is ongoing, severe, significant, it's not going to change over time but you still have to annually go through the hurdles of the hoop jumping of establishing eligibility for someone who is obviously entitled. We find that very frustrating. The other issue about determining eligibility is assessment and how that assessment has happened. Our members have expressed the view they're probably the most over-assessed group in Australian society and don't particularly want to go through that.

Disability can't be seen as separate from other disadvantages in people's lives. One of the issues for that is that we know that population models disadvantage people who have multiple disadvantages. So when a person has a disability and they're from a CALD background, a person has a disability and they're from an indigenous background, if a person has a disability and they're homeless, a person has a disability and mental illness, there's this football game that goes on about who's going to or not going to provide service and people are excluded. So one of the principles that has been suggested is that where there's a government program to address disadvantage, like indigenous programs or homelessness programs or mental health, there might be a variance to a population model to account for who does assessments, how they're done, et cetera.

So that perhaps on the whole it may be a FaHCSIA team or something that do assessments but in the case of indigenous people they might train indigenous community agents to do that assessment. So we're not asking for variance for every disadvantaged group; what we're saying is there should be a variance for any disadvantaged group - young mothers included, young people who don't engage with services and don't engage with bureaucracies. You could actually have a variance that places workers for those specific groups where there are programs to redress disadvantage that do something about it.

MS SCOTT: Can we talk about how you'd operationalise that and what it might mean?

MR REIMERS (QPPD):   The only example I could think of would be Micah Projects at South Brisbane who have funding under sector capacity funding from Disability Services. With that, the department were meant to do all referrals to that service; however, the agency knew that people with disability and mental health aren't on the books of Disability Services Queensland, they're never going to walk in the door, and that in order to be eligible to disability service you had to have a registration of needs and you had to prove citizenship. Well, for that group of people with mental illness, intellectual disability, some with physical disability who are homeless, it could take six months to get them some identity papers.

So what Disability Services did was said that, "We will entrust the responsibility for you to get those assessments done and the information about eligibility determined within six months. If it's going to take longer than that, inform us and that can be extended." They devolved the responsibility to a community agency to do the engagement and work over time because there are people who won't respond, so people with psychiatric disability, for instance, may not want to give you their information because they're scared they'll be revictimised or hospitalised or abused.

MS SCOTT: Yes, I've got it now.

MR REIMERS (QPPD):   So that's an example of how it was just devolved. Now, they were the only agency under sector capacity that didn't have Disability Services give them the client group to work with. It was a variance to a population model that they had statewide. We also know that when there are multiple disadvantages, people slip through the cracks and we want that to not happen as part of a new way of doing business. So it's over to you.

MR TOMKINSON (QPPD):   I'm speaking to the third and fourth points on our document. Point 3 is about the issues that parents have raised with us about difficulties they experience when their child transitions through different phases in life. When you talk about these transitions we're not talking about unexpected events in a person's life - the transitions from home to somewhere else - and what we're looking for under a new system is policies and practices that encourage parents to plan and supports them in making these plans and having this vision, having something that their child can move to, rather than waiting for the lotto that might be a funding package.

Point 4 talks about the image of people with a disability as a burden. We'd hope that a new system would not encourage or support that in any way; that it would not be necessary in any application that is made for a service that you are required to portray your child as negatively as possible. The sort of competition that we have at the moment is perception that the prize will go to the person who can paint the worst possible picture of their situation. We would like to see a system that does not require that, does not encourage it and does not reward it.

MS BRIDLE (QPPD):   I'll move on to the other points and I've got Phil's notes here. In the paper you raise the question about assessment tools and I guess our view would be very strongly that currently we've had that deficit-focused model which has very much been about professionals determining need and we get this kind of misery olympics approach to getting funding. What we would like to see - in fact a lot of resources are spent on multiple periodic reassessments - actually working with families in a more strength-based approach, so actually working with families to reclaim a vision of an ordinary life for their family member.

We think that's actually where you're going to get reductions in cost blow-outs is by investing in families in that early vision rather than necessarily getting some fantastic, spot-on kind of assessment tool, that it's really about the way - to work with families and individuals around things like informal supports, natural, normative pathways of life. I guess I have some hope that a new system would actually dismantle some of the things that I've actually described as theft from families.

For example, in Queensland one of the things we have these positive futures environments for people who are subjected to restrictive practices, so people with challenging behaviour. $68 million has gone into these positive futures environments for a very, very small number of people - I haven't got the figures in front of me. But it's theft from those families who actually need a very small amount of money to make the life of their family member. So currently we're wasting the disability budget in extravagant ways. So I don't think it's about cutting people off entitlement, but it's about how we encourage people to use that money more wisely.

I think it's very, very important that our early intervention models are about encouraging family members not to see their family member as a burden, but actually as a citizen, as a child, as a valued family member.

MS SCOTT: Before you go on, could you just remind me what the name of that program was?

MS BRIDLE (QPPD): Positive Futures Environments. I guess one of the things we would be arguing is that when we talk about what services should be eligible, we want services to only be as special as they need to be. We're not denying that sometimes people need specialist support but my view would be that nobody actually needs a day service, what people need is something meaningful to do during the day. They need a job or they need the opportunity to be a volunteer or they need some meaningful leisure, some support perhaps to socialise in their community. So I think again the way that we've constructed our support systems in terms of day service, accommodation service, respite service have actually led to very expensive inefficient models that lead to a service life rather than a real life for people with a disability. We see that placing some of the control back in the hands of the person and their family or the people closest to them, may be some antidote to that system.

In that I guess our sixth point is that we need to reinforce the natural authority of families and not the authority of disability, medical or bureaucratic experts. That actually requires, I think, some general resourcing, I guess some block-funded services perhaps for - and who would fund those, I'm not sure - places that in fact families can approach to learn how to plan for the future. Our seventh point is that we believe that the models of support should include self- and family-managed solutions and funds. I think that actually requires things like people having access to the stories of people who have tried to work in a different way. It requires training events, learning events for families. It certainly requires advocacy because none of this happens early.

One of the areas QPPD works very strongly is in the inclusive education area and so people can start off with a positive vision but that vision gets knocked around fairly much in our current system. So because we don't believe in fact impairment is a problem but rather the social barriers of the problem, we certainly need some of the infrastructure to be about advocacy and about training and education for families to know how to negotiate through the current maze that exists.

I just had a few more points about that infrastructure. We were thinking of things that funding should be eligible - some of the eligible expenses might be for people to have access to mentors, to have access to community navigators, to have planning and implementation assistance, certainly some assistance around recruitment of paid support and about assistance with all that payroll and administrative responsibility and the development and trialling of models which might see some of the administrative burden taken off families so that they can actually concentrate on the management of what really matters in terms of the support needs.

MR REIMERS (QPPD): There are a couple of other points, I suppose, just about parents' ability to engage in the workforce is a huge one and people with disability's ability to engage in the workforce. I've had a couple of calls in the last six weeks from parents who have a child with a disability in a normal school; however, the principal refuses to allow teacher's aides to toilet the child so the parent is expected to go three times a day to the school to toilet the child and therefore can't engage in employment and has to remain on a supporting parent benefit. That is not an uncommon story amongst members who have their children in inclusive settings. So you've actually managed to get your child in the setting, but everyone's basically saying, "Well, it's a bit of a welfare model here and you've just got to support the whole thing because we're not going to make it as easy as possible for you to do it."

MS SCOTT: Will you be able to resolve that issue through advocacy, do you think?

MR REIMERS (QPPD): We've given advice on how to resolve it but it's a difficult one because while the act says one thing and while the guidelines say another, the practice of people is very difficult and it may in fact take somebody to take them to court legally to stop these silly practices. So that's just one little example of that. The other example is the savings through government from really good family and disability support. The characteristics of parents involved in child protection in Queensland last year, some significant developmental or physical disability in low socioeconomic areas 43 per cent of families in child protection have a child with a disability. However, if you include, and I love the way they don't differentiate - there's mental health and behavioural problems - that's up to 64 per cent but it's not included in the disability run.

The stats are so in Queensland because if you go to the communities and ask for assistance you go on the maltreaters register. So there are systemic problems and the department - - -

MS SCOTT: Just tell us a bit more about that.

MR REIMERS (QPPD): The department says they're resolving that issue but if you live in a regional area, there's not a disability service, there is the Department of Communities. So you need help because you're not coping with your child who may have some behavioural issues or a significant disability, so you ask for support. In order for you to get support you go on the maltreaters register, so you end up in the stats for people in child protection.

MS SCOTT: That's not for maltreating a child or anything - - -

MR REIMERS (QPPD): No, this is a request for support. But there is an over-representation of families with disabilities in something like child protection because there's no support services.

MS BRIDLE (QPPD): One example that was given to me by, actually, someone works on the tribunal was that a family had been asking for some support, they had a young child - who's a single parent, a young child who escaped regularly. They actually wanted support to build a fence to keep the person safe. That wasn't considered an eligible expense. The family ended up coming under Child Safety because the child did escape. The child was then subsequently removed, is obviously in a very expensive system. The foster carer now has a fence that's been built around the foster care situation, but in terms of the cost of that response rather than building the fence at an early stage it's just - - -

MR REIMERS (QPPD): That's often the systems aren't natural, aren't simplistic; it's the disability solution to, you know, weirdness for a family rather than a natural solution as, "I need a fence. I can't afford it. If we have one then my child will be safe." But it never seems to happen that way. So there's the whole savings in child safety of people. The other thing is the incredible number of parents of people with disability who are single supporting parents because relationships break down through lack of support for people to have the natural supports they need in order to sustain a family. Then you've got a single supporting parent on a low income who is struggling to meet the costs. We know the additional burden of disability.

An example that was given to me from a parent on the north coast was that she would love when she needs to go to hospital, and which has happened a few times, for - there's a family member in Cairns and there is a family friend in Darwin who know the child really well, who has significant disability and communication difficulty. He loves spending time with them. They will pay a fortune for him to have a month in respite care but nobody would assist with the air fare to get somebody to and from, which would be a saving of maybe nine or 10 thousand on the expense. It would be a natural way for things to happen, but because she's a single supporting parent she can't afford the natural thing. She would be expected to go through the service system which would be incredibly pricey to do stuff. So when we're talking about natural supports and natural ways of doing things there are huge savings.

The other example that's often used, and I've had a few times this: if I need a cleaner I need a cleaner, it does not have to be a hack cleaner who can't clean above their shoulder. It could be a generic agency who do it for a lot less and they don't change my cleaner every four months so that they don't become attached to me and I don't become attached to them, which is a very bizarre - and also they come without gowning, masking sometimes now in order to provide a service to people, which are the occupational health and safety things which have come into the disability service but aren't in a generic cleaning service, and families would prefer to use the generic solution.

The other was nannies rather than disability support workers - you know, the cost of having someone looking after your three-year-old who's trained as a nanny rather than a disability support worker is a lot less. However, you can maybe use funding to employ somebody under an award because of the way things are structured currently. You couldn't get funding to have a nanny do it.

MS BRIDLE (QPPD): I guess we see a lot of times as well where the lack of a timely response drives people into crisis. I work in a service for adults with intellectual disability and many of whom have challenging behaviour. The number of people who have not been able to access, I guess, behaviour support intervention during their adolescent years, so by the time they turn 17 or 18 things are very, very entrenched and kind of the social impact on the individual and on the extended family are extreme. So it's just ends up being a much more costly service.

MS SCOTT: You've got a plethora of quite curious stories. Will these make their way into your submission?

MS BRIDLE (QPPD): I hope they will.

MR REIMERS (QPPD): If you want them to they will.

MS SCOTT: Someone earlier raised the issue of the level of funding in Queensland relative to other states and was making the point that it was a powerful political tool. I'd be interested in your views on that, your parental view, and also your views about accreditation, accredited services, flexibility and accredited carers or attendants versus - you've talked about nannies, but would you insist that in a new scheme everyone has certificates III and IV or would you - - -

MS BRIDLE (QPPD): No.

MS SCOTT: No, all right.

MS BRIDLE (QPPD): I guess our view would be that the quality of service is best monitored - I mean, I think Fran talked about the need for independent advocacy and I guess the need for kind of complaints and investigative processes. I think that the quality will come from empowered individuals and families being able - and choice - you know, genuine choice. I guess I would like at this point to acknowledge that if we think things are difficult in Brisbane as a statewide organisation, we're very, very aware of how much more difficult it can be for people living in - - -

MR REIMERS (QPPD): Goondiwindi.

MS BRIDLE (QPPD): - - - regional areas in terms of choice particularly. That's why I think - I guess that's another argument against some of that accreditation kind of process. I think it seems - you know, yes. We really need to - - -

MR REIMERS (QPPD): Or the other thing about that training is that many families would prefer to get somebody without those qualifications because they believe that people have been trained to have a certain value system and attitude towards people with disability through their training that leads them to be not as normal as somebody who they employ for their values and ability to relate to both them and their family and the person with the disability, and they would prefer to do the training of the things themselves rather than to employ people who have been inducted in a certain way of viewing people. To talk about people having normalised lives is not to give them one and that's the thing.

The other area that's of major concern is people who have multiple issues. Like, in Queensland, what, there are two psychiatrists who deal with people with an intellectual disability and psychiatric disability and one of those was off sick for four or five months and so we had one person in south-east Queensland who has got a waiting list longer than most. You know, people can't get access to that. If you've got an intellectual disability and a drug addiction drug services won't have you, other services won't.

MS BRIDLE (QPPD): I guess we - I mean, I would say that there is a pervasive devaluing that has its impact on that recruitment into kind of some of those key areas.

MR REIMERS (QPPD): Yes, it's a huge problem if there's a multiple disadvantage and we would hope that the system might take into account some flexibility around issues that are across domains like mental health or psychiatric disability and intellectual disability. There's no drug and alcohol facility that takes people with a disability.

MS SCOTT: John?

MR WALSH: Yes, I do have a question, commissioner. It's a little bit off the track. I'm interested in the interface. You mentioned getting away from the medical model to a foster - you know, getting away from a model where you had to - I think you called it a misery olympics - - -

MS BRIDLE (QPPD): Yes.

MR WALSH: - - - to an extent of ability before you could get anywhere and that's very much driven by a medical-type model, I think. But I have met carers of children with disabilities - and I know it depends on the type of disability, but my observation has been and people have told us that there's a time during which, although it's fully dependent on the medical profession to diagnose the problems with your child and, you know, is looking for a cure, how do I get the best for my child and so on in the early childhood years? Then it seems to be almost like a need for acceptance, that we've got a lifetime issue here. What I'm interested in is how best to help people to make that transition in the first place and, secondly, to make the distinction about when they need a medical or a health professional guidance, when they can take an opportunistic view of the potential of the person with the disability?

MS BRIDLE (QPPD): I guess I'd say a couple of things. One is, I think, obviously professionals do have enormous power to define those early years and the path that people are on. I work in a centre that tries to educate medical professionals about how to do that better in a non-stigmatising way. I think where I've seen things work very well is where there's collaboration between professionals and parent support organisations, and certainly, I mean QPPD sees that its work is very much about probably promoting a different view from that cure and prevention of disability to seeking that disability is a kind of a natural part of the human condition and that in fact you don't have to give up - you don't actually need a cure for your child to live a good life. What you need is for those kind of barriers to the ordinary life that we want for our children to be removed.

So I guess I'm saying that I think some of that peer mentoring that can happen from parents, if it sits alongside - I mean we're not saying no medical treatment of impairment but are saying that has to sit alongside the kind of the medical - the search for a diagnosis, some clarity about what issues the person has, because I think - again, I guess, working with medical professionals I'm often struck by how little they know about the day to day of what families are really kind of struggling with, or the ordinary kind of joys of being a parent of a son or daughter with disability. I think they - you know, the tragedy burden kind of approach permeates all levels of professional knowledge, I think.

MR WALSH: Have you got any examples on how that works well? That would be really good to put in your submission please.

MS BRIDLE (QPPD): Yes, okay. I mean I've seen it - my son has Down's syndrome, so the Down's Syndrome Association of Queensland has for many years operated a new parent support model which it kind of - visits parents in the early days in hospital and at home, and as well as kind of providing the facts about Down's syndrome, also tries to kind of promote information about that ordinary life.

MR KALISCH: One aspect I wouldn't mind you touching on in your submission is just the experience of assessment and how within a - certainly within the context of a large national scheme we can have assessment that's responsive, respective and that is also reliable and will have community support, broader community support as well as support within the disability sector. I know it's quite a tricky issue so I'd welcome something in the - - -

MR REIMERS (QPPD): Well, it's probably not - the disability services have got their Growing Stronger strategy and part of this is a new way of assessing. The Toowoomba, Darling Downs sort of region has been trialing that model. I've had a number of phone calls from parents giving that, so we might actually try and do a focus group with some of those parents and inform a bit more in terms of that, because there's - it's a lack of - what they'd say - I'll try to precis it.

It's probably Margaret Ward's terms, really, that they're not on about people with disabilities and families thriving. It's still about, you know, "Tell us all the problems. Tell us this, that, tell us that." A parent I was talking to last night whose been in this commission said, you know - like when the service finally sat down and said to her, "Well, tell us what the things you love about your son are and what you aspire," she said she took this big gulp. She thought, "No service has ever asked me that in 17 years," and then she said she cried, because it's always about deficit and it's always about the minimum you can have in order to survive. Nobody goes, "What would a good life look like for him?" Well, this service did. This service actually said, "What would a good life look like? What do you aspire? What are you dreams? How can we get there? Let's collaborate."

MS BRIDLE (QPPD): It's the ways of asking those questions. Like I think as parents there's lots of things that we do for our sons and daughters that we certainly don't resent but are different from what other - you know, that is an extra kind of responsibility from that of other parents. That needs to be recognised in the assessment process. But at the same time it's recognising that the greatest barriers we face are about kind of access to the goods of society that other people take for granted. It's not about the fact that we may need to feed our son or daughter or toilet them into adulthood. Do you know what I mean? They're the things that are traditionally focused on, whereas I guess we would be saying there's a real opportunity in the new model to recognise more the social nature of disability.

MR WALSH: I didn't get the start of that. I think it was Phil who was talking. This is the new Growing Stronger program?

MR REIMERS (QPPD):   Yes.

MS SCOTT: In Darling Downs, did you say?

MR REIMERS (QPPD):   Yes, in Toowoomba, Darling Downs region it's being trialed. It's the Growing Stronger assessment tool.

MR WALSH: Okay, thank you.

MR REIMERS (QPPD):   But part of that is people are very unhappy about the carer burden component of that. There's a carer burden assessment that's part of the assessment of whether you get a service or not, rather than what would it take for you and your son or daughter to have a good life.

MS SCOTT: Okay, John. Look, we might wrap it up there. Thank you very much.

MS BRIDLE (QPPD):   Thank you.

MS SCOTT: I now adjourn the hearings and we're going to resume the hearings in Sydney next week. Thank you.

AT 4.45 PM THE INQUIRY WAS ADJOURNED UNTIL
MONDAY, 19 JULY 2010