Submission about the
National Disability Strategy

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Introduction

The Disability Advocacy and Complaints Service of South Australia Inc. is a Commonwealth funded disability advocacy agency, which is managed by a Board of Management of people with disabilities. Our agency is part of the National Disability Advocacy Program funded by the Department of Families, Housing and Community Services and Indigenous Affairs (FaHCSIA).

Disability Advocacy and Complaints Service of South Australia Inc. is funded to deliver individual and systemic advocacy to people with disabilities and their families. Our clients come from all socio-economic backgrounds. Anyone with a disability, including anyone with a mental health problem, can access our service if they have a complaint or grievance related to their disability.

Wherever possible we act on the expressed wishes of the person with a disability.

At the beginning of October we attended the National Disability Advocacy Conference and were asked by Leslie Hall from the Australian Federation of Disability Organisation (AFDO) whether we would be prepared to assist AFDO to consult in the regional areas of South Australia.

Therefore our submission is not only based on the work we are doing as an advocacy organisation but it is also informed by the consultations we held.

The consultations took place in Whyalla, Port Augusta, Berri (Riverland) and Mount Gambier. In addition we also organised consultation at the Tauondi College, a TAFE College for indigenous people in Adelaide.

All of our consultations were reasonably well attended (on average 10 – 15 people).

In June and July we undertook community consultations about individualised funding which has also informed our submission to the National Disability Strategy.

About the Consultation Process

Many people commented, and our agency agrees, that the National Disability strategy is such an important issue and development that the short time frame to respond does not do it justice.

We assume that writing the discussion paper took about four months. Why is it assumed that community members are able to think quicker, identify strategies quicker, and are able to respond comprehensively in only six weeks? Many people did not receive any notifications about the strategy until we invited them to our consultations. Some of our consultations were held on the 28th of November, two days before the deadline for submissions.

We believe that the first round of consultations can only have scratched the surface, and from what we experienced at the Adelaide consultations, it seems that only very few people could get their issues of their chests.

We therefore recommend that the initial comments ought to be collected, put into some order. A more thorough discussion paper ought to be circulated to provide the opportunity for all people with disabilities to think more deeply, and at more breadth, about a National Disability Strategy and what this strategy should include.

Maybe a third round of consultations is needed where the strategy is developed from the feedback of the first and second round and people than have the opportunity to comment on the nearly finished product.

It is simply not good enough to waste the opportunity for a comprehensive strategy that would affect so many people in Australia to be developed from a two hour community consultation.

The Discussion Paper

The discussion paper provided some information about the state of affairs of the disability sector. The idea to make this Strategy a whole-of-government, a-whole-of-life approach to disability issues is important.

Yet in other parts of the discussion paper and in relation to upcoming reforms in disability service delivery this approach appears to be abandoned.

On page 10/11, the list of current national initiatives shows that there is no whole-of-government approach. The Council of Australian Governments' reform agenda indicates that disability services may become the responsibility of the States and Territories, while aged care remains the responsibility of the

Federal Government. Helping Children with Autism is a small package that leaves children with autism over six years old to the mercy of the education departments in the States, where access to specialist support is only available if the child has been diagnosed, and a diagnosis can take up to 18 months.

This is certainly not a whole-of-government, whole-of-life approach. The initiatives outlined on these pages illustrate how separate these initiatives are administered, and how each department works separate from the other departments.

Further the discussion paper states on page 11: “To be successful, the Strategy will need to prioritise the national actions that best tackle …”

Once again community consultations are used to identify the most important crumb that has fallen from the table, rather than integrating all of these important initiatives with what else is truly important to people with disabilities.

Why should community members be put in a situation where they have to decide what is more important, the outcomes of the Inquiry into Better Support for Carers, or the Inquiry into Australia’s Future Tax System?

Such an approach divides people with disabilities again from the needs of family members and carers. Likewise to have a package for children with autism, but no mention of services for the deaf-blind for example, divides the disability sector.

If Ministers and the Government are truly interested in how to improve support and remove barriers for people with disabilities why do we get a new consultation every year, where we continue to state the obvious, without any tangible outcome, year in year out?

People have clearly indicated that they are consulted out. People still want to make a contribution and they want to be part in the process of developing a strategy that will truly address the most important issue people with disabilities face. But they have been telling the government in several inquiries over the last five years (and probably many years before as well) what is needed. The government has not taken any notice and comes up with a new consultation plan every year.

People do no longer want talk fests. One way of recognising a talkfest is the time provided and thoroughness required of community consultations. We are afraid that this discussion paper, its minimal questions and short consultation time is an indication that once again people will not see any results from the consultations.

Proposed High Level Structure

Most people and our members agree with the proposed high level vision set out on page 9 of the discussion paper.

People and our members also agree with the proposed high level structure, although it is difficult to explain what is meant with these words. High level structure of decision making, or administration, or will there be a high level structure of service delivery, or some kind of body which will take on the monitoring of outcomes?

People in the consultations and our members agree with the vision, although by now it should be clear that discrimination is unlawful and that timely and dignified support for people with disabilities and their families is part of their human rights. We wish we could get on with the business of supporting and integrating people with disabilities in our society rather than starting every time from scratch again.

People in the consultations and our members agree with the principles, as we agreed with these principles as part of the UN Convention. These principles are over 20 years old and it is a pity that we have not had the opportunity to put these principles into government action so far.

In terms of the outcomes it must be stated that if the first two outcomes are achieved for people with disabilities: economic participation, social inclusion, choice, wellbeing, and the opportunity to live as independent as possible, that families and carers will be automatically well supported.

Many people with disabilities are angry that it seems as if the ‘carer agenda’ is more important than the agenda of people with disabilities. For example, the South Australian Government has a Carers Rights Charter, but there is no charter or Bill of Rights for people with disabilities. While we understand that this kind of discussion is not helpful and divisive, governments need to understand that most people with disabilities are able to make decisions for themselves and able to participate in planning and delivery of services for them. It is only a minority of people with disabilities (under 2%) who are in need of decision making by family members.

People with disabilities need to be recognised for their contributions and their rights, they are also able to speak up for those who cannot speak up for themselves. They understand what it means to live with a disability, most carers or family members only know what it means to care for someone.

Question 1: What do you think should be included in the National Disability Strategy?

The simplest answer to this question is: Anything that affects people living with disabilities, including those living with a mental illness.

Some principles arising from the consultations are:

The Strategy must:

- Address all areas of life, transport, education, employment, service provision, respite services, access to justice, housing, income support, social inclusion, citizenship.
- Include all kinds of disabilities, including mental illness sufferers and sufferers of multiple chemical sensitivities;
- not be written to incorporate vastly disjointed strategies which may have vaguely to do with disability, but the NDS should be an instrument within which strategies in the different sector should be developed;
- address recruitment and retainment strategies for specialist professionals and for support staff;
- include community awareness raising initiatives, for the wider community but also for employers and educators, and for other professionals, such as health care staff;
- include a strategy to develop a Bill of Rights for people with disabilities and/or other legislation which enshrines an entitlement to services for people with disabilities;
- Provide a mechanism to monitor and report on breaches to the International Convention on the Rights of People with Disabilities.

Question 1a: What are the greatest barriers that people with disabilities face to participating fully within the community and what specific local or national actions could be taken to overcome these barriers?

Transport

Most of the regional centres we visited had no public transport. There may be a bus that comes through once a day from Adelaide, but there are no buses going around the towns and villages.

Many smaller towns, such as Berri, do not even have taxis. If they have a limited taxi service, often they only have one accessible taxi. Yet there are many people who must rely on public transport because they cannot drive a car.

At one consultation a vision impaired person attended. He had walked three kilometres in 35^{o} heat in order to attend the consultation.

Obviously without transport people cannot get to work nor access education. People with intellectual disabilities cannot access day care services or business services. Elderly people who no longer drive cannot access their medical appointments, or anything to do with recreational activities.

The lack of transport does not only affect people with disabilities but also the elderly and those families who cannot afford to have two cars.

Solutions:

Encourage volunteers to drive local council owned small buses or people movers which are made accessible. Or provide funding to the local council so they can set up a service on demand for people who need access to public transport.

It may also be possible to better share the resources available in a community. There could be an accessible car pool where parents or support workers could rent a car for a small fee to transport people to their appointments.

Many organisations have cars which take people with disabilities to work or school and bring them home, maybe these cars could be made more available for other users as well for a small fee.

Education

Many people were very concerned about the lack of access to specialist services for young children who have a disability which has not yet been diagnosed. Several children had to wait for more than 18 months to get a diagnosis.

In all the regional centres we visited there were no specialist children services available. Novita workers would come once per term, stay maybe for a few days and work with up to six children.

While children and their parents are waiting for a diagnosis and for appropriate assistance the children are missing out on their education and specialist services such as speech therapy and physio therapy. School are unable to provide a School Support Officer and teachers are struggling with the special needs children with undiagnosed disabilities have.

It is inhumane and absolutely against the spirit of the UN Convention on the rights of people with disabilities to exclude these children from accessing education due to the delay in their diagnosis. This is almost state enforced child neglect.

Solution: The NDS should include a strategy to recruit and maintain specialist for country areas. More specialists must be employed by Disability SA to reduce the waiting lists for diagnosis.

Another solution would be a simpler system of assessment such as is currently used in the UK by the In-Control group. Their assessments can be conducted over the internet with a small questionnaire which establishes the ability to function with daily tasks and assesses the needs of people based on their ability to function. Then specialists can be used to provide early intervention and therapy services rather than being restricted to assessments.

Children and students who are deaf are also at a great disadvantage as there are only a limited number of AUSLAN interpreters available and they are flown into the regional centres from Adelaide.

Access to vocational education and apprenticeships also seems to be problematic in many country towns. Several participants reported that they had not been able to access TAFE because they were told that TAFE could not accommodate students with disabilities.

This problem seems to be more prevalent in country areas because in Adelaide TAFE is providing accommodations, including for students who have learning disabilities and are unable to read and write. Parents in the country have been told that their children had to undertake an introductory test which would assess their children's literacy skills. This was in one case to get someone into a forklift training course, in another case it was to enable their daughter to access a horticulture course.

Yet recently Bedford Industries and other Business Services enabled their employees to access TAFE Certificates and 220 people graduated, many of them were certainly illiterate.

Many people did not know that universities will accommodate students with a disability, hence many parents did never encourage their children to go to university in regional areas. There is the tyranny of distance, the assistance they thought their children need from them, because in the regional centres they were not getting enough assistance to live independently, there was the problem with transport, and generally they thought there was no point occurring the high fees only to find that their child would not get a job afterwards.

People with disabilities in the country are therefore double disadvantaged when it comes to accessing higher education.

Solutions: Provide clear guidelines about what TAFE Colleges and other Registered Training Organisations (RTOs) must provide to accommodate students with disabilities to the RTOs and to school leavers with a disability.

RTOs have an obligation under their accreditation requirements to provide access to all students.

More AUSLAN interpreters are needed everywhere. It seems that DEAF SA has a monopoly on interpreters. To achieve this every TAFE College should provide AUSLAN training or AUSLAN interpretation must become part of the Community Services Certificate in Disability Work

Students with disabilities from rural and regional areas should be given scholarships to enable them to study at TAFE and university. Each student with a disability should be able to identify their needs and these extra services must be made available either through Disability SA or the university or RTO where they are undertaking the study.

Employment

There were some examples of people with disabilities getting jobs in regional and rural areas. Unfortunately most of the jobs offered by the Disability Employment Network were menial jobs with little income prospects.

Not all people with disabilities have an intellectual disability, but it seems that most disability employment network providers only look for jobs for people with intellectual disabilities.

This situation gives employers in rural and regional areas the impression that people with disabilities can only push supermarket trolleys, stack the shelves, or mow lawns.

People with disabilities commented that discrimination in employment is rife. Some have applied for office jobs which never required them to drive a car, yet they did not get the job because they did not have a drivers licence. Others did not get a job because their employer felt it was not suitable to have a lady in a wheelchair looking after children, despite her being on duty always with at least two other child care workers.

Many people complained that it was so difficult to find evidence for this kind of discrimination, and many people were unaware of their rights and the processes to assert their rights. They gave up looking for work.

One gentleman shared that he had worked in many volunteer jobs successfully. He had repeatedly shared his ideas for programs with organisations who implemented his ideas, but without asking him or offering him a job.

Solutions: Many people believed that there needs to be better advertised incentives for employers to employ people with disabilities.

Many people thought that a quota scheme should be introduced so that larger employers are forced to employ 5% of their workforce from a pool of people with disabilities. If they do not fulfil their quota they should be fined.

Other people thought that rather than a punishing approach we should have one that rewards employers of people with disabilities by relieving them from paying payroll tax and reducing their income tax, or by paying part of the wage for the person with a disability.

Most people believe that more can be done than just providing awards for employers.

One lady who is hearing impaired has been asked many times to interpret for other hearing impaired people who needed to communicate with sign language. She is regularly asked to interpret for people when they visit the doctor or at the hospital and on other occasions. The regional centre where she lives has no accredited AUSLAN interpreters and the interpreters are flown in from Adelaide. She has asked several times if she could become accredited, so that she can earn a living and be paid for her work, to no avail.

Deaf SA has stated that only hearing people can become interpreters. They currently have three accredited interpreters which serve the whole state. Many hearing impaired people have questioned the quality of those three interpreters and would like to become interpreters themselves, but they are prevented from doing so by their own organisation, which believes that only hearing people should be AUSLAN interpreters.

People who are deaf are very disadvantaged and isolated in rural and regional communities. Some suggested that all public servants and teachers ought to learn sign language so that they can participate and access the same services that other people can.

Solution: Allow people who have a passion and the skills to interpret to do so. This lady was able to communicate by speaking and lip reading and she was able to communicate by signing. Government would only gain if they would pay for her training,, because there would be a lot of savings for the flying back and forth of interpreters.

Access to disability services

Here are some of the comments people made in the consultations:

“The recent disability services reform in South Australia has been disastrous. Previously specially trained disability coordinators had at least some ideas of what a person with an intellectual disability needed. Now they do not seem to care. They just have meetings after meetings, and nothing gets done.”

“There is never any money available. Whatever I am asking for, I cannot get it and I always get the same answer: we do not have any money at the moment. When will that ever change, I am not asking for much, just a bit of respite sometimes!”

“They say that they were doing the one-stop-shop. I cannot see any one-stop-shop, nor any client-centred services! That was another occasion where they so-called consulted with us. The bloke from Disabilty SA appeared, rolled out his slideshow, told us what was happening and then there was no time to even ask questions. Since then we had no new services, not a hint of improvement or even client centred service provision, we have not heard anything from our Disability Coordinator."

" We do not have a disability coordinator anymore. They have all become duty officers now, and they change all the time. There is no consistency in the service provision. I think they are changing all the time because people who work there cannot face the disappointing news they have to give to their clients."

"I have given up on them (Disability SA) because we never got anything from them, even when I had to go to hospital, there were no extra services to help my husband with my daughter. When I came out he was ready to go in, he really was at the end of his tether. Why do they abuse us to such a degree? They know we will keep on going until we drop!"

These were only a few of the desperate comments people made about disability services in the region. Another common recurrent theme was that people are unable to complain about any service provider or Disability SA because they knew that their comments would be passed on to others and they feared that they would be black listed in their small town.

Therefore most people decided to withdraw and cope by themselves. Most parents had given up on finding their child appropriate accommodation, they knew their child would live with them until they died. Several people with disabilities felt embarrassed about the lack of opportunity.

People complained about the lack of choice. Many rural and regional centres only had one or two accommodation services, on day care options place and one business service.

In one small town everyone knew that certain people with disabilities were abused by support workers in their accommodation. Some people had spoken about it, and had tried to complain to authorities and advocacy agencies. But Disability SA could not find any other support workers in that town and hence they and to continue with the existing workforce. People had given up hoping for change. The advocates were told that the choice was to close the home or leave it as it is. People with disabilities involved chose to leave it as it is, because otherwise they would have been homeless.

Well trained staff is hard to get and training opportunities are often not accessible, and where they are, employees do not feel that they have to attend because there are no other support workers any way, hence they are not at risk of losing their job. Other support workers, who are doing a great job, are at risk of getting burned out because they are in demand by everyone.

People with sensory impairments felt that they were very much neglected in country areas. There are no services available for them, they have to wait until Guidedogs SA or Deaf SA is travelling to their area, which may happen once per year. The Royal Society for the Blind is providing an employment service, but again only puts people into menial jobs and there is never enough time to thoroughly consult with the sensory impaired person.

Solutions: Everyone at the consultations was in favour of introducing **individualised funding or self managed care**. People believe that they can stretch the dollars further than a top heavy department can. People are also tired of being told what they can and cannot do and access.

People thought if they were in control of their own funding they would be able to choose their support workers, and they would be able to find or even establish services that would meet their needs better. Many people with disabilities indicated that they were tired of the day options programs they have been offered. Parents and family carers also believe that they could arrange more quality experiences than sitting in a shopping centre and staring at by-passers.

Some people with disabilities want to explore setting up their own small business, and they believed if they had their own funding they would use their care hours to get assistance with this venture.

Most importantly people believed that in order to access the services they truly need Australia needs to **enshrine an entitlement for services** into some kind of legislation, whether it may be a Bill of Rights or a Disability Services Entitlement Act.

People are truly tired of being dependent on the mood in government whether their needs are taken seriously or not.

Access to Equipment

A father of a child with physical and intellectual disabilities described what his family has to do when their son needs a new wheelchair, which ought to happen every three years at least:

The whole family has to move to Adelaide for at least a week. His son needs two carers for lifting and getting dressed and they cannot get support workers while they are in Adelaide, hence his wife and their other two children have to come too.

It takes about a day to measure the wheelchair. They then have to get the bits and pieces for the chair and his son has to frequently appear at the equipment centre. During the time his son does not have a wheelchair, and the equipment service is unable to provide a temporary wheelchair. It usually takes a week to get the chair right.

There are significant costs associated with getting a new chair for this family and it is clearly a discriminatory process. People in the city can remain in their homes, but this family has to be uprooted. It also takes about two years on the waiting list before they are getting a chair. Hence almost as soon as they have been given a new chair they put their son on the waiting list to ensure that when he has outgrown the chair he can access a new one.

Solutions: This family and the needs of their disabled son are known to Disability SA. When the son gets a new wheelchair there is really no need to take the wheelchair of the son while the new one is measured up and put together.

If it is necessary to keep the old wheelchair in the workshop then at least another wheelchair should be made available.

It should also be possible to visit the family rather than the family having to come to Adelaide. Why can the team not come to (in this case) Mount Gambier and even bring some of the more common bits and pieces with them so that the chair can be fitted in Mount Gambier?

Some people complained about the unfairness that those who receive equipment through Disability SA do not need to pay for their equipment whereas those who by coincidence first got their equipment from Domiciliary Care still have to pay for their equipment.

Some people also complained that their ability to choose their equipment repairers has been hampered with. Before they had a choice about who they wanted to repair their equipment and many people had an established relationship with their repairers. They knew they could rely on their repairers to come out as soon as possible and to assist the person.

Nowadays the repairers from Disability SA seem to be overwhelmed as it takes double as long to get someone to come out and repair a wheelchair.

Solutions: In the era of competition policy South Australia's government has reverted back to a monopoly, only they are providing equipment free of charge and only are repairing equipment.

If they would provide a best practice service no one would have a need to complain about this, but they do not and our agency is receiving weekly calls about the equipment scheme.

Although it may be cheaper to distribute equipment from one outlet and purchase it cheaper because of the amount of equipment they turn over, there is also the fact that people have no choice in service provider. Disability SA could identify some suppliers they may want to accredit them and set a limit of what they are funding. People then can purchase their own equipment from whoever they want. If they want to buy it from someone who sells it at a higher price people should have to pay the difference. The same system can be implemented for repair services.

Most people in the rural and regional areas are absolutely dismayed that it takes such a long time to get equipment at all. Several people we spoke to had turned to alternative providers such as the Rotary or Lyons Clubs who fundraise for equipment for people with disabilities. Some even had purchased their own equipment.

One young girl had a very severe and risky surgery to have a titanium rod entered into her spine. She had to wait almost three years to receive a new cushion for her wheelchair. Her old cushion made her sit crooked in the wheelchair, she urgently need the cushion after her surgery so that the rod could straighten her spine. The surgery was almost rendered useless because she could not get new cushions for such a long time.

Solutions: All equipment should be made available as soon as it is needed. Able bodied people are not put on a waiting list when they want to go out. Why should people with disabilities have to wait for their legs?

Again, often the needs of people with disabilities are known to Disability SA. A bit of early and preparatory planning could prevent the incidence of long waiting lists. If people could choose their suppliers their may not be a need for waiting lists.

The Importance of Advocacy Services

While many people complained that not enough progress has been achieved for people with disabilities in Australia, all agreed unanimously that advocacy services are fulfilling an important role and that their role needed to be strengthened.

People felt that the existing advocacy services needed more funding to reach out to people in the rural and regional areas. Especially Indigenous people felt that they had a hard time accessing independent advocacy services.

People thought that advocacy services should remain independent albeit decently funded by the government. Advocacy services should not be threatened with defunding by the government because of the work they do. In South Australia all advocacy and information services have been defunded by the State Government supposedly to put the money into services for people with disabilities.

Many people indicated that they rather give up an hour of their weekly services in order to strengthen advocacy. However many felt that it was more appropriate if the Commonwealth Government was funding advocacy services because the States were delivering the majority of services for people with impairments. People believed that advocacy services should not be funded by the same department that also delivered disability services.

Solutions: Develop a new funding model for disability advocacy services. Advocacy services need to maintain their independence so they should not be funded by the same department they often have to criticise. It may be better to fund advocacy services through a consumer rights department or through the Attorney General’s Department

Generally people thought that recent suggestions to fund advocacy through private sector sponsorship would not work because the sponsors may become the target of advocacy interventions.

Many people suggested that advocacy services should receive more funding to advertise their services on the TV or on the radio because not all people know that there are people out there who can assist them to uphold their rights.

People also suggested that if advocacy services were to move to alternative funding that those who are receiving complaints should have to pay for the advocacy service.

Furthermore, our agency supports the statements of the Disability Advocacy Network Australia.

The capacity of the independent advocacy sector must be significantly enhanced, in part, to counteract the dominance of carer and service provider influences on the national disability agenda. Persons with disability must take precedence over other influences on this agenda.

A strategy to improve advocacy for persons with disability in Australia ought to be a foundation initiative of the first NDS. This ought to be the subject of a specific budget bid for 2009. This strategy would include at a minimum:

> A very significant expansion of social advocacy responses under the NDAP to ensure adequate 100% program coverage across Australia (this will require a multi-component system with some innovative models to reach particular population groups and locations). - As a sub-component of this strategy, funds should also be made available to expand the role of the DDLS network to ensure that it operates on a cross- disability, cross-jurisdiction basis.

The Commonwealth ought to accept principal responsibility for the development of independent advocacy for persons with disability. In exercising this lead responsibility, it is vital that the Commonwealth recognise the importance of local knowledge and conditions to its planning processes and the need for program diversity and the tailoring of the program to effectively respond to regional and local conditions. States and Territories ought to still be required to provide substantial financial contributions to the national advocacy program and assist the Commonwealth in identifying and developing appropriate responses to regional variations in need but program leadership would rest with the Commonwealth.

The NDAP ought to be provided with a new legislative base that provides for a comprehensive system of independent advocacy. This legislative base would also set out quality assurance and complaint mechanisms that are tailored to the sector. It ought also to provide for the NDAP’s independence from FaHCSIA.

The NDAP ought to be administered by an agency with an activist human rights based culture.

A national representative body for disability advocacy organisations ought to be established and appropriately resourced. This body would be responsible for sector coordination, sector development, sector representation and liaison with government and the professional development of advocacy agency personnel. The establishment of this representative body ought to be the subject of a specific budget bid for 2009.

An appropriate independent agency ought to have the responsibility for the development and implementation of a non-government financing strategy for the advocacy sector. This strategy would need to be developed with initial government support and in close consultation with the disability advocacy sector.

In relation to the **Australian Human Rights Commission** people believed that they had their teeth pulled. People were very unhappy that the AHRC only had the power to conciliate but not to pass judgement on whether an organisation, business or service had discriminated against a person on the basis of their disability.

Most people do not have the money to take an issue to court where the opponent had refused to conciliate. There should be at least a fine or some other sort of punishment if there is a legitimate complaint of discrimination and the other side refuses to conciliate.

While all States and Territories are funding a Disability Legal Service which ought to assist people with their court cases about discrimination the jurisdiction still remains a cost jurisdiction. If a person loses their case, they will have to pay for their own and their opponents court costs. People with disabilities do not have the money and hence they are shying away from fighting for their rights.

In South Australia the Disability Legal Service is managed by a welfare organisation, which has itself received complaints of discrimination. Naturally these complaints could not be supported by the legal service. There were other instances when requests for assistance were declined due to conflict of interest. As this legal service is the only one which provides a lawyer for discrimination cases free of charge several of our clients have missed out on achieving the justice they were entitled to. In one year we had six cases rejected which were identified by the AHRC as having merit to be pursued further.

As a matter of fact Disability Advocacy and Complaints Service of South Australia Inc. has a greatly reduced incidence of people claiming discrimination. Many of our clients have found the process took too long, was frustrating, and in the end useless because the other side did refuse to change their policies, procedures, or venues. And in cases where people were willing to conciliate they were often not following up on the outcomes. For example, disability awareness training was not delivered, despite agreeing on it, or certain policies and procedures were not changed. There is no way of enforcing anything that was agreed upon through the conciliation process.

The South Australian Equal Opportunity Commission provides at least a lawyer to assist someone to get their rights before the court. But the Equal Opportunity Act does not include discrimination on the basis of mental illness. That will change in the near future, hopefully, as the Equal Opportunity Act is in the process of being amended.

Solutions: The AHRC must be given more teeth. It should be up to the Commission to determine whether a case can achieve a good outcome and then the AHRC should fund the legal procedures on behalf of the person with a disability.

There should be independent disability legal services and there must be an alternative for those cases where a legal service cannot assist a person due to conflict of interests.

Each State and Territory ought to have a Public Interest Clearing House which undertakes research into legal issues for people with disabilities and which can possibly act on behalf of people with disabilities who have been rejected by the Disability Discrimination Legal Service.

The Role of an NDS in relation to the United Nations Convention on the Rights of People with Disabilities

All people in the consultations agreed unanimously with the following statements from the Disability Advocacy Network Australia submission:

Australia must accede to the CRPD Optional Protocol.
The CRPD must be declared an international instrument pursuant to s 47 of the HREOCA.

The AHRC's jurisdiction and functions ought to be expanded by legislative amendment, to provide it with the power and capacity to effectively deal with complaints and undertake policy and education work in relation to all CRPD rights.

The AHRC ought to be provided with jurisdiction to initiate complaints.

The disability and human rights (including discrimination) jurisdiction ought to be costs-free.

A national disability complaints authority ought to be established under legislation to deal with complaints relating to disability services provided or funded by the Commonwealth. This would include Commonwealth funded or provided disability services, mental health services, carer support services and disability aids and appliances. The authority ought to have royal commission-like compulsory powers, but it is essential that it is a specialist agency.

This new complaint handling authority ought to have a clear structural relationship with disability advocacy organisations which recognises their independence and their duty to represent the needs and interests of persons with disability over other interests.

Any proposal for an Australian Bill of Rights ought to include measures for incorporating the CRPD into the Bill. Such measures should be part of the forthcoming public consultation process.

Question 1b: What areas of research do you think should be a priority to better inform the National Disability Strategy?

In our consultations people mentioned the following areas of research which they thought ought to have priority and underpin the development of a National Strategy:

a. **Unmet and future needs – future needs for services and accommodation (for example, what kind of specialist services are needed in the school system to assist students with their development)**

b. **Cost of disability**

c. **Action research with people with disabilities about what works in regards to participation and inclusion**

d. **Quality of life and life expectancy of people with disabilities**

e. **Community attitudes and how to change them**

f. **How the health system can be improved so that people with disabilities get a decent service**

Question 2: Personal Experiences

We have encouraged all participants to write their personal stories up and submit them themselves as there was really not enough time in the consultations to discuss too many personal stories. If case studies are needed we can certainly supply lots of case studies.

If the consultation team provides us with some extra time we can make a significant contribution in relation to case studies and personal experiences.

Question 2b: What local action has made a positive difference to your life or other people with disability, their families and carers

What has made a difference in some locations is:

A diversional Court program, because it has assisted people with intellectual disabilities, brain injuries and mental health problems to stay out of prison;

A local disability advocacy program, open five days per week, accessible to all people with disabilities in Whyalla;

Local networks and services working together with parents, carers and people with disabilities;

Miriam High Special School and early intervention programs for parents of children with disabilities;

GP training program to work with people with mental health problems, it has reduced prejudice and increased good relationships between the medical profession and people with mental health problems;

Carers Association set up a network of part and current carers which assisted carers because they could call on the experience of past carers, also the carers got five sessions of therapeutic support and there should be more one on one support;

Disability Employee and Employer of the Year Award, which was run in the by Disability Action, did make a difference, because everyone in the town heard about those who won awards and employers were more willing to employ people with disabilities;

Port Pirie did develop a disability strategy which was supported and initiated by the Port Pirie Council. At some point people invited all councillors to push a wheelchair around in Port Pirie and the Mayor nearly had a heart attack. He made sure that footpaths were built in the town;

Local Disability Expos and conferences for people with disabilities, which raised the awareness of issues for people with disabilities;

Indigenous people praised Tauondi College which provides disability days and expos, information for indigenous people about disability services and trains Indigenous people as disability support workers;

The Riverland Respite and Recreation Service for people with intellectual disabilities has made a huge difference to the lives of people with disabilities in the Riverland, they are very active and undertake a lot of different activities;

The Riverland Group Housing Association, which was formed by a group of parents, who needed accommodation for their children with disabilities. They purchased or organised the housing and provided the care for their children themselves by taking turns. After a while they received funding for a care package;

The National Disability Coordination Officer Program has assisted people to get into employment;

Early Links/Inclusive Directions have assisted people with access to early intervention programs in Mount Gambier;

Rotary and Lyons Clubs have assisted people with equipment;

The Variety Club has provided equipment and assistance to the Mount Gambier Special School.

Question 3: Do you have any other ideas or suggestions

We believe that it would be very important to continue to involve people with disabilities, their families and disability services in the development of the strategy.

People have become very cynical as a result of numerous consultations which have all not led anywhere.

People are putting a lot of time and effort into these consultations and for many people it is very stressful to open up their heart and show their pain of feeling neglected and overlooked.

Many people with disabilities in our community are only able to shower twice a week, many cannot access a hot drink during the day, many have to eat their breakfast on the toilet during bowl care because their care hours are limited.

People feel tremendously ashamed about their lives.

Hence people and their families deserve to be kept up to date with the developments and they should continue to be consulted about the development of the National Disability Strategy.

Most importantly of all, this strategy has to make a difference. We all have and enough of empty promises. Not much has changed in the last 20 years despite of all the efforts to make life easier and more fulfilling for people with disabilities.

It takes eternal vigilance to make life better and things urgently need to change. Our agency is aware of at least four people who have died in the last year, many because they did not feel they could go on feeling so neglected.

While this may sound dramatic, the fact is that lives lived without dignity affect people’s mental health very badly. The incidence of depression is high among people with disabilities. Unless the National Disability Strategy will make a difference many more people will succumb to their depression and hopelessness.