# RESPONSE TO THE DRAFT REPORT “DISABLILITY CARE AND SUPPORT”, PREPARED BY THE PRODUCTIVITY COMMISSION.

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Att: Roberta Bausch

The following comments represent the personal responses of a Valued Independent People (VIP) Board sub-committee convened to discuss the Draft Report. Those individuals on the Sub-committee are Syd Borman (Chairman), Richard Diermajer (Vice-Chairman), Marian Cross (Treasurer), Joan Martin (Secretary) and Sue Rogers (Board Member) as well as some staff members of VIP. All members of the sub-committee have severe or profoundly disabled children.

We believe that there is a need for a glossary and index for the whole document

We believe that throughout the draft report there is confusion between the meaning of the following terms

**Self managed** – we understand means that funding is allocated to the individual and managed by the individual and / or their representative / advocate

**Agency Managed** - we understand means that funding is allocated to the individual and managed (**maybe** with input by the individual and / or their representative / advocate) by an agency with chosen by the individual and / or their representative / advocate

**Self directed** - we understand means that funding is allocated to the individual and managed (with input by the individual and / or their representative / advocate) by an agency with chosen by the individual and / or their representative / advocate

**Person centred approach** – services which are planned and centred on the individual
Individually focused funding and services – funding and services for an individual using funding specifically allocated for that individual and portable if the individual chooses to move

**Shared Management** – we understand to be funding managed jointly by an agency and the individual or their family who have responsibility for planning of services, selection and employment of staff and the agency is responsible for accounting to the funding and monitoring of standards.

We believe that there is particular confusion where self-directed is used in situations where self managed may be intended

## Overview

We strongly agree with the opening preamble and believe that this must be retained in the final report to Government. It is essential that government recognises the need and acts to bring about change in the disability sector. People with disabilities and their carers need certainty regarding the adequacy of funding to meet their needs. The "lottery" of access to service and the inadequacy of resources must change. The big gaps in the availability of support at key transition points in people's lives must be addressed. Entitlements must no longer stop at state boundaries – we are all Australians irrespective of where we live within the country. Currently, when faced with budget restraints, systems have little choice but to give priority to families in crisis which has caused further rationing over time. This is unsustainable and as the Draft Report points out needs to be addressed. Valued Independent People (VIP) of Western Australia believe that all the failings of the current system as outlined by the Commission should be retained in the final report. There should be no room left for Government not to act; they must not ignore the findings of the Commission due to budgetary constraints.

We are enthusiastic about the key features of the proposal namely:

1. The creation of a National Disability Insurance Scheme (NDIS) to be overseen by a new organisation, the National Disability Insurance Agency (NDIA).
2. The creation of a National Injury Insurance Scheme (NIIS) to address catastrophic injuries. The importance of no-fault arrangements for providing lifetime care and support is essential.

With regard to the NDIS we agree with the proposal that policy should be set nationally but stress the importance of local decision-making. Those of us a long way from Canberra are loath to see local input being devalued in anyway as there are many good aspects to the care and support that is currently provided, such as here in WA. In Western Australia having a Disability State Minister and a dedicated stand alone Disability Services Commission is an excellent model. We see the NDIS improving our lot not undercutting current services. A national scheme would deliver consistency and equity across Australia and would ensure portability and allow for relocation in the event of family members moving interstate. We believe that the provision of local support to answer queries and solve problems is essential. For example, we do not wish to speak to NDIA by phone and discover that the person we are speaking to is based in the Eastern States with no local knowledge.

## Chapter 3: Who is the NDIS for?

While the three tier structure proposed by the Productivity Commission means that more people would be eligible to benefit from the scheme we agree that those individuals falling into Tier 3 would account for the bulk of the funding. The recommendation that the scheme would provide information on available services to allow people to move easily and connect with appropriate services at Tier 2 level is pertinent as is the need for taking into account cultural and lingual diversity.

While assessment criteria need to be clear and concise individuals falling into Level Tier 3(b) or those with intellectual disability not already included in Tier 3 (a) we recommend that the needs be defined by function rather than by a specific diagnosis. There are many individuals in this category who do not fit neatly into a specific diagnosis but still have great functional needs. For some individuals who might not meet the criteria for support under Tier 3 the Commission needs to consider how a low cost response could be offered to them to assist them to move through periods of transition such as entering or leaving school or leaving home. We do not want to be left yet again with individuals who need a lower level of support to help achieve good results missing out on that much needed support. Currently in WA, Local Area Co-ordinators assist clients to develop community-based options sometimes with access to a small amount of funding. We see an ongoing role for Local Area Coordinators. We note on page 3.13 that the Commission states:

> *State and territory definitions are a useful starting point – they take broad account of the nature, frequency, intensity and duration of care and support needs. However, one major limitation is that they place undue emphasis on an individual's present state of functioning.*

We disagree with the premise that there is an undue emphasis on an individual's present state of functioning. At the same time we fully agree with the comments on the importance of early intervention which can help avoid rising levels of need and costs at a later stage. There will be many individuals whose quality of life can be improved by early intervention but who might still require funded support due to on-going intellectual disability or having significant limitations in communication, mobility or self-care or in other words their functional ability remains much impaired. We therefore agree with the Commission's comment on page 3.15 which states:

> *… the assessment criteria should be clear and precise without being unduly prescriptive such that individuals who did not neatly slot into categories missed out on much needed supports and services.*

Some individuals require a small amount of support in order to achieve a better quality of life. The involvement of Local Area Coordinators would also assist in the monitoring of the effectiveness of early intervention and also would be able to identify increased support needs in this group thus being able to facilitate assessment for Tier 3 supports if required. As stated previously there must be local support and input into the NDIA. Valued Independent People (VIP) would also recommend that disability service providers also have expertise in this area. Currently we liaise with LACs and other service providers. FaHCSIA's criteria for providing carer allowances for care of children with a disability which depend of several overlapping classification approaches should continue to be used as a useful tool for determining eligibility.

## Taking account of the broader context of service delivery

### Aged Care:

We agree with the Commission's first option recommendation that the NDIS would fund the care and support needs of people aged up to the pension age, including disability arising from age-related conditions like strokes and early onset dementia. We also agree with the second part of the recommendation that the aged care system would fund the care and support needs of all people over the pension age. However, the importance of ensuring that people who acquired a disability before reaching pension age would not end up with different levels of care and support must be stressed. We also agree with the NIIS fully funding people over pension age who have catastrophic injuries. We appreciate the Commission's recommendation that recipients would have the freedom to elect to stay in the NDIS upon reaching pension age with those assessment tools being used to determine their funding. People reaching pension age must not fall into a gap between the two systems. People with disability will need good support from both sectors.

We do not agree with the following paragraph in Draft Recommendation 3.5

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

We would point out that many people with an intellectual disability are living in group home supported accommodation. Just because they reach pension age they should not have their lives disrupted by being moved to an aged care facility if they have no age related problems requiring additional care. They would simply be taking up beds in aged care facilities before they needed to. If they are capable of continuing to live in their "home" they should be encouraged to do so just the same as any other citizen.

We also note the following statement that was made in the same recommendation:

> *… after pension age, the person with a disability should be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care.*

Provided that they are in an Aged Care facility then their contribution would the same as any other resident. If they are continuing to live in a group home then their contribution should remain the same, that is, their current rent and housekeeping contribution.

## Health

We agree with the Commission's statement that *gaps between disability and health services persist. (3.21)* particularly in the areas of chronic debilitating illness requiring long-term support, research and early intervention.

We therefore support Draft Recommendation 3.4 about the establishment of memoranda of understanding with the health, mental health, age and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes and to have effective protocols for timely and smooth referrals. We would stress however the need for effective monitoring of the MOUs.

## Mental Health

We believe that boundaries do need to be drawn between the mental health sector and the NDIS. We agree with the statement made in the Draft Report (3.27).

> *The mental health sector would be responsible for:*
>
> - *Specialised services such as psychology, psychiatry (which would include early intervention), acute and inpatient services and pharmaceuticals for all types of mental illness*

  - *Provision of all services to people with non-permanent mental illnesses (such as many affective disorders).*

> *The NDIS would have a significant role in meeting the support needs of individuals with a dual diagnosis, such as those with an intellectual disability and a mental illness.*

We would add that the NDIS should not cover the health expenses of individuals with a dual diagnosis but that individuals should receive treatment from specialist mental health services. There must be good liaison, co-operation and co-ordination between any services for any individual through formal service level agreements.

People with drug and alcohol addiction issues should remain in the province of mental health unless they also have another significant disablility.

## Palliative Care:

We agree with the Commission's recommendation that for those individuals who are currently receiving funded support when they then required palliative care that the NDIS would source, and the palliative care sector would fund, any specialist services to address the palliative aspect of their care needs. We would endorse the view that such an approach would ensure continuity of care in the individual's final stages of life.

## 3.8 Implementation Issues

We note the comment on page 3.32 that …*traditional service users are captured by the proposed assessment criteria, the overwhelming majority of current users would be likely to access their supports from the NDIS after its implementation. Indeed, most would get more supports given the expanded funding of the NDIS and an obligation for the system to deliver the supports determined by the independent assessment process.*

Most of the writers of this submission have waited years for adequate funding for their child and indeed some are still waiting. It is therefore essential that those with current funding do not have to face a situation under the new arrangements where they receive no or fewer supports under the NDIS after years of fighting or waiting for adequate services. No individual with significant or profound needs should be worse off under new funding arrangements.

We agree with Draft Recommendation 3.6 that the NDIS should fund all people who meet the criteria for individually tailored supports, and not just people who acquire a disability after the introduction of the scheme.

## Ch 4. What individualised supports will the NDIS fund?

We endorse the view that NDIS would meet *disability-related needs* and not ordinary life expenses. However, when there is a high expenditure on these items due to a disability then the cost difference should be covered by the NDIS. The scheme should also provide adequate equipment and technology with individuals meeting the cost differentials of upgraded versions. There needs to be transparency here as to what is available, in other words supports should be clearly listed and reviewed regularly. We support the view that additional electricity costs arising from disabilities should be funded through the NDIS rather than through State Government rebates provided the varying costs of electricity from State to State is taken into account.

The Scheme must be flexible to cater for individual cases in such a way that individual circumstances can be assessed on merit especially in situations where the items concerned would not normally be covered by the NDIS.

We are pleased to note that respite care is included in the recommendations as is specialist accommodation support. We note that the commission states *that the NDIS should facilitate the transition of young adults, into public or private housing or supported accommodation, if they wished to do so, in line with community norms. (4.7)* If this is to be in line with community norms, then it would need to definitely be available before the individual turns thirty and preferably in their early twenties. Young adults need to be as independent as possible in line with their 'normal' peers.

## 4.3 The role of 'mainstream' services.

We agree in principle with Draft Recommendation 4.5

*Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:*

- *Health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them*
  *- but specialised employment services, disability-specific school to work programmes. Taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.*

### Employment:

We would stress the importance of the West Australian model of Alternatives to Employment for those individuals whose level of disability precludes them from finding meaningful employment such as many individuals in Tier 3(b). Funding for this important alternative **must** continue.

We also believe that people assessed as needing support to meet their desire to work should receive assistance to do so.

### Housing:

We note that the NDIS would fund home modifications on a reasonable and necessary basis for people in both public and private housing which is both necessary and noteworthy. Real choice in housing and accommodation is dependent upon the availability of options.

### Education

The NDIS needs to assist with the provision of goods and services such as specialised equipment and education assistants. The provision of education assistants maximises the individual's ability to develop educationally to their full possible potential thus perhaps saving funds later on. State and Territory Governments need to continue to provide a range of options for children with special needs including "mainstreaming", education support centres and units attached to mainstream schools and special education schools so that the most appropriate educational institution for an individual would continue to be available. Children with disability must be adequately supported in education.

## Health

We agree with the Commission's recommendation that people with disability, as is the case with the community more generally, will continue to access the existing health care system as the need arises. We also agree with the Commission that people with disability, and in particular intellectual disability, encounter a number of barriers to good health care. We endorse the view that NDIS would have a role in reducing disability-specific barriers to receiving good health care. People with intellectual disability need extra support when hospitalised especially from support staff that they know.

## Transport

We note on page 4.22 that the Commission states *overall, taxis will continue to be of great importance, particularly given public transport networks are not fully accessible.* We agree with the comment that *the need for these services (and the associated budget) would be considered as part of people's individual NDIA assessments.* The fact that currently there is state/territory assistance programmes as well as the provision of the mobility allowance through Centrelink we believe that any provision under the NDIS should be capped to ensure sustainability.

We ask about the provision of grants for agencies to purchase vehicles to assist in the transportation of clients. Valued Independent People for example run a fleet of 28 vehicles to transport their 100 plus clients on a week-day daily basis. This also applies to agencies who provide accommodation support with most homes having a vehicle. At the moment Valued Independent People rely on grants from the Lottery West to help fund the modification of vehicles purchased through DSC grants. This issue needs to be addressed by the NDIS.

## Encouraging Savings

We note in the Commission's report that disability trusts have historically had low take-up rates and endorse the opinion that they appear to be of limited use for most people with disability, bearing in mind that many families experiencing disability have lower assets for income. We agree with the Commission's comment (4.23) *that the role of Special Disability Trusts should be reviewed once the NDIS is up and running.*

## 4.4 Income support

We agree with the Commission that the DSP should be outside the NDIS. Many people currently receiving the DSP are doing so due to illness or injury and do not need the individualised supports that the NDIS would provide. We agree with the Commission's comments that people with non-permanent conditions could be encouraged and helped into employment participation. We do not agree that Carer Payment, Carer Supplement and Carer Allowance should fall within the scope of the NDIS. However, Mobility Allowance and the Child Disability Assistance Payment could well be included in the NDIS provided the recipient is receiving assistance from the NDIS.

## 4.5 The basis for providing specialist disability supports

We acknowledge that service provision is bounded by the concept of "reasonable and necessary" while applauding the fact that funding will be based on an independent assessment of need rather than the present arbitrarily rationed amount.

We applaud the Commission's findings that *the scheme would facilitate the transition of young adults into independent living or supported accommodation, if they wished to do so, in line with community norms. (4.29)*

The scheme must be able to respond appropriately to individual cases.

## 4.6 Means testing, front-end deductibles and co-payments

We believe that access to the NDIS should not be means tested provided that the disability is sufficiently severe, such as Tier 3. We agree with the Commission's findings that the well-off would be paying a much larger contribution towards the NDIS than medium and low income earners so it would be inequitable and inefficient to exclude people from NDIS supports solely on the basis of income. It must be needs based and not income based. We therefore support Draft Recommendation 4.2 *There should be no income or asset tests for obtaining funded NDIS services.*

We do not support Draft Recommendation 4.3.

*There should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS, with free access to services after that point. The NDIS should waive the amount where families have already contributed significantly towards the costs of support through unpaid care.*

Families of severe or profoundly disabled children who live at home have obviously contributed through unpaid care. However, when their child moves into supported accommodation they are no longer supplying unpaid care apart from when their child spends time in the parental home. If the Recommendation is implemented then clear guidelines would need to be established as to whether or not or when an upfront payment would start to apply. A profoundly disabled person who is already contributing to the rent and house-keeping of their supported accommodation would experience financial stress if they also had to contribute an annual up-front payment to access the NDIS services.

We support Draft Recommendation 4.4 which has the premise that co-payments are a function of the value of a specific service to a targeted group of individuals.

*People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.*

With regard to contributions post age pension age we would reiterate our earlier comments that this should not be arbitrarily tied to pension age but rather when the recipient requires aged care. While they remain in supported accommodation with no specific aged care component their existing funding should remain status quo. Some individuals will require aged care before they reach pension age.

## Chapter 5: Assessing care and support needs

### 5.2 What is being assessed?

Valued Independent People support the Commission's findings that assessment should be focused on needs and in particular, reasonable needs. We agree with the Commission's findings that individual's aspirations should also be taken into account. We would agree with the use of the International Classification of Functioning (ICF) produced by the World Health Organisation (WHO) with regard to the nine activities and participation domains that should be considered in a needs based assessment as being valid.

### 5.3 What is the purpose of the assessment process?

Valued Independent People support the purposes outlined in the Draft Report namely:

- Determining whether an individual would receive NDIS funded individualised supports. This initial assessment would determine eligibility.

- Determining the service offered including fluctuating needs. Support needs including type, intensity and frequency would be determined.

- Determining what supports could be reasonably and willingly provided by unpaid family carers and the community. We applaud the comment that *it would not be reasonable to expect elderly carers to provide the bulk of the support.*

- Determining an individual's budget

- Determining suitability for self-directed funding.

- Providing a referral to other schemes which will help reduce the need for overlapping assessments. We applaud the comment (5.10) that *assessments should be portable across the system – subject to protection of privacy – so that people do not have to repeat information for different providers or government agencies.*

- Providing data for programme planning and cost management

### 5.4 Desirable features of assessment tools

Tools used need to be both valid and reliable and there should be a uniformed national approach to promote fairness. We strongly advocate that assessment must be as streamlined as possible. Individuals and carers need less assessment rather than more. Valued Independent People advocate the minimum required to provide necessary and adequate information. We would recommend the use of tools that are in the public domain as this facilitates transparency and reduces costs. We endorse the Commission's comment (5.15) that they favour a "toolbox" *that would be employed nationally …since it would ensure more equitable access to nationally funded support services and allow portability of funding across borders when people move.*

## 5.6 A single tool or a 'toolbox'

Valued Independent People support the Commission's recommendation of employing a toolbox rather than a single tool. However the more tools that can be selected can create opportunity for inequality of outcomes. It is therefore important that thorough research is employed to select as few tools as is practicable.

## 5.7 Who should conduct assessments?

Valued Independent People endorse the Commission's findings (5.20)

*Assessment should be carried out as a collaborative process, and in a way that is understandable for the person* (and carers) *seeking support so that they are able to:*

- *Gain a better understanding of the purpose of assessment and its implications for their situation*
- *Actively participate in the process*
- *Identify and articulate the outcomes they wish to achieve (a support plan will also be key here)* VIP note that this addresses some of the issues involved in self- assessment. The client/carers need a voice.
- *Identify the options that are available to meet these outcomes and to support their independence and well being*
- *Understand the basis on which decisions are reached.*

## 5.8 When should assessments occur?

After initial effective and adequate assessment VIP believe that individuals and their families and carers should be able to initiate the re-assessment process. VIP believes that certain life stages could trigger the opportunity for timely reassessment. Some of these stages have been identified in the Draft Report – refer 5.21. We would stress the need for a minimal re-assessment model.

## 5.9 Should carers have their own assessment

VIP supports the Commission's view that there should be greater assistance for unpaid carers through properly funded training and counselling services. Carers should be able to request an assessment as supporting carers should be a priority given their important role in the lives of people with disability.

## 5.10 How assessment might work in practice

At first glance the suggested framework as outlined in Figure 5.2 (5.26) appears to be very complicated. VIP would refer the Commission to the National Disability Services (NDS) Response to the Draft Report and we quote:

*Assessment processes should be*

- *Timely*
- *Have mechanisms to help ensure consistency when used by many assessors*
- *Are as comprehensive as is necessary (covers all relevant domains)*

- *Use existing information about the degree of disability and the supports required*
- *Seek permission to share information with necessary partners/providers*
- *Use an initial screening tool to determine likely eligibility*
- *Minimalise assessment tasks (but gives valid and reliable results)*
- *Consider information provided by the person with disability (on needs and aspirations)*
- *Consider the availability of informal supports (and, where possible, engages them in discussion)*
- *Seek to re-assess at important life transitions or when instigated by the person with disability, their families and carers; and*
- *Provide for review and appeal.*

VIP would add that relevant assessments and information should be readily available to those providing services to a client provided that authorisation by the consumer or carers has been granted.

## Ch 6. Who has the decision-making power?

Valued Independent People work with clients who have severe and profound disabilities who do not have the capability to make informed decisions regarding self-directed funding. Their family/carers largely would make these decisions. VIP notes that the thrust of Chapter 6 in the Draft Report is about designing a workable form of self-directed funding in the NDIS. Due to the nature of our clientele we would endorse the statement in the Draft Report (6.8) *There should be no obligation to use self-directed funding.*

We support the developing trend towards giving people with disability more choice over their supports. If clients opt for a self-managed package then Disability Support Organisations must give support. The implications would be onerous for many families: the direct employment of staff, superannuation, OHS and other work/industrial arrangements that would need to be put in place. In effect a self-managed package would need to be run as a small business. Accountability requirements would need to be put in place proportional to the level of funding to avoid funding mismanagement.

As the Commission points out (6.48) *there should be certainty that direct payments to people made under self-directed funding are not treated as income for taxation and welfare purposes, since that would have the unintended impact of reducing the available funding and the incentives for uptake of self-directed funding.*

VIP would request that the Final Report clearly distinguishes between “self-directed” and “self-managed” funding. Our understanding of “self-directed” is where the client and family/carers have input into how the funding is used. Whereas, “self-managed” funding is where the client and family/carers actually manages the funds themselves.

We endorse **6.6 Exercising power at the family level** where the Draft Report states that there are strong grounds for guardians (such as a parent or partner) familiar with the person with a disability to act as their proxy under self-directed funding. Valued Independent People would endorse this view to also apply to direct funding which has been provided to a service provider.

The NDIS must have an appeals mechanism in place.

It would appear that all of the Draft Recommendations in Chapter 6 deal with self-directed funding and appear to be well written and thought through with good checks and balances.

**Valued Independent People wish to state that individualised funding is not the only route to the personalisation of services.**

**We are concerned about the following issues:**

- Individual budgets might be inadequate
- The financial viability of services could be undermined
- The financial undermining of services could deplete the quality of services
- While there is a real desire to have a control of the supports that are received we question how many people receiving funding would want to become employers of disability support workers and be responsible for all that entails (establishing a small business, being in compliance with legislation, OHS issues, taxation etc)
- How do individuals provide staff with training and professional development?
- How would support staff be supervised?

**Valued Independent People believe that the NDIS must provide a diversity of choice in the delivery of funding. These should include at the very least:**

- Self- managed funding to individuals
- Choice about just how active clients are in the administrative aspects of the support they receive.
- The option to use a financial intermediary
- The direct funding of service providers.

## 6.9 Paying relatives for care

We agree with the Commission's findings that family members who are resident in the same household as the service user should not be paid to deliver services. (They could well be eligible for the Carer Payment through Centrelink). VIP would be supportive of the Commission's recommendation that *there are strong grounds for at least intermittent (rather than just recurrent) payments to non-resident family members for activities like respite and holiday care.* Payment of non-resident family members could also be warranted in rural and remote areas where the availability of support workers is limited.

## 7. Governance of the NDIS

Valued Independent People believes that the work done by the Commission on the area of governance is pertinent and appropriate. We would however like to make comments on the following:

### 7.3 The role of the NDIA and others within the NDIS

The Commission has been at pains to spell out in great detail the functions of the NDIA. We agree with the proposal that direct provision of services by the NDIA could create conflicts of interest. (7.7) The NDIA would be responsible for establishing the policy framework of the scheme and the setting of efficient prices. VIP believe that for people eligible for Tier 3 support the NDIA should be responsible for undertaking assessments and allocating support entitlements

### What would the NDIA do?

We note (7.11) the Commission's suggestion that in the initial stages of the scheme, while both clients and providers are becoming accustomed to a new way of operating, that entitlements should be given effect by the use of vouchers that clients would take to providers of their choice. A voucher model would involve more certainty and would be a simpler approach than self-directed funding where consumers choose to have direct control over their budgets and would then have to enter into negotiations with providers over price and services. Valued Independent People would recommend that the Not for Profit organisations who are intimately involved in providing clients with service have some input into the setting of appropriate "prices" for each support to be purchasable by voucher. We believe that negotiation with suppliers re prices is important when the NDIA is setting what it judges to be 'efficient' prices. We note (7.12) that the Commission states that *these prices would need to be amended periodically, as costs and market circumstances changed, and made transparent.* Valued Independent People would add that they must also be tied to indexation (that is CPI plus wage fluctuation considerations etc) and that an annual review be legislated to ensure that their value is not eroded. Valued Independent People have real concern about the concept of the NDIA possibly issuing tenders and forming contracts with particular providers for the supply of services at a given per-unit price for a given tender period. While cost control is important for the sustainability of the scheme so is the quality of delivery to clients.

### The role of NDIA case managers

VIP is of the opinion that too great reliance has been placed on case managers. Ambiguity about 'case management' needs to be resolved as case management is an expensive service which should be provided only to those with complex support needs. Not every potential client needs a case manager.

### The role of DSOs (intermediaries)

VIP agree with the roles as outlined in Box 7.2 (7.15) of the Draft Report for DSOs. We would also add that DSOs can be involved in case management for the small proportion of people who need it. We note that *the Commission proposes that people would in effect pay a fee to DSOs out of their allocated funding plans, if they chose* *to use their services.* VIP are concerned that client funds could be eaten up by this recommendation. At present many service providers are currently performing many of the services proposed for DSOs. We believe that under the NDIA they should be allowed to continue to do so if this is the desire of the client and/or family or carers. If they do then they should be funded accordingly. Choice for clients would still be available with the provision of the independent DSOs. VIP believes that the element of choice in all areas should be built into the final proposal.

## 7.4 Why have just one agency?

As stated earlier Valued Independent People is a Not for Profit Agency delivering services to over 100 clients in the northern suburbs of Perth, Western Australia. We are fortunate to be located in a State which has been in the forefront of Disability Service within Australia. As such we are concerned with the proposed total centralisation of funding and would stress the need for State and Territory Governments to retain a role in directly providing services and supports to people with disability. We note (7.16) that *the NDIA and NDIS would draw on the existing federal model for disability services, but into a more coherent national framework and with a clear single organising agency.* Valued Independent People would stress the need to draw on best practice elements from all State and Territory Systems. VIP would endorse a model where funding is allocated to each jurisdiction – based on summing people's individual budgets following the assessment.

## 7.5 Creating a National Disability Insurance Agency

VIP is in agreement with the Commission's Draft Report regarding governance issues and would agree with the importance of the Agency's independence from day-to-day government control. We would agree that the NDIS should have its own legislation.

## 7.6 Measures to encourage high performance

The Commission's reference to the fiscal problems encountered by the NZ ACC, are timely and we agree with the absolute importance that the reporting and monitoring arrangements for the NDIA must ensure against similar difficulties. VIP therefore fully endorses Draft Recommendations 7.6 and 7.7 which ensures regular reporting at various levels and puts in place financial risk management. Draft Recommendations 7.8 and 7.9 which recommend independent reviews and benchmarking against comparable agencies are also necessary safeguards.

## 7.7 Managing the Funding Pool

VIP believes that the Commission's recommendation that the Future Fund for investment appears to be the most appropriate is correct provided that the Board of the NDIA has an appropriate role in setting guidelines for acceptable levels of risk and in specifying the required mix of investment types.

## 7.8 Complaints and dispute resolution

VIP acknowledge the importance of Draft Recommendation 7.10 which proposes the establishment of two service charters that specify respectively the appropriate conduct of the NDIA and specialist service providers and disability support organisations . We also consider that Draft Recommendation 7.11 is fair.

However, we are concerned with Draft Recommendation 7.12 which places the handling of all complaints and disputes under internal investigation. VIP believe that while internal review is desirable there must be a place for an external process. These matters must be dealt with as independently as possible. An external process, while having the potential to be more costly, will help to ensure public confidence in the NDIA. An efficient and effective process to receive, investigate and resolve complaints is required by the Disability Service Standards. VIP would therefore support the implementation of Draft Recommendation 7.13. We would support the notion that the risks (especially financial) of review processes should be curtailed through clear legislative guidance (7.52).

## Ch 8. Delivering disability services

### 8.1 Disability support services

We believe that here is a need for a glossary and index for the whole document

We believe that throughout the draft report there is confusion between the meaning of the terms noted on page 1 of this document ie **Self managed, Agency Managed**, **Self directed, Person centred approach, Shared Management**.
We believe that there is particular confusion where self-directed is used in situations where self managed may be intended

Consumers experience profound difficulties in finding services that can specifically cater for people who have profound disability and very high support needs and also those who have severe challenging behaviours. We are concerned that these groups of people have extremely limited choice in service providers and often wait for long periods after allocation of funding until a service provider will eventually take them on as a client.

We strongly support the need for

- The national internet database featuring information about service providers and indicators of service quality
- Provision for local case managers to assist decision-making and to monitor clients' wellbeing
- A confidential and longitudinal database containing client information, for the purposes of reducing administrative requirements for both service providers, government and consumers, as well as client outcomes, which can be used by the NDIS to monitor quality of service provision and evaluate the effectiveness of different types of services, rehabilitation, appliances etc.
- The use of individualised packages is already is practice in WA and we have successfully provided high quality services through this method for the past 19 years.

We have also operated with a very small amount of block funding which is extremely flexible and useful for short term crisis situations where no opportunities for application for additional funding would be possible. It has assisted many of our families in times of crisis and has at times supported opportunity for innovation

The model of a ‘local area coordinator’ (LAC), as used in Western Australia, is a particularly valuable contact for most families however the satisfaction and success is very dependent on the ability and commitment of the individual LAC. This role needs to have facility and adequate capacity to case manage for individuals and families requiring this service. It needs to be available to ALL people who require advice.

We support Draft Recommendation 8.1 The NDIA should support consumer decision-making by providing:

...We agree that .... supported decision making should be an integral part of the process of identifying support needs and responses to those support needs ... The level of decision making support required will be different for each person with a disability. Providing funding for supports on an individualised basis will enable and support greater choice for people with a disability but in some cases, the person will require support to make informed choices. All people with a disability need portability of funding to enable them to exercise choice about and to change support providers and individual disability support workers.

This requires caution as to the effect on service providers and may need to employ more casual staff to accommodate possible frequent transfers

Brokerage potential of the NDIS could be good in that consumers may have greater choice if more service providers are set up or bad through potential for corruption / favouritism, competition that may result in compromised services / decreased quality and increase administration costs

With introduction of “total life funding”, there may be a need to quarantine some % of total individual $ for some specific services eg all ATE funding could be converted into covering extra accommodation cost. There would be a need to ensure flexibility for change in future.
Possibility to educate PWD & families about services available – provide information
Electronic submission of forms & applications – Many will need assistance eg from a coordinator or case manager

Management of funding / monitoring of use of funding and services provided to ensure accountability and good standards of services – potential to great amount of financial abuse

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.

The benefits of a shared electronic record are strongly supported including the need for the system to link to the Personally Controlled Electronic Health Record (PCEHR) in the Australian Government's E-health strategy.

The Commission seeks further feedback on the effectiveness of these monitoring instruments and any others that could potentially be used to assist oversight of the disability sector.

8.1 Safeguarding quality

These standards should be developed which should be understandable, agreed upon, state-of-the-art, achievable, practical, relevant, outcome orientated, measurable, and cost-effective. Above all, they should be as simple and short as possible and should include the WA 9th Standard on Prevention of Abuse and Neglect.

As such, the NDIS should be accompanied by clear legal obligations on service providers regarding restrictive practices. Specific ongoing monitoring measures will also be necessary to ensure compliance. Auditing should remain a feature of the NDIS,

Community Visitors Schemes. as operating in New South Wales and Victoria are supported.

Need to preserve standards and monitoring system already in place in WA and to include unscheduled visits. Any comparison / rating needs to compare like with like eg client level of ability.

DRAFT Recommendation 8.3 - The NDIA should develop and implement a quality framework for disability providers

A condition of funding granted should be that consumers participate in all monitoring and surveying without need to get new permission every time

Table 8.1 Potential indicators and sources of evidence about service provider quality

Hours provided might be another useful indicator, however service providers need to have right of reply before publication

8.4 Block Funding

We agree that sometimes block funding or government provision of services, may deliver better outcomes for consumers than market-based, or may be required to overcome specific sources of market failure. It needs to be available where people with disability experience unforeseen crises, such as medical complications or changes to life circumstance, such as a death of a partner, loss of accommodation or the sudden breakdown of an essential aid or appliance. The maintenance of block funding to specialty disability providers offering crisis care (or for crisis care as service type in its own right) is one way of addressing this.

We believe there are grounds for competitive grants to support research and experimentation in areas that are likely to provide broad social benefits. This could be funding a trial, or ‘seed capital’ to start a new highly innovative service. In some cases, there may also be benefit in research funding on an ongoing basis

Putting it all together
We agree block funding should continue to play a role:

- to ensure that crisis care needs are met
- to support research, experimentation and innovation in the industry
- as a tool to redress market failure.

Government, not-for-profit and for-profit service providers (8.48)
We are concerned that
NFP’s flexiblity and ability to adapt to client needs, as well as having the ability to package government-funded services with other services may be lost with heavy regulation. The risk of competition may jeopardise viability and limitation of access to funders such as Lotterywest for capital. NFP’s cannot afford to cut fees etc to get business

Some consumers who are slightly more difficult to manage may fall between cracks if they are not cost effective for provision of services.

Rural Issues 8.51
The concern regarding is the lack of access to specialists (such as occupational therapists, speech therapists, physiotherapist or even GPs) could be assisted by Access to equivalent of Patient Assisted Travel Scheme (PATS) in WA or provision of “Disability flying squad” to take services, advice, case management and training to country areas
Costs in NW in particular are extremely high eg property, rental, utilities, communing, fuel – which all need to be taking into account.

## Ch 9 Disability within the Indigenous community

VIP acknowledge that this chapter of the report lies outside our area of expertise. We would however like to state that we are well aware of the difficulty in supplying adequate services in remote areas and in the indigenous community. We would suggest that this is an area where block funding could continue to be a viable option to assist in the provision of such services.

## Ch 10 Collecting and using data under the NDIS

We would endorse the need for good data as well as research and analysis capability under the scheme. We agree that good data would facilitate financial sustainability, help to ensure cost-effective services and interventions and should also assist in performance monitoring of service providers. WA has increasingly focused on outcomes for people with disability as well as external monitoring of service providers so we endorse the application of this on a national basis. With a national register the compatibility of data systems across the jurisdictions is essential and this should be a high priority at the outset of the NDIA’s implementation. The national longitudinal database of clients' information with a one-time registration is an excellent proposal. VIP agree that research capacity must be built into the NDIA.

VIP endorses all Draft Recommendations 10.1 to 10.4.

## Ch 11 Early Intervention

VIP fully endorses the second part of Draft Recommendation 11.1 *NDIS funding for early intervention should be additional to that allocated to clients for their ongoing care and support and should not be able to be cashed out under self-directed (*managed*) care packages.* We do not fully support the notion in the first section of this recommendation that *Early intervention approaches used by the NDIA should draw on evidence of their impacts (*we do agree with this*) and be based on an assessment of the likelihood of cost-effectiveness.* Obviously wherever possible evidence of their impact is important but for service providers to provided economic assessments to the NDIA would be very difficult as currently there is very little evidence available in literacy reviews (as the Commission itself points out). This is definitely an area for the NDIA to fund research. We would hate to see early intervention denied simply due to lack of evidence of future cost-effectiveness. On-going assessment of the client before, during and at the end of the intervention is not only essential for the client but would also help to build the necessary data base for the effectiveness of particular early intervention strategies. The quality of life of a client is not always measured by cost-effectiveness. We fully support Draft Recommendation11.2 *The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.*

VIP believes that intervening early can help prevent the escalation of need and therefore would be cost effective. We are also pleased to note that the Commission sees early intervention as being something more than purely applying to the first years of life. We endorse the view that it applies when a disability first arises at any age and also the need for re-assessment and possible intervention at specific transition points in an individual's life such as leaving school or home and supporting an individual entering the workforce. We would encourage an approach which does not delay early intervention simply because a specific diagnostic label has not been applied. Recognisable developmental delay should be a sufficient to warrant early intervention. On-going re-assessment would both act as a monitor as to the success or otherwise of the intervention as well as providing data as to the need for continuing intervention.

It would be hoped that early intervention would help fill the very large gap between Tier 2 (information and referral) and Tier 3 (lifetime support).

## Ch 12 Where should the money come from? Financing the NDIS

This is not our area of expertise as it falls to economists and economic modelling to recommend the most appropriate strategy.

We would agree with the Commission's findings that people with a disability need a financing source that needs to be both sufficient and predictable and cannot be cut as part of changing budget circumstances.

## Ch 13 Workforce issues

Our mode of operation is to employ staff to work together as a team to provide services to small groups of consumers who have similar interests or a desire to participate in similar activities. Most services are provided in the community and aim to achieve planned outcomes for all individuals.

Most staff work for our organization because they what to work as part of a team and as part of a community organisation. They are not interested in working with individuals in their private homes or in services managed and operated by families.

The nature of disability services means that support may be needed at any time of day, which results in less routine working hours. Our support workers are sometimes required to work multiple short jobs during a shift or work during the night in providing respite services.

Training
The old system of "traineeships" for people coming out of school into the TAFE system seemed to produce a better supply of more knowledgeable staff who could be assessed during and employed at the end of their practicum's.
A new system could follow the trades systems of providing traineeships during later school years

In WA, Silver Chain's Disability Health Training Team provide valuable training for staff of agencies and carers in homes in skills of a nursing nature eg medication, mitrofanoff, peg feeding, pressure care, diabetes management, epipen
Traineeships can be available for people working in the sector – low cost easy access

High staff turnover
Our staff turnover rates are relatively low compared to the disability sector and is generally related to the desire to travel or to look for higher wages or the psoibilty of promotion elsewhere in the sector.

We consider the presence of workers who only intend to work in the industry for a relatively short period (such as university students), as a value to the community in educating these professionals where ever they go in future whatever profession in needs of PWD

The supply side
Workers who are immigrants from CALD backgrounds create difficulty in services with consumers from predominantly English speaking backgrounds. There is a large demand on our industry (seen as a place to "practice English skills" and where there is no requirement for background and training and people who are "parents or

carers" can fit in) where no skills are required as a prerequisite, to employ these workers.

### OH&S requirements

There is need for better standards, training and monitoring of services provided in private homes to prevent the "disasters that are waiting to happen when things go wrong". Employment of people who have no training or experience on low wages as family members will eventually lead to more OHS issues for both staff and consumers.

More than one worker may be needed to perform a task because of excessive concerns about safety is a new regular requirement.

There is danger in employing older people where manual handling is required for people who have high support needs and challenging behaviours and increase in risk of injury

### The demand side

The biggest pressures on the disability workforce are due to increasing demand resulting from expansion of disability services.

Attracting more workers to the disability services industry.

Paying higher wages as a strategy to address impending shortages

We believe that an increase in wages will attract new staff to the industry. For instance, those who left the industry because the wages were low might be drawn back if the wages were higher, or it might mean that people do not leave the industry in the first place. Furthermore, an increased wage would make disability services more attractive to young people when choosing between a number of career options.

### Working hours

Working hours in our service is ideally suited to mothers of young children retuning to the workforce after children become more independent and this group are well suited and usually well qualified to provide care for our consumers. They can be provided with much on the job and informal training to assist in equipping them better to work toward better outcomes for individuals.

### Improved recruitment services

Use of a dedicated Disability employment service to attract, screen, train and allocated staff to NFP agencies would be useful.

### Immigration

457 visa wage requirements and conditions make our staff ineligible

Working holiday visas restrict people who could provide a valuable workforce from longer term employment

### Paying family members

Family members as paid carers should have the same requirements as carers employed by agencies eg police checks, training 1st aid etc

Technological aids will make it easier for a broader range of workers to support people with a disability. Lifting aids have become more sophisticated over time, and developments in robotics may offer additional scope to assist with lifting and other tasks

High cost of anything “medical or disability” focused at present limits use of many items

## Ch 14 The costs of the scheme

Again this is not an area on which we can appropriately comment.

VIP notes that while the level of funding under the NDIS would be much better than what is currently experienced there could still be the situation where a client receives adequate funding only to find that they are unable to source an appropriate service provider (such as in accommodation support). Support must be given to the expansion of services which must be appropriate, cost efficient and professional.

## Ch15 and Ch 16 Insurance arrangements for injury and the NIIS

VIP endorses the establishment of a no-fault national injury insurance scheme (NIIS) which would provide fully-funded care and support for all cases of catastrophic injury. We would support the notion that State and Territory governments would be the major driver of this national reform and that it should draw on the best schemes currently operating around Australia. National consistency needs to be achieved.

VIP would stress that the implementation of the NDIS and the NIIS should proceed as separate entities and that delivering the NDIS should not be dependent upon obtaining agreement to proceed with the NIIS.

## Ch 17 Implementation

VIP is concerned that the Draft Report recommends that the pilot scheme for 2014 would only be trialled in one jurisdiction. We would suggest (along with NDS) that three jurisdictions should be chosen (perhaps those with a smaller population) so that differences between and within jurisdictions could be examined. This would provide more information for fine-tuning the National rollout. Given that the current WA model is a leader we would suggest it should be one of the trailed jurisdictions in the pilot scheme.