*Who should be in the new scheme and how could they be practically and reliably identified?

- I think that anyone with a condition that fits the definition of disability in the *Disability Discrimination Act,* specifically paragraphs (a) and (h) of the definition in s4, should be covered by the scheme. This definition seems to cover what are considered to be "medical conditions". This has two major implications:
    - Coverage should be solely based on symptoms.
    - Coverage should be independent of an "official" diagnosis, which is unfair on people who have genuine symptoms but no diagnosis.

    An alternative approach is to offer assistance for an initial period, eg 6 months, provided there are appropriate symptoms. At the end of the 6 months, assistance could be terminated unless a diagnosis is provided. However, it would be vital that all parties have a clear understanding that this would happen.

- Functional tests done by Occupational Therapists, Physiotherapists and even case managers would show these symptoms and how they affect the persons activities of daily living showing that they need assistance at home. If there was any doubt of a diagnosis perhaps this kind of test could be done and then the initial period of 6 months used.

*Which groups are most in need of additional support and help?

- I think the age group between 18 and 64 is the group that misses out the most. This age group, no matter what disability category they are in, are expected to be working and able and they therefore miss out. Further, there are numerous children's services and children's charities, and aged care for 65+, but not a lot in between.

*What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

- The important thing is to establish an enforceable, uniform set of national standards, with the same eligibility rules and people with the same level of needs getting the same amount of services/funding. At present, people who complain and have a voice get more than people who can't or don't – and this is unfair. The level of support is also related to where you live, because of differing State disability systems.

- Another idea which may help reduce the unfairness is to use self directed funding giving people with disabilities and their carers the choice of how they spend the money. At least if they were able to choose one service over another, they would have made that decision not someone else. That way they would be able to use the money how they want to, not how someone from outside tells them to!

*How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

- I think having self directed funding again would help this aspect.

- I think any national system should have an ombudsman which could handle complaints and which had the power to enforce the new national standards.

- I think the national system should have a clearly defined grievance procedure:
    - The client seeks a remedy from the agency responsible for provision of their care
    - If the client remains unsatisfied, they can consult with a specific advocacy agency (eg DACSSA) who will try to resolve their complaint, or appeal directly to the Ombudsman.
    - If the client remains unsatisfied after both of these steps, there should be a national or State-based ombudsman as a last resort. I would anticipate that an advocacy agency would be able to assist in any appeal to the Ombudsman.

- Being given the choice of who is your support worker, when they come and what services they are allowed to provide would be good.

***How should the amount of financial support and service entitlements of people be decided (and by whom)?**

- Service entitlements should be based on individual situations of need. Consideration should be given to the severity of the conditions and the resources available to the client.

- However, the presence of a family carer should not wholly disqualify clients for services. Broadly I think it is better for a family carer to work outside the home rather than being a full-time carer, both in terms of work satisfaction and burnout prevention. Family carers should definitely not have to do both at the same time. At the very least the family carer should have a choice whether they want to be a full time carer or not and they should be entitled to adequate respite and support.

- I think a national body should set uniform eligibility standards, and have a role in training GPs and specialists in implementing these standards. Beyond that, eligibility (in terms of these published standards) should be determined by a combination of health professionals physio/OT/psychologist/GP etc who work with the disability agency. The disability agency should have regard to the input of a client's private physio/OT, rather than requiring all claims to be approved by the agency's in-house specialists. Requiring claims to be vetted by in-house specialists imposes an unnecessary strain on specialist resources and leads to delays in the provision of care.

- There are pros and cons for using a person's GP. Basically a GP would technically know the person really well, but if they don't realize how severe the condition is, or have no idea how to apply for the disability support, then the person is going to be left with no help! On the other hand, the problem with using someone independent is that the person might not feel comfortable having to explain their whole medical history to another doctor. A central repository, provided that privacy issues can be addressed, might overcome this problem.

*What kinds of services particularly need to be increased or created?

- Short answer everything. There are services but they are just so under funded! Services like personal care, cleaning, respite for carers, equipment provision, transport subsidy schemes, education/training/employment assistance for people with disabilities they are there but nowhere near enough they all need to be increased.

- I think that in order for people with disabilities to be able to work (if they are physically capable of work) they need to have adequate support at home first and that support services at home should take priority. It is all very well to say that people with disabilities should be at work, but if they need dressing and transport assistance before they can even get to the workplace, work becomes an unattainable ideal.

- There is not enough respite for carers: they are placed in a difficult situation being forced to care for a loved one, but they only get 3 days off a year. An allowance of 4 weeks per year, in line with minimum employment standards, could be justified.

- As for equipment provision, it is no good being given equipment you can't use and being told there is nothing else available. For example, a 25kg or even a 15kg wheelchair is not suitable for someone with chronic fatigue and pain and muscle weakness. If a broader national body were established it could have a larger stock of equipment which makes this situation less likely.

- In terms of equipment once someone has a diagnosis I think that if someone needs a wheelchair for ongoing use they should be entitled to specialized equipment meaning something that has been made specifically for them and their needs. And it makes it very difficult when you are told "Sorry, we don't have anything under this weight. We can't get you any funding." So I think this needs to be improved. As stated in question 1 the discrepancy about medical conditions and disabilities is a big problem in the current SA system. The equipment service should be based on need not on what the Government can afford.

- A standard assessment process needs to be set in place so that unsuitable equipment cannot be supplied. Such a process could also identify any modifications which need to be made to equipment, and take steps to have these modifications performed, or even to make specialized equipment where this is necessary.

***How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?**

- Coordinators need to be trained and aware of what is out there. I have a coordinator, but most of the benefits I have gained I had to research for myself. Especially given that my agency used to be solely for the elderly and I am a young person with disabilities. My coordinator is unable to keep up with the range of services that are available. A single state-based research area (like the Disability Information Resource Centre), if properly resourced, could serve as a "one-stop shop" for coordinators, enabling them to concentrate on liaison with clients.

- Agencies need to be properly staffed. It is inefficient when agencies have to hire temporary staff from other agencies because their own staff are on leave. This may perhaps be achieved by the economies of scale of a national body.

- My agency supplies equipment on a loan or hire basis, so the equipment cannot be modified even when this would cost less over the term of use. I think, where it is reasonably foreseeable that the client's condition is long-term, and especially where such modifications are reversible, such modifications should be permitted. Organisations such as Technical Aid for the Disabled (TAD) do exist for modifying equipment, and the service could be more efficient if they were involved.

- Also with equipment it would be better in the long term if people were prescribed wheelchairs and other equipment that were designed especially for them because then the equipment would meet their needs. This may be more expensive, but in the long term it may make someone more independent, and if it is a better quality wheelchair then it is less likely to require lots and lots of maintenance. This might cost more at the beginning but if you are sitting in the chair all day everyday I think it's worth the money.

- As I remarked above when speaking of how decisions as to eligibility are to be made, I think that the agency should have regard to the input of the client's private practitioner (who knows the client's condition better than anyone) without having that opinion vetted by an in-house specialist. This avoids the absurd situation where a private practitioner makes a recommendation, but it is not carried out because of a delay in making an appointment with the in-house specialist. If the person doesn't use a private physio, an agency one could be provided. Using in-house specialists in this way is a far more efficient use of their time.

- I think that a major priority should be getting as many young people with disabilities out of aged care facilities as possible. They simply should not be there. They should be provided with adequate support services to stay in their own home should they choose to do this. It would actually be cheaper in the long term to provide services out of Aged care facilities than in them. This would improve the way the services are delivered. However there is no point taking them out of a facility and not providing them with adequate in-home support. This seems to be what has happened over the last 20-30 years people with disabilities were put into institutions but when they were deinstitutionalized they were not provided with adequate care at home in the community forcing family carers to take on the role of caring which was previously provided by the Government, a similar thing is occurring currently in the mental health care sector. I think people with disabilities should be in the community but MUST be provided with adequate support.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

- Early intervention is clearly indicated in many cases, eg where children need intervention before school age, but find themselves on waiting lists for years.

- Emphasis should be placed on early intervention, if necessary at the cost of later, palliative intervention. If the early intervention leads to the outcomes that some people foresee, the benefits will manifest in savings later and in job satisfaction for practitioners.

- Perhaps there needs to be more "special education" teachers and classrooms in kindergartens and primary schools to provide for those children who need this care.

***How could a new scheme encourage the full participation by people with disability and their carers in the community and work?**

- A new scheme would involve better training of advocates and disability agencies to ensure that people with disabilities can access benefits directly without having to carry out time-consuming research – in short doing the work of disability agencies.

- Thus by not having to do all the work themselves they would be able to spend their energy on other things.

- Part of this might involve a rationalization of disability services so that it is easier for agencies to access information for their clients.

- A scheme could proactively encourage employers to consider people with disabilities for employment, not merely by avoiding discrimination.

- The abilities of a full-time carer to contribute to the workforce are largely lost to the workforce. Unless they are specifically qualified for caring, this is an inefficient use of resources. I think carers should be allowed to have this choice to work – or to be a full time carer and certainly not have to do both which is like having two full time jobs. If a carer cannot find employment, they should be offered training in the work of a carer.

- A lot of people with disabilities are actually too sick to participate in the workforce. Between countless medical appointments and fluctuating symptoms, they find it difficult to work regular hours. There are not always activities in the community for them to participate in, and many that do exist present barriers such as transport, wheelchair access or participation costs.

***How can a new system ensure that any good aspects of current approaches are preserved?**

- The simplest initial approach is a “no disadvantage” test. Such a test would enable a relatively smooth transition into any new system.

- Subsequently it will be necessary to determine which parts of the various systems have to be discarded; these would probably be those services which are used least or which are otherwise least efficient.

- Someone is going to have to look at all the systems and how they work and then choose what parts of what current state systems are good and join them all together to make a new system!

What should be done in rural and remote areas where it is harder to get services?

- A network of regional offices, possibly with a system akin to the Royal Flying Doctor Service to serve people in remote areas.

- In some cases it might be more efficient to facilitate their move to the city or to a more populous regional area, though we cannot force such a move.

***How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?**

- A new system could establish a national electronic repository for records relating to disability support claims. This would enable the imposition of standards for such records so that they could be used throughout a person’s life, rather than requiring a fresh assessment for each claim.

- Such standards would also facilitate the preparation of reports by specialists by establishing a standard set of questions, though they would have to give sufficient scope for variation.

- Such a repository would also enable better statistical analysis of disability nationwide, which would help in future planning. It is even possible that research into these records might bring to light possible statistical correlations with some disabilities.

- Finally, this repository could be used in cases of progressive disabilities to provide timely notice of the necessity for periodic review.

- One other thing is to make sure that this system is very clear on who is entitled to receive support (see my answer to the first question). This will hopefully avoid the shifting of responsibility between various agencies arising from overlapping specialties.

***How should a new scheme be financed?**

- Initially a specific levy would be required, along the lines of the Medicare levy. Contributions could be made from the health and employment portfolios, and hopefully in the future the system could be financed in part through efficiencies and productivity increases among carers who are able to work more.

- An alternative is an increase to the Medicare levy.

***How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?**

- The central electronic repository would provide a significant resource for planning purposes.

- The system could be aligned with the health portfolio so that the disability workers could be multi-skilled and, where necessary, transfer into hospitals if they are not needed for disability work.

- Employed carers should not be required to be a carer merely because they have a family member who has a disability. Part-time caring, along with part-time or even full-time work, should always be an option. This will help to ensure that the vital part that these carers play will still be played in the future.

What are your views about the ‘nitty gritty’ aspects of a scheme that will make it work practically?

- I think the most important aspect is the economies of scale involved in a nationally co-ordinated system.

- One concern is that a single national body lacks competition which may tend to lower service standards.

- Another important aspect is the establishment of a central data repository allowing use of data for several claims rather than requiring a fresh report for each claim.

- The third most important aspect is mandatory and improved training for care workers so that they can best serve their clients, and for advocacy agencies so that they can most efficiently access care for their clients.

***How long would be needed to start a new scheme, and what should happen in the interim?**

- I think it is important to put together a plan for what is intended in the future, even if it cannot currently be funded. Such a plan, including working out the level of need, should be possible to finalise as a plan within six months, and to start implementation within twelve months at the outside.

- Obtaining the funding for such a plan should be part of the plan so that when the plan is completed it can be funded more or less immediately.

- In the interim, currently active care arrangements should be maintained.

- Claims that have been made but not yet fulfilled (ie unmet need) should be fast-tracked with a view to resolution by the end of the twelve-month period. Another possibility is that the unmet need is actually dealt with now while this inquiry is going on and this would reduce the unmet need by the time this National Scheme is put into place.

- I emphasise that I envisage a national system; after the plan is made, during the second six months the current situation should be compared to the plan, with a view to working out what has to be changed, what increased services are required, and what services, if any, are surplus to the plan.