RESPONSE TO THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT DRAFT REPORT AND RECOMMENDATIONS

By the

COUNCIL OF REGIONAL DISABILITY SERVICES (CORDS) Western Australia

CORDS Members:-

Accessability (Upper Great Southern) Narrogin **Advocacy Southwest** Bunbury **Enable Southwest** Bunbury Goldfields Family Support Association Kalgoorlie Kimberley Individual & Family Support Association Broome Lower Great Southern Community Living Association Albany Lower Great Southern Family Support Association Albany Strive (Warren Blackwood) Bridgetown Wheatbelt Individual & Family Support Association York

PURPOSE OF CORDS RESPONSE

CORDS strongly support the need for changes in Disability Care and Support. We acknowledge that Western Australia has a solid basis of support to people with disability, with a functional and responsive Disability Services Commission (DSC), Statewide Service Coordination and Local Area Coordination (LAC) systems. CORDS considers that parts of the existing system should be retained when reforms are considered, in particular some block funded programs that facilitates and promotes innovative practice throughout regional, rural and remote areas of the nation.

Currently around Australia there are pockets of individualised and flexible responses that work very well for people, particularly in regional, rural and remote areas. These support arrangements must be quarantined. The risk of moving to a national system is that we end up with a system that is based upon the requirements of the State that is least ready to move to individualised supports.

In WA we have a system that results in people waiting between one and nine years for funding via the combined applications process. 35% of people wait more than three years and between 86 and 91% of applicants are rejected each funding round¹. Funding is still delivered via programs that compartmentalise peoples' lives and support needs. The injection of additional resources would result in reduced waiting times for services and more timely responses.

The Productivity Commission draft report proposes an entitlement scheme. Any scheme that removes the requirement for people to paint the worst possible picture and expose their lives bare to others to receive any support is a step in the right direction. Further, people should not have to compete with others in similar situations, pitted against each other in the process of securing the support they need to maintain a quality of life in their own homes and communities.

Disability support should be an entitlement. The current scheme is unfair, underfunded and inequitable, particularly for people with disabilities, their carers and families living in regional, rural and remote areas. CORDS intends responding to those areas and recommendations affecting regional issues.

ABOUT CORDS

The Council of Regional Disability Services was established in 2004 to provide a forum for people in leadership roles in regionally governed disability services to share information and discuss common problems. This allowed the Executives of these organisations support from their peers and greatly reduced the isolation experienced due to distance. In 2010, CORDS membership voted to appoint a Chairperson and Vice Chairperson to ensure the group has a central contact person to speak on behalf of the group and coordinate meetings.

¹ National Disability Services, Western Australia – Pre-budget Submission 2011-2012 pp. 12 - 15

CORDS TERMS OF REFERENCE

- 1. To provide a strong coalition voice for regional organisations working in the disability field.
- 2. To provide collegial support to CORDS members.
- 3. To identify issues and concerns specific to regional service providers.
- 4. Provide feedback to funders, government and peak disability groups on issues and concerns as identified by CORDS.
- 5. To provide an opportunity to act as a regional network of service providers.
- 6. To advocate for equity of service provision for all people with a disability regardless of geographical location.
- 7. To have a united voice in presenting ideas, solutions and issues to the broader sector.
- 8. To advocate for equity of support, including training, to regional service providers.
- 9. To promote partnerships and collaboration between regional service providers.

ABOUT REGIONALLY GOVERNED DISABILITY SERVICES

The term, "Regionally Governed Disability Services", refers to organisations that are:

- governed by a Board drawn mostly from the local regional community where the organisation is based; and
- Disability Service Commission funded and Not-For-Profit.

Regionally governed disability organisations are an important component of the disability sector in regional Western Australia. They allow people with disabilities and their families to receive the support they need in their regional community, thus allowing those families to continue living in their local community without the need to move to a major city to receive the support they require.

Regionally governed services offer the following benefits:

- they tend to know their community well and therefore can develop local responsive services;
- they are able to gain and mobilise local community support;
- they allow for local people to have a strong voice in the local services;
- they keep decision making at a local level;
- they promote local employments and economic stimulus; and
- they develop local capacity and expertise.

CORDS RESPONSE

Where possible, regionally governed disability services should remain the foundation of the regional disability service sector. They provide a valuable resource to people with a disability and local communities and are the foundation of good regional solutions. Many innovative programs have arisen from regionally governed disability organisations finding local solutions to issues and working in collaboration with local communities.

CORDS urge the Productivity Commission to ensure there is no loss of the innovation and strong practices in place throughout regional, rural and remote WA.

Response to Draft Recommendations

CORDS supports recommendations 3.1, 3.2, 3.3, 3.4, 3.6, 4.2, 4.3, 4.4, 4.5, 4.6, 5.1, 5.9, 6.1, 6.3, 6.5, 6.9, 6.10, 7.1, 7.2, 7.3, 7.4, 7.7, 7.8, 7.10, 7.11, 7.13, 8.1, 10.1, 10.2, 10.3, 10.4, 11.1, 11.2, 12.1, 12.2, 16.1, 16.2, 16.3, 16.4, 16.5, 17.1, 17.2, 17.3, 17.4 with the proviso that consideration of, and steps to address, the inequities of living in regional, rural and remote areas are embedded in the processes and funding levels.

Whilst CORDS are pleased the Commission gave consideration to "rural areas" (8.4) we are concerned that no specific recommendations were made regarding these considerations. CORDS urges the Commission to reconsider this and make a recommendation regarding point 8.4 to ensure that people with disabilities, their carers and families can be assured that they will receive equitable services and supports of their choice in their own community without the necessity of "relocation" as the Commission suggest in the Draft Report on page 8.52 (final paragraph).

People want to live in their regional, rural and remote communities; they have greater opportunities for meaningful community participation and involvement, a sense of belonging, and should be supported to do so. People's contribution to the community in which they belong is productive and enhances the community itself.

Many people in the country are third or fourth generation farmers and they have always lived on the land. To have a child born with a severe disability means they can be expected (as stated on page 8.52) to "relocate" to the city. For these people, that is just not an option because farming is their whole identity. They simply would not know how to live in a metropolitan area, they would be isolated from their families and community, suffer more depression and experience increased health problems which compound the ability of the family to cope.

A study by Samara McPherson² concludes that regional people with a disability experience disadvantage on many socioeconomic and social connectedness indicators, and, in some instances, that disability and location have cumulative negative influences. She found that

Regional living and community participation: are people with disability at a disadvantage? *McPhedran,S, Research and Analysis Branch, Department of Families, Housing, Community Services and Indigenous Affairs.*

regional people with disability report higher involvement in volunteer work, more frequent attendance at community events, and stronger feelings of being part of their community, which partially supports the hypothesis that location and social participation are related. The findings show that despite greater relative socioeconomic disadvantage regional living can be associated with enhanced social connectedness.

CORDS urges the Commission to change the wording of Chapter 8.4 – Rural Issues, p. 8.52 to reflect a person or families right to choose to live in their community of choice without the requirement of "relocation".

Many innovative programs and services have arisen in regional, rural and remote areas, from block funding such as:-

- * A Collaborative Holiday Program involving several disability providers in the region and youth centres to provide school age children and their siblings support during the school holidays. Feedback from this program included one young girl, on her way home from a sibling holiday activity, stating "I thought I was the only one who had a sister with Down Syndrome".
- * A Holiday Program providing families with the opportunity, some for the first time ever, to partake in a holiday with the supports needed. Supports are flexible and range from financial assistance, support worker assistance whilst on holiday, support for in-home respite to enable families to holiday and have a break, assistance to locate accessible holiday locations and facilities, transport assistance or any other supports to enable a family holiday.
- * A Young Adults Respite Service providing tailor made respite options for young adults aged 17 25 in Regional WA. This service enables young adults to tailor their respite needs to their own interests. For many of these young adults this is the first step towards independence and having some control over their lives rather than simply being told where and when they are going so their families can gain a respite break. Examples include, concerts, sport and recreational opportunities, river cruises, leisure courses, hot air ballooning, sky diving, and many other activities of their choosing.
- * Targeted Programs. Targeted groups of Aged Carers (65 and over) and Younger Carers (18-35) are catered for. As service users are only required to be "eligible" for DSC registration the programs are able to reach a much wider group. These groups provide much needed support, respite and contact for people and are a great way to assist with the isolation experienced by people in these groups. Many important topics are covered within these groups such as; challenging behaviours, protective behaviours, relaxation techniques, taking a break and futures planning.
- * Remote Services. Block funding is utilised in remote areas of WA to deliver services to communities that are not bound by limits or criteria involved in individual funding. This

allows services to respond to the changing needs of the clients and the communities in which they live. For example: Block funding was used to provide an ATE Service to Fitzroy Crossing in an effort to provide a service that was previously non-existent. The benefit of being block funded was that when people were 'hard to find', 'went missing', or 'temporarily dropped out' the project was able to continue regardless of numbers. This resulted in remarkable outcomes: 16 people participated, some have moved to register with an employment agency and are looking for work, some were granted recurrent ATE funding while many others enjoyed the opportunity to participate and engage with others. This would not have been possible without block funding.

Far from undermining choice these innovative block-funded programs promote freedom, equality, rights and dignity of people with disability.

CORDS Service Providers have worked for many years to redress the inequities in regional, rural and remote communities by creating innovative and responsive services that are unique to each region. We urge the Commission to support and build on these existing resources and support local service providers. This would provide some certainty of infrastructure and recognition of existing innovative service models whilst organisations adapt to a self-directed funding model.

In fact, Regional Western Australia would be a perfect choice for a trial of the NDIS in regional, rural and remote areas, give the collegiality of our CORDS Members!

CORDS urges the Commission to make a recommendation (8.4) that any legislative formula take into account the higher costs (arising from diseconomies of scale) of living and providing supports to people with disabilities living in regional, rural and remote areas of Australia.

These legislative formulas must acknowledge the variances experienced in service delivery costs between regions. This consideration is critical when determining prices and individual entitlements.

CORDS urges the Commission to make a recommendation (8.4) in relation to continuing or establishing Block funding, or an Innovation Fund, to Service Providers in regional, rural and remote areas.

This will ensure continuity of existing innovative programs, certainty and equity of service provision for people living in these communities given their specific circumstances.

CORDS provide comment on all other recommendations as follows:-

CHAPTER 3. Who is the NDIS for?

DRAFT RECOMMENDATION 3.5

Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement.

Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- move to the aged care system, then they should be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches)
- stay with NDIS care arrangements, their support arrangements should continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.

Either way, after the pension age, the person with a disability should be subject to the cocontribution arrangements set out by the Commission in its parallel inquiry into aged care.

Any co-contribution arrangement must take into consideration the reduced opportunity for people with a disability to gain wealth over their life span, reduced opportunities for work and increased costs of living associated with living with disability.

If a person over the pension age required long-term aged residential care then they should move into the aged care system to receive that support.

In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

Consideration should be given as to how this recommendation may be in conflict with the Young People in Residential Aged Care program and the national policy of reducing the number of younger people with disabilities who live in aged care facilities.

DRAFT RECOMMENDATION 3.7

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people's current service use.

Whilst CORDS supports an individual's right to an independent assessment we consider it imperative that the assessor has local knowledge of the region involved. We consider it

imperative that assessors are either based in or travel out to regional, rural and remote areas to gain a first-hand account of the circumstances and issues of each individual in relation to their community.

CORDS considers that some of the innovative individualised services in existence should be retained i.e. 'don't throw the baby out with the bath water'. Many of the existing supports currently being used have been achieved through innovation and adaptation and should not be lost as a result of the introduction of a new system.

CHAPTER 4. What individualised supports will the NDIS fund?

DRAFT RECOMMENDATION 4.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in draft recommendation 8.3).

In assessing what supports are "reasonable and necessary", CORDS considers the NDIS should take into account the persons geographical situation and the equity (arising from diseconomies of scale) of the increased costs of providing the full range of disability supports.

The difficult circumstances of people living in rural and remote areas should influence the type/s and level/s of supports provided. The assessment process should identify the adjustments people living in rural and remote areas require. CORDS members regularly have cases where support workers have a 'round trip' travel time of up to 6 hours to deliver 2–3 hours of support. Even living just an hour and a half from the city has a huge impact on the services available and the travel costs needed to access these services.

Supporting existing innovative practices is imperative whilst also finding better ways of providing good support under these difficult circumstances must be a priority for further research and program development.

CHAPTER 5. Assessing care and support needs.

DRAFT RECOMMENDATION 5.2

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- draw on multiple sources of information, including:
 - information provided by the individual with a disability, including their aspirations and requirements for supports
 - information provided by unpaid carers
 - current medical information on the person with a disability

assess the nature, frequency and intensity of an individual's support needs. The
process should be person-centred and forward looking and consider the supports that
would allow a person to achieve their potential in social and economic participation,
rather than only respond to what an individual cannot do

The assessment process should have regard to the person's geographical situation and the equity (arising from diseconomies of scale) of the increased costs of providing the support.

- determine what supports outside the NDIS people should be referred to, including referrals to Job Network providers and mental health services
- consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')
- translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports
 - When assessing a person's "natural supports" and "reasonable needs" the NDIS should take into account the person's geographical situation and the equity (arising from diseconomies of scale) of the increased costs of providing the supports.
 - Planning and service delivery should not automatically be separated. Having the same person undertake the assessment and develop the individual's plan may prove problematical. Someone writing up a plan and not being familiar with the person and the environment, in which the person is living, will make the task of developing an appropriate plan extremely challenging. Assessment should be supported to provide flexible, responsive services that undertake planning for immediate, medium and long-term support needs within a person's local community.
 - This may lead to more restricted services and work against flexibility if people are deemed to be able to provide some informal support and the level of funding provided is lower than that required for an individual option. It is suggested that people get an entitlement to particular supports (hours of respite and attendant care, aids and appliances etc.) but can elect to 'cash out' this entitlement and elect an individualised budget
- provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.

DRAFT RECOMMENDATION 5.3

Any tools employed by the scheme should exhibit validity and reliability when used for assessing the support needs of potential NDIS users. The preferred assessment tools should be relatively easy to administer and exhibit low susceptibility to gaming. The toolbox should be employed nationally to ensure equitable access to nationally funded

support services (and allow portability of funding across state and territory borders when people move).

CORDS support the portability of funding across state and territory borders when people move.

DRAFT RECOMMENDATION 5.4

Trained assessors should undertake assessments. To promote independent outcomes, assessors should not have a longstanding connection to the person. Assessors' performance should be continually monitored and assessed to ensure comparability of outcomes and to avoid 'sympathetic bracket creep'.

CORDS propose that in regional, rural and remote areas the use of local assessors would be imperative to realistically assess an individual's needs in relation to and having regard to their local community.

Inequities may exist in regional, rural and remote regions in a broad range of areas:-

- Lack of services and access to medical and health services e.g. Occupational Therapy, Hydrotherapy, Physiotherapy, Behaviour Counselling, Psychologists etc.
- Lack of employment/volunteer opportunities.
- Lack of social, recreational and educational opportunities and services.
- Lack of support services, e.g. Interpreters, CaLD services, advocacy etc.
- Transport services and cost of travel to attend services.
- Lack of a public transport system.
- Lack of respite services e.g. respite house/facility
- A lack of accommodation services (group home situations in most small country towns is not possible).

By having Local Assessors working within and familiar with each particular region people having their needs assessed could be assured of their true requirements being understood and interpreted during the assessment process. An assessor with limited local knowledge would not be equipped to assess the person's needs. Conversely, an assessor with a longstanding connection with the local community would increase the likelihood of a fair and reliable assessment.

Locally trained assessors could be applied to other regional areas, as the issues would be of a similar nature and the assessor would be highly aware of regional community needs.

To equitably provide national consistency and enable portability the Productivity Commission needs to consider the additional costs involved in living in a regional or rural area. A person's needs assessment in a metropolitan region will be considerably different and inequitable if moving to a regional or rural area.

There is no obvious indicator as to how the additional costs associated with service delivery in regional and rural areas will be acknowledged. Costs will vary according to the

region and geographic isolation so one formula applied to all organizations outside of a major city would prove problematical. Even being one hour from a major city raises challenges in service provision, not experienced by metropolitan based services.

If funding is to be individualized then consideration has to be given to regional and rural situations where congregate care is not possible, nor desirable. Assessments for funding accommodation services must be based on each individual's circumstances within their own community.

Should local assessors not be a viable option, CORDS considers that provision must be made for assessors to travel out to regional, rural and remote areas to assess people's needs. People will undergo undue hardship if required to travel to a city based assessor and would also find it difficult to travel from small outlying towns to a major regional town due to the cost impact of travelling long distances and accommodation. CORDS considers that assessments will be more meaningful and realistic if done in a person's environment.

DRAFT RECOMMENDATION 5.5

The NDIS should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

CORDS consider that reassessments should not only be at 'key transitional points' but must also be available for emergency situations (e.g. a carers injury, sickness, death in family etc). An 'Emergency Contingency Reassessment' must be made available, at short notice and without a waiting period to provide additional supports in these situations. A Carer of someone who requires lifting, transferring and other weight-bearing assistance, who sustains a shoulder or back injury, needs to be able to access additional, short term supports without waiting any length of time for a "periodic reassessment of need".

DRAFT RECOMMENDATION 5.6

Where an informal carer provides a substantial share of the care package, they should receive their own assessment. This should seek to identify their views on the sustainability of arrangements and the ways in which they could be supported in their role, including through the initiatives recommended in draft recommendation 13.3.

The assessment process should take into consideration the needs of the informal carer and CORDS supports the development of additional services and supports for carers. These should not be in competition with existing support services such as state based peak bodies and carers representatives and advocates.

CORDS urge the Commission to recommend that siblings be included as part of the 'informal carer' assessment process. Siblings are often the 'hidden carer' in families and communities and can be particularly isolated and vulnerable in regional, rural and remote communities. Their needs and supports should be considered to enable a holistic assessment to be completed.

DRAFT RECOMMENDATION 5.7

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (attendant care, aids and equipment, home modifications).

CORDS consider that when delivering the "toolbox", through assessment of needs, that provision must be made for assessors to travel out to regional, rural and remote areas or that assessors be based in regional, rural and remote areas. People will undergo undue hardship if required to travel to a city based assessor and would also find it difficult to travel from small outlying towns to a major regional town due to the cost impact of travelling long distances. CORDS consider that "toolbox" assessments will be more meaningful and realistic if completed in a person's own living environment.

The toolbox should allow for greater choice and flexibility for the person with a disability and their carer. It should not be too prescriptive as this will lead to a continuation of people accessing services from a menu rather than developing the support they require from the ground up around the person. Too often people accept a service that doesn't quite fit what they need as this is what is on offer and current funding streams can be very prescriptive and only focus on one area of a person's life

DRAFT RECOMMENDATION 5.8

The assessment tools should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

The scheme needs to ensure that decision making is devolved to the local level. There is a risk of backlog and system driven (not individual) responses to individuals with one national body managing over 3600 assessments, especially as the numbers will grow over time.

CHAPTER 6. Who has the decision-making power?

DRAFT RECOMMENDATION 6.2

Self-directed funding should include the following key stages.

- It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (draft recommendation 5.2).
- The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices.

The person with a disability — and/or their support network or chosen disability support
organisation — would create a personal plan and a concrete funding proposal to the
NDIA that outlines the person's goals and the type of support that is necessary and
reasonable to achieve these within the allocated budget.

If Disability Support Organisations are to assist people to create a personal plan and construct a solid funding proposal what provision is there for organisations to afford the staff time, travel costs (presumably for several visits before finalisation) and administrative funding required to formulate these?

This is even more apparent in regional, rural and remote areas where the 'tyranny of distance' would compound the time and funding required to create realistic and individualised plans and proposals.

Small to medium size organisations, particularly not-for-profit organisations, may not have the capacity to offer this service, placing them at a market disadvantage over larger possibly metropolitan or interstate based organisations.

• The resulting funding proposal would require approval by the National Disability Insurance Agency (NDIA).

There should be a capacity for a person to:

- obtain quick approvals for changes to a funding proposal
- add their own private funds to a funding proposal
- allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that:
 - the person spend the budget in areas related to his or her disability needs and consistent with the funding proposal
 - the scope to cash out funds set aside for large non-recurrent spending items should be limited to the (rare) circumstances where the NDIA has approved this as an appropriate decision.

DRAFT RECOMMENDATION 6.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- care is intermittent and provided by a non-resident family member
- exceptional circumstances are present and after approval by the NDIA
- the person is in the family employment trial spelt out in draft recommendation 6.5.

This will require very clear guidelines and accountability measures with ongoing monitoring at the local level to safeguard the person with a disability.

DRAFT RECOMMENDATION 6.6

The NDIA should:

- inform people with disabilities and their proxies of the various options for self-directed funding
- provide support for people using self-directed funding, including easy-to-understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds
- promote the use of self-directed funding, with examples of innovative arrangements
- provide training to local case managers and front-line staff about self-directed funding

CORDS have concerns that there is no provision for training of staff in regional, rural and remote areas. Staff may need to travel considerable distances and pay accommodation to attend training. Organisations would have to pay the often high additional costs associated with bringing trainers to regional, rural and remote areas if this was deemed necessary and/or appropriate.

• encourage the formation of disability support organisations to support people in the practical use of self-directed funding.

DRAFT RECOMMENDATION 6.8

In offering self-directed funding, the NDIA should ensure that:

- it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:
 - ensuring easy and cheap access to police checks
 - giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated
 - monitoring by local case managers
- it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints
- it adopts a risk-management approach for receipting and other accountability requirements, which:
 - requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well
 - takes into account the compliance costs of excessive accountability measures
 - allows a small component of the individual budget to be free of any receipting requirements.

CORDS have concerns regarding the checks and balances that would be necessary to monitor the safety and well-being of people with disabilities being cared for by family members and by self-directed services. Although families have the best of intentions in arranging their own supports CORDS are concerned that a minority of people with a disability may be exposed to exploitation or abuse in some circumstances if families manage their own supports.

CORDS are also concerned that this could result in 'over-protection' where the person with a disability does not have any real control over their lives or dignity of risk.

Although the Commission has considered the possibility of "funding not being spent as intended" CORDS would like to see the Commissions consideration of developing robust 'checks and balances' that will be required to ensure people with disabilities are not subject to exploitation, abuse or over-protection.

CHAPTER 7. Governance of the NDIS.

DRAFT RECOMMENDATION 7.5

The Australian Government, with the agreement of state and territory governments, should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review body (draft recommendation 7.8).
- An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.

CORDS agree that peoples' entitlement to support should be enshrined in legislation to ensure continuity and accessibility to appropriate supports for people into the future.

Future changes to the legislative framework should be undertaken only by explicit changes to the Act itself, made transparently, and subject to the usual processes of community and Parliamentary scrutiny, and in consultation with all state and territory governments.

• Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme.

DRAFT RECOMMENDATION 7.6

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator, the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

This will need to be monitored carefully to ensure that individual entitlements are not eroded over time. There is a risk that a finite budget that must be shared with all people with a disability results in smaller packages of support being available. This can lead to poor outcomes for people in community based supports or a decision to increase the number of congregate care arrangements as the pooled funding may result in additional hours of support being provided for some people. This may lead to more restrictive support options for some people and, inevitably, less community involvement and participation as a result of living in a congregate care arrangement.

DRAFT RECOMMENDATION 7.9

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

Any benchmarking needs to take into account the additional costs of living in and accessing services in regional, rural and remote areas/communities (given the diseconomies of scale).

DRAFT RECOMMENDATION 7.12

The NDIA should include an internal complaints office that would:

- be separate from the other parts of the NDIA dealing with clients and service providers
- hear complaints about breaches of the service charters (draft recommendation 7.10)
- reassess contested NDIA decisions on a merit basis.

The office would be headed by an independent statutory officer who would review appeals made by people with disabilities and support providers against the decisions of the NDIA.

- The NDIA legislation should create this role and specify that the officer would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.
- A person or support provider should only be able to appeal the decisions of the office on matters of law, rather than on merit, to the courts.

The NDIA should publish the number, types and outcomes of complaints and appeals (subject to privacy protections).

CORDS consider that any complaints office should be external to the NDIA to ensure fairness and impartiality. It should have the status of an Ombudsman and be attached to HREOC.

CHAPTER 8. Delivering disability services.

DRAFT RECOMMENDATION 8.2

The Australian Government should fund and develop a national system for a shared electronic record of the relevant details of NDIA clients, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items with privacy safeguards.

Consideration should be given to the nature of information that is stored on the national database. People with a disability and their informal carers provide much more detailed information about their lives to secure support than would traditionally occur with bodies, agencies, departments, etc.

DRAFT RECOMMENDATION 8.3

The NDIA should develop and implement a quality framework for disability providers, which would include:

 the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should monitor compliance with thee standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, surveillance by case managers and interrogation of the electronic disability record

CORDS consider that parts of existing systems should be retained when reforms are considered. This is essential in being able to minimise Government bureaucracy. Currently around Australia there are pockets of individualised and flexible responses that work very well for people, particularly in regional, rural and remote areas. These support arrangements must be quarantined. The risk of moving to a national system is that we could end up with a system that caters for the lowest common denominator of Standards (i.e. the State that is least ready to move to individualised supports).

- arrangements that encourage the diffusion of best practice throughout the disability sector
- providing consumers with information about the quality and performance of service providers on the national internet database of service providers
- establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.

Many innovative programs and services already exist and have arisen from regionally governed disability organisations finding local solutions to issues and working in collaboration with local communities.

CORDS urge the Productivity Commission to ensure that there is no loss of the innovation and strong practices in place throughout regional WA.

CORDS support the Innovation Fund. The development of an innovation fund that both supports and extends existing innovative programs and services and also provides opportunities for developing new approaches would be extremely beneficial to regional, rural and remote communities.

CHAPTER 9. Disability within the indigenous community

DRAFT RECOMMENDATION 9.1

The Australian Government and state and territory governments should consider the feasibility of overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by:

- fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers
- employing Indigenous staff
- developing the cultural competency of non-Indigenous staff.

In its initiatives for delivering disability supports to Indigenous people, the NDIS should be mindful of the wider positive measures addressing Indigenous disadvantage being adopted throughout Australia.

To equitably provide national consistency and enable portability the Productivity Commission needs to consider the additional costs, arising from diseconomies of scale, involved in living in regional, rural and remote areas. A person's needs assessment in a metropolitan region will be considerably different and inequitable if moving to a regional, rural or remote area.

There is no obvious indicator as to how the additional costs associated with service delivery in regional, rural and remote areas will be acknowledged. Costs will vary according to the region and geographic isolation so one formula applied to all organizations outside of a major city would prove problematical. Even being one hour from a major city raises challenges in service provision not experienced by metropolitan based services.

Communication in Remote regions is problematical – access to a telephone or telephone service, lack of electricity – are just some of the issues. Cultural sensitivity during the assessment process is imperative and local knowledge of these cultural regions is extremely sensitive and important.

Besides addressing the socioeconomic disadvantage, high rates of disability, barriers to service delivery access, staffing and training issues that the Commission have considered, CORDS suggest that environmental and cultural factors should also be taken into account. Matters like the weather, the differing seasons and how communities respond and adapt to the different seasons impacts on service delivery and need to be taken into account when assessing someone's needs in a remote area. For example, during the 'wet season' people have had to be evacuated or have been cut off from the outside world for weeks on end or in the event of a family bereavement services may have to cease for a considerable length of time.

Additionally, the transiency of indigenous people must be taken into consideration, particularly when looking at the issues of accessibility of housing. Often in an Indigenous community one house may be modified to provide access, however, Aboriginal and Torres Strait Islander people can be transient and move from house to house. Accordingly housing is not always suitable and accessible for the person with a disability. CORDS consider that some innovative techniques will be necessary to assist with this issue. Portable ramps, hoists, air conditioners and other equipment that could be moved from house to house could assist somewhat in these circumstances. Perhaps a collaborative program between universities, TAFE, engineering companies, independent living centres, etc. could invent some innovative and flexible responses.

The Commission needs to carefully analyse the assumption that small locally based service providers require assistance from larger more bureaucratic service providers. The benefits of being small, local and responsive can and have led to innovative, cost effective and collaborative responses.

CORDS support Recommendation 9.1 and urge the Commission to add a further recommendation that supports Prevention and Early Intervention services to remote Indigenous communities and that this includes consultation with those communities.

CHAPTER 12. Where should the money come from? Financing the NDIS.

DRAFT RECOMMENDATION 12.2

The Australian Government should direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using an agreed formula entrenched in legislation that:

- provides stable revenue to meet the independent actuarially-assessed reasonable needs of the NDIS
- includes funding for adequate reserves.

If that preferred option is not adopted, the Australian Government should:

- legislate for a levy on personal income (the National Disability Insurance Premium), with an increment added to the existing marginal income tax rates, and hypothecated to the full revenue needs of the NDIS
- set a tax rate for the premium that takes sufficient account of the pressures of demographic change on the tax base and that creates a sufficient reserve for prudential reasons.

CORDS support the funding coming from consolidated revenue.

DRAFT RECOMMENDATION 12.3

The Australian Government and state and territory governments should sign an intergovernmental agreement specifying that:

- the Australian Government should:
 - collect all of the revenue required to fund the NDIS through the National Disability
 Insurance Premium Fund
 - make no further special purpose payments to state and territory governments for disability supports.

CORDS are concerned that under the current draft the Commission will potentially keep a two tiered system – the NIIS is recommended to be a state based system, i.e. a federation of separate state based schemes. However, the NDIA would be a national scheme. We wonder why they wouldn't/couldn't both be the same. CORDS are concerned that we risk keeping the same challenges we face now with employment and advocacy being Commonwealth and accommodation etc. being State based.

CORDS consider that advocacy services should be included in the NDIS to ensure that people with disabilities are able to access affordable and timely advocacy supports as and when needed on an equitable nation-wide basis.

- state and territory governments should offset the Australia-wide fiscal implications of the transfer of responsibility by either:
 - (a) reducing state and territory taxes by the amount of own-state revenue they used to provide to disability services or
 - (b) transferring that revenue to the Australian Government.

The Commission sees particular merit in option (a).

Any NDIS funding arrangements should ensure that state and territory governments that provide less own-state funding for disability supports than the average should not be rewarded for doing so.

CHAPTER 13. Workforce issues.

DRAFT RECOMMENDATION 13.1

The Australian Government should attract further support workers into the disability sector:

- by marketing the role and value of disability workers as part of the media campaign launching the creation of the NDIS
- by providing subsidies to training of disability workers

Locating specialist training and information for disability workers to support people with disabilities requiring higher levels of support worker skill is compounded in regional, rural and remote areas. The cost of sending a disability worker to city-based training, or bringing the training to the region, can be extremely costly with an associated negative impact on people's individual funding and the organisation's training budget allocations.

CORDS urge the Commission to ensure that the additional costs of training (given the diseconomies of scale) for disability workers in regional, rural and remote areas be taken into account when assessing training subsidies.

• through immigration of support workers, but only in the event that acute and persistent shortages occur, and drawing on the lessons from the Canadian Live-In Caregiver program and other similar programs.

DRAFT RECOMMENDATION 13.2

Australian governments should ensure that, across all jurisdictions, police check arrangements for paid workers providing services to people with a disability:

- apply only in cases where both the person with a disability is vulnerable AND the risks associated with delivery of services are sufficiently high
- not include disclosure of crimes covered by spent convictions legislation
- cover people for a given period, rather than for a particular job.

CORDS consider that a National Police Check system should be adopted, that it should apply in all cases and should be relevant for a chosen period.

A nationally consistent police check such as a "Working in the Health Industry Check" (similar to the Working with Children Check) could be developed to cover the Aged, Disability and Mental Health Sectors across the nation. This could be tailored to only report serious crimes, spent convictions and information relevant to the industry.

A mandatory minimum checking system could be developed similar to the Western Australian "Volunteer National Police Check" system which would provide a national minimum checking Standard with relevant, industry agreed, inclusions and exclusions. In this manner costs could be kept to a minimum, ensuring everyone could equitably apply for a clearance, whether a person is deemed to be 'vulnerable' or not, family member or friend, whether delivery of services are high or not, whilst also ensuring expedited checks.

National consistency would enable workers to move or travel to other parts of the nation without having to apply for clearances only relevant to a particular state or territory.

DRAFT RECOMMENDATION 13.3

In order to promote training and counselling for carers, the NDIS should:

- assess carer needs as well as those of people with disabilities (draft recommendation 5.6) and, where needed, use the assessment results to:
 - refer people to the 'Carer Support Centres' recommended in the Commission's parallel inquiry into aged care and to the National Carers Counselling Program
 - include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability
- assess the best training and counselling options for carers of people with disabilities as part of the NDIS research and data collection function.

CORDS urge the Commission to include siblings in the training and counselling assessment. Siblings, as the 'hidden carers' in families are often in need of counselling and support services. This is even more apparent in regional, rural and remote communities where siblings may not have the opportunity to meet other siblings of a person with a disability, or to see other people with a disability. This can result in feelings of isolation, confusion, anger, resentment and can lead to family breakdown or rejection of their family all-together.

The inclusion of siblings in the capacity for accessing counselling and support services is imperative to ensure strong families and future support from siblings. A holistic view of the family assessment should be taken to ensure that siblings don't experience isolation and undue pressure from a lack of support services.

DRAFT RECOMMENDATION 13.4

The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a sufficiently high level of care.

After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act to include employees caring for people other than children.

CORDS consider that the Fair Work Act 2009 should be amended to permit parents to request flexible leave from their employer if their child is over 18 years of age. However, the decision whether a person can take flexible leave should not be assessed by the NDIA. This won't be timely enough, may be cumbersome and bureaucratic and should be determined between the employee and employer.

REFERENCES

¹ National Disability Services, Western Australia – Pre-budget Submission 2011-2012 pp. 12 – 15

² Regional living and community participation: are people with disability at a disadvantage?

⁻ McPhedran, S, Research and Analysis Branch, Department of Families, Housing, Community Services and Indigenous Affairs.