



**Community Development and Justice Standing Committee**

# Client driven? Or driven to despair?

Inquiry into Accommodation and Intensive Family Support  
Funding for People with Disabilities

Report No. 3  
May 2014

Legislative Assembly  
Parliament of Western Australia

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# **Community Development and Justice Standing Committee**

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## **Client driven? Or driven to despair?**

### **Inquiry into Accommodation and Intensive Family Support Funding for People with Disabilities**

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Report No. 3

Presented by

**Ms M.M. Quirk, MLA**

Laid on the Table of the Legislative Assembly on 8 May 2014



## Chair's Foreword

**T**HE disability sector in Western Australia is in a period of significant transition. In signing up to the National Disability Insurance Scheme, the State Government has given the people of this State reason to hope for a more equitable system of meeting the needs of people with disability. If it delivers what is promised, it will be a most welcome change.

The disability sector has been woefully under-funded by state governments on an ongoing basis, leaving the government agency responsible for supporting people with disability little option but to allocate funds according to urgent and critical need. The Combined Application Process (CAP), the system for allocating funds to house and support those most in need for the past 14 years, has been the subject of this Inquiry.

The Committee has been told that it is a system that is being phased out to make way for newer systems and programs of support. What better time, then, to take a snapshot of how this system has been operating?

The Committee has been given a thorough appraisal of the CAP by its users, disability advocacy groups and disability service providers. They paint a gloomy picture of a system struggling to cope, leaving in its wake a distressed and desperate group of people who are struggling to cope even more. Hence, it will be of great interest to observe whether the picture is brighter after 2020, when the NDIS is forecast to be introduced.

In the meantime, it looks as if the CAP system will continue in some guise (even if the names of the programs within it change) for the next six years. For people in crisis waiting for funding support, that is a long time. They want to see immediate improvements to the system that might make their lives a little more manageable.

There appears to be an unwarranted level of complacency about the current levels of service provision. There was no evidence before the Committee to confirm the assertion that Western Australia is relatively better off than other States. Even if this is the case, it is clear we can do better.

The title of this report reflects that the principal focus of disability services should be the individual needs of the disabled and their families. If this does not occur, as we found in the many case studies set out in this report, then families under stress become despairing and lose hope.

In addition to examining the adequacy of the CAP, this Inquiry has sought to take a measure of the types of people whose needs are currently not being met (and there are many) and has highlighted the areas and issues that should be considered in planning for the future.

In conducting this Inquiry, the Committee was privileged to be able to hear from people who care for family members with a disability. Who better to tell their story, in their own words, than those at the coalface of the CAP process? The Committee was frequently moved by what it heard and is extremely grateful for their bravery in sharing what were often intensely personal stories.

These frank accounts were in stark contrast to the opaque and adversarial approach adopted by the Disability Services Commission. It was somewhat alarming also to learn that some people had chosen not to appear before the Committee because they feared it might jeopardise their chances of funding.

I would like to acknowledge the contributions of my fellow Committee members in the conduct of this Inquiry: Mr Ian Britza, MLA (Deputy Chair), Dr Tony Buti, MLA, Mr Chris Hatton, MLA and Mr Mick Murray, MLA. I also thank the Principal Research Officer, Dr Sarah Palmer, previous Principal Research Officer, Ms Dawn Dickinson and Research Officer, Ms Niamh Corbett, for their diligent and professional support of the Committee's work.

On behalf of the Committee I would like to acknowledge all the contributions to this Inquiry. Various disability sector organisations went to great lengths to canvass their members in order to accurately capture and present the views of people with disability, their families/carers and service providers. The assistance of Developmental Disability WA in facilitating a forum so that the Committee could hear these views first hand is also greatly appreciated. Finally, our special thanks go to people with disability and their families and/or carers who, often under difficult circumstances, found time and courage to share their personal experiences.



MS M.M. QUIRK, MLA  
CHAIR

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## Executive Summary

**T**HE decision to conduct an Inquiry into provision of funding for accommodation and intensive family support services (provided by the Disability Services Commission (DSC)) was driven by concern that the process for allocating funding (the Combined Application Process) was stressful for applicants and that many people in need were missing out.

While the Combined Application Process (CAP) will be phased out if and when the National Disability Insurance Scheme (NDIS) is rolled out in 2019-20, at present it is the primary method of accessing higher level funding for disability accommodation and family support. It was therefore considered an appropriate time to assess the adequacy of the CAP, creating a benchmark for comparison with future disability funding models.

Inquiring into the CAP would also provide an indication of needs that are not currently being well-served by the system. Given reports of a high level of unmet need, the Inquiry also set itself the task of outlining the nature and extent of planning required to meet increasing demand for disability support services.

Following a brief introduction (Chapter 1), this report provides an overview of disability funding in WA (Chapter 2), followed by three chapters presenting the Committee's findings in relation to: the adequacy of current processes for determining funding support (Chapter 3); the level and type of unmet need (Chapter 4); and planning required to meet future demand (Chapter 5). An overview of the content of these chapters follows.

**Chapter 2** outlines the current status of disability funding in WA. The majority of the Disability Services Commission's budget (85%) is directed to individual funding, which is used to allocate funds to individuals through a variety of accommodation and family support programs. The accommodation and family support programs which deliver the greatest amount of funding are Accommodation Support (AS) and Intensive Family Support (IFS) – two of three programs which can be applied for using the CAP. (The third, Alternatives to Employment, is outside the scope of this Inquiry.)

AS can be used to fund accommodation in group homes, individual homes or the family home. IFS funds typically provide for a support worker to assist in the home. The number of people who receive new AS or IFS funding is determined by the amount of money allocated to the DSC for growth funding by the State Government, which is never enough. In the most recent CAP round, there were 679 applications for AS and IFS with only 68 awarded funds.

Reforms are being made to the disability sector at both the national and state level. WA became part of the national reforms when it signed up to a two-year trial of the

NDIS in August 2013. The NDIS trial will begin in the Perth Hills on July 1, alongside a trial of the State's My Way model in the Lower South-West.

State-wide reforms include the transition to a person-centred approach, whereby a person with disability is assessed on the basis of "reasonable and necessary supports" and an appropriate level of funding is determined (not unlike NDIS). According to the DSC's Individualised Funding Policy, program boundaries will be dissolved, meaning funds can be used across a range of support programs. The DSC asserts that it has been actively promoting alternative forms of funding, rather than relying so heavily on CAP, but knowledge of other funding among clients was inconsistent.

Apparently in line with the philosophy of providing greater consumer choice, the DSC has begun transitioning the bulk of its accommodation services to the non-government sector. The DSC has also been reforming its procurement practices in line with State Government policy. This has meant a greater emphasis on outcomes, resulting in considerable readjustment on the part of service providers who need to be able to demonstrate how they can achieve the required outcomes.

**Chapter 3** begins by explaining how the CAP works. An applicant must be deemed to have a disability according to DSC guidelines to be eligible to apply. After completing the application form (either online or hard copy), the applicant submits it to the DSC and it is assessed with hundreds of others in that particular CAP round by the Independent Priority Assessment Panel (IPAP), which scores the applications and prioritises them according to critical and urgent need. If unsuccessful, the application is automatically submitted to the next round.

Evidence collected by the Committee shows that applicants experience difficulty with each stage of the process, which was described overall as intrusive, distressing, onerous, stressful and demeaning. The CAP application form was felt to be too long and to disadvantage people with poor English literacy skills. Competition for funds was so great that applicants felt they must focus on the most negative aspects of their lives to demonstrate that they were in greater need than other families.

The manner in which applicants were told that they were unsuccessful (a standardised letter) was described as callous and there was insufficient detail about the reason for the outcome. Complaints also persisted about a lack of transparency on the part of DSC with regard to the IPAP composition, the assessment criteria, and statistics related to the outcome of each round. The fact that each CAP round is a discrete process, with the potential for a person to be ranked lower in subsequent rounds rather than moving up the list, made it impossible for people to plan. Applicants had no idea of how long it may be until they received funding.

Complaints were also made that some Local Area Coordinators (LACs), employed by the DSC to help people with disabilities in their area access support and services, were not well trained and were biased. It was argued that the high attrition rate meant they did not understand a family's situation well enough to provide useful help with CAP applications.

There are a number of negative consequences of the CAP process, chief among them that intense competition for limited funds can result in families taking extreme measures, such as threatening suicide. There is often a negative impact on family health and wellbeing, not only from the stress of completing the application but as a result of lack of support. Carers with insufficient external support often had to give up paid work, which had ramifications for their mental health. They also experienced shame and guilt if they were not able to cope.

The Committee concluded that lack of transparency in regard to the system of assessment leads to conjecture as applicants try to work out why their application was not successful but someone else's was. It also impacted on trust in the DSC generally.

As a consequence of the procurement reforms, there is evidence to suggest that some disability support organisations are charging more for their services, which means that an individual's CAP funding does not go as far as it used to. The IPAP noted that an increase in "changed need" applications (i.e. requests for top-up funding) may have been as a result of the new service agreements.

**Chapter 4** explores the level of unmet need for people with disability in WA, beginning with an acknowledgement of the difficulty of measurement. There is general consensus that there is insufficient available data to accurately determine the number of people who require disability support. In addition, some suggest that what data there is is deliberately not shared and should be made public.

The number of unsuccessful CAP applications is not regarded as an accurate measure of unmet need, partly because there are people in need who have never bothered to apply for CAP (because of its reputation for being difficult to attain), and partly due to the group of people who have given up applying but are still in need.

Ageing carers who have looked after a person with disability (unsupported) for many years represent a hidden need which is expected to increase. As people with disabilities are living longer, increasingly parents who were caring for them will become too old to do so. An increase in the number of people diagnosed with Autism Spectrum Disorders (ASD) is also predicted, with even more families expected to struggle to find appropriate support than at present.

The number of people in Aboriginal and culturally and linguistically diverse communities with disability is also thought to be under-estimated, since the disability sector does not engage well with these groups.

The CAP system also does not cater well for changed need. People who have been funded but whose needs have changed (as is often the case with degenerative conditions) are often over-looked, representing another type of unmet need.

The Committee heard that younger people with disability are still being inappropriately housed in aged care facilities because of a lack of purpose-built 24-hour accommodation suited to younger people. News of State Government funding to tackle this issue over the next three years (starting in 2014-15) has been welcomed. People with acquired brain injuries or catastrophic injuries were also often stuck in institutional care or were blocking beds in hospitals because there was nowhere else to go and/or no chance of securing CAP funding. People with degenerative and genetic diseases, such as Young Onset Parkinson's Disease, were also often accommodated in aged care facilities because there was no other suitable accommodation.

Some areas of unmet need can only be addressed in cooperation with sectors outside disability services. Housing is one example. While a State Government-funded social housing project in partnership with the Department of Housing is expected to provide housing for 340 people registered with DSC, it is uncertain whether this program will continue beyond 2014. A shared approach with the Mental Health Commission is also required to address considerable unmet demand in mental health services for people with disability. It is hoped that the Mental Health Services Plan, due for completion mid-2014, will address this need.

**Chapter 5** considers the planning required to meet future demand for disability support services, including planning for an NDIS and/or the My Way model. The DSC acknowledges that the NDIS and My Way trials will exert pressure on DSC resources, but is confident that areas outside the trial areas will not suffer as a result. Non-government service providers would be assessed to ensure that they met the required standards.

Both My Way and NDIS are based on individualised planning processes. Ensuring that plans truly reflect the needs of the individual takes time and this should be factored into future planning, according to one organisation. There is currently some concern over the planning process being managed by an individual coordinator, with service providers claiming that a team approach (from service providers who know the clients well) is preferable. Training would be required for both service providers and service users to ensure that they are able to manage the planning process and the employer-employee relationship.

The disability sector is concerned that growth funding between now and the introduction of the NDIS is maintained, since there are many people who cannot wait until 2020 for help. There are also some other misgivings in relation to the NDIS and My Way, one of which is the emphasis on “natural supports” – family, friends, neighbours, organisations – which must be seen to be fully exploited before funding is considered. If this is expected, greater support for these informal networks will be needed, according to disability sector organisations. Greater investment in early intervention strategies, which would reduce demand for higher level support in the future, would also be required. The system of self-nominating for support was seen as inappropriate for people with cognitive disabilities who typically lacked initiative.

The NDIS and My Way trials will be evaluated by an independent consultant appointed by the DSC. The DSC has undertaken to keep the supervision and administration of the evaluation separate from its operational activities related to the My Way trial. The DSC can be assured that the sector will be watching closely to ensure that this occurs.

There is concern from some in the sector about the future of the DSC’s Sector Development Plan, designed to identify current and future demand across the State and areas for development. The DSC is still finalising the plan (which was due for completion in 2013), but the focus seems to have been readjusted to short-term requirements.

Concern about future staffing capacity has been fuelled by recent cuts to government services and the claim that wages and conditions in the private sector will not attract the experienced retrenched public sector workers. Not-for-profit providers are said to be struggling to meet the demand for services and there was concern that this would continue.

Future planning should also take into account the need for greater consumer choice in type of accommodation. At present, people wanting to live in a group home have little choice with regard to who they live with. People with disability also have other cultural and lifestyle preferences which should be accommodated.

Finally, the introduction of a no-fault injury insurance scheme would take pressure off the CAP and, into the future, would complement the NDIS. The State Government has yet to commit to a National Injury Insurance Scheme and is being urged to do so by disability sector groups.



## **Ministerial Response**

In accordance with Standing Order 277(1) of the Standing Orders of the Legislative Assembly, the Community Development and Justice Standing Committee directs that the Parliamentary Secretary representing the Minister for Disability Services reports to the Assembly as to the action, if any, proposed to be taken by the Government with respect to the recommendations of the Committee.



## Findings and Recommendations

### Finding 1

Page 11

The director general of the Disability Services Commission presented evidence that was inconsistent with the majority of service providers, advocacy groups and clients.

### Finding 2

Page 29

Completing the Combined Application Process application form is difficult, time-consuming and stressful.

### Finding 3

Page 29

The format and requirements of the Combined Application Process application form disadvantages applicants with poor English literacy skills and those with less ability to articulate their needs.

### Recommendation 1

Page 29

The format of the Combined Application Process application form should be reassessed for any possible reductions in length and for improvements to accessibility.

### Recommendation 2

Page 29

Alternative methods of submitting information for the Combined Application Process application should be implemented.

### Finding 4

Page 33

Combined Application Process applicants are overwhelmingly dissatisfied with the outcome letter and feedback following a funding round, regarding it as callous and lacking in detail.

### Recommendation 3

Page 34

The Disability Services Commission should revise the method by which news of an unsuccessful funding application is conveyed, to ensure: a) applicants have a better understanding of how the decision was reached; and b) it is delivered in a timely and compassionate manner.

### Finding 5

Page 39

The lack of a waiting list for people who apply for Combined Application Process funding makes it impossible for people to plan how they will care for themselves/their disabled family member.

**Recommendation 4** **Page 39**

The Disability Services Commission should explore options for weighting applications according to how long people have been waiting and the age of the carer.

**Recommendation 5** **Page 39**

That the Disability Services Commission considers implementing a maximum waiting period for Combined Application Process applicants.

**Recommendation 6** **Page 39**

Consideration be given to establishing a separate pool of funding for urgent, extreme cases, independent of Combined Application Process funding, thereby facilitating the establishment of a waiting list for all other cases.

**Finding 6** **Page 45**

The release of more information would not hamper the operation of the Independent Priority Assessment Panel, subject to the provision of additional administrative resources.

**Finding 7** **Page 45**

The lack of availability of the Combined Application Process assessment criteria is at the heart of applicants' dissatisfaction with the system.

**Finding 8** **Page 45**

There is a lack of transparency surrounding the operation of the Combined Application Process and a lack of publicly accessible information about the outcome of each Combined Application Process round.

**Recommendation 7** **Page 45**

The Combined Application Process application assessment criteria should be made available to applicants.

**Finding 9** **Page 52**

While many Local Area Coordinators act as an effective conduit between families and the Disability Services Commission, feedback from submissions and evidence suggests some lack training and communication skills.

**Finding 10** **Page 52**

The high attrition rate of Local Area Coordinators means that many do not get to know a family sufficiently well to provide quality advice and support.

<b>Recommendation 8</b>	<b>Page 52</b>
Close attention should be paid to the inadequacies of the Local Area Coordinator model, given that a similar model of individual coordination will be used for NDIS/My Way.	
<b>Recommendation 9</b>	<b>Page 53</b>
Any evaluations of the Combined Application Process and the Risk Assessment Framework commissioned by the Disability Services Commission should be made available to the public.	
<b>Finding 11</b>	<b>Page 55</b>
Because only the most critical and urgent cases are funded, Combined Application Process applicants feel compelled to emphasise the negative aspects of their lives, and in some cases to exaggerate.	
<b>Finding 12</b>	<b>Page 57</b>
The continual stress of applying for Combined Application Process funding has an adverse impact on the health and wellbeing of carers, who may also end up needing support.	
<b>Finding 13</b>	<b>Page 60</b>
A lack of factual information about how the Combined Application Process works and how decisions are made leads to dissatisfaction with the system.	
<b>Finding 14</b>	<b>Page 62</b>
Procurement reforms may be putting more pressure on funding for people with disabilities.	
<b>Finding 15</b>	<b>Page 66</b>
Major deficiencies in collection and sharing of data in relation to the unmet need of people with disability in WA make it impossible to plan future services.	
<b>Recommendation 10</b>	<b>Page 66</b>
That in order to better inform public debate and service provision, the Disability Services Commission augments and makes publicly available, in a variety of formats, its data and analysis relating to the levels and types of unmet need after each Combined Application Process funding round.	
<b>Finding 16</b>	<b>Page 67</b>
People who give up on applying for Combined Application Process funding are lost from the system and mask the true nature of unmet need.	

**Finding 17****Page 70**

There is a significant cohort of people with disability unknown to the system because they have never applied for disability support funding.

**Finding 18****Page 72**

The changing needs of people with disability throughout their lives is not sufficiently recognised or catered for, resulting in an under-estimation of the number of people in need.

**Finding 19****Page 78**

The highly inappropriate accommodation of younger people with disabilities in aged care facilities is still occurring.

**Recommendation 11****Page 78**

While the Committee supports the funding commitment for housing for younger people currently in aged care facilities, further initiatives in this area of unmet need should be encouraged. Securing positive, long term outcomes to divert adolescents and young adults from aged-care residential facilities should be made a priority.

**Finding 20****Page 80**

The Disability Services Commission currently supports only about half of all people in WA known to have acquired brain injuries, representing a large unmet need.

**Recommendation 12****Page 90**

That the Minister for Disability Services ensures that adequate training is provided to ensure disability service providers and disability service users are equipped to negotiate and manage the terms of individual plans and employment relationships.

**Recommendation 13****Page 92**

The level of growth funding for disability support must be maintained at the current level (including indexation) or increased in the intervening years from now until the introduction of a national disability insurance scheme.

**Finding 21****Page 95**

The Committee is concerned that genuine comparison of the WA NDIS and My Way trials with those of the NDIS trials in other States may be compromised due to the evaluations being conducted by different bodies.

**Recommendation 14****Page 95**

That the Minister for Disability Services ensures that evaluations of the NDIS and My Way trials are independent and compatible.

**Recommendation 15****Page 97**

That the Minister for Disability Services ensures that contract arrangements for disability services contain a commitment that wages and conditions for disability care workers in the non-government sector are at least equal to those of disability care workers in the government sector.

**Finding 22****Page 100**

There is a lack of accommodation to appropriately meet the cultural and lifestyle preferences of people with disability.

**Recommendation 16****Page 100**

That the Disability Services Commission's quality management framework focuses on providing accommodation services appropriate to gender, age, cultural and lifestyle values.

**Recommendation 17****Page 100**

That the Disability Services Commission and Department of Housing provide a greater variety of accommodation options for people with disability, such as cluster living arrangements.

**Recommendation 18****Page 102**

That the State Government expedites a timetable for the adoption and implementation of the National Injury Insurance Scheme.



# Chapter 1

## Introduction

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**The rationale for conducting an inquiry into support funding for people with disability.**

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*With the possibility of a six year time-frame before the NDIS is fully implemented (and even if then), we need to maintain concern and vigilance on behalf of those people who are still waiting. - CASA*

The disability sector in Western Australia is entering a period of significant change. State Government systems for delivering support and services to people with disability are undergoing a process of gradual reform, including transition of the majority of services to the non-government sector, and an emphasis on self-directed support and individualised funding. At the same time, the State is preparing to participate in an Australia-wide trial of the proposed National Disability Insurance Scheme (NDIS) alongside a trial of the similar state-based scheme, My Way.

What will this mean for people with disability and their families and carers – and in particular, for those seeking funding for support to live at home or in other accommodation? People seeking funding for this kind of support are required to apply to the Disability Services Commission (DSC). The DSC is the State Government agency responsible for providing direct services and supports to people with disability and their families and carers, as well as funding non-government agencies to provide services.

Since 2000, the DSC has allocated larger sums of money (typically around \$80,000 per year but sometimes up to \$150,000 per year) through a system known as the Combined Application Process (CAP). The funding might provide suitable supported accommodation (such as in a purpose-built group home with 24-hour care) or support for families in the home (such as the provision of a care worker several days a week). The CAP is used as a single application point for Accommodation Support (AS) funding, Intensive Family Support (IFS) funding and Alternatives to Employment funding.

While the CAP system is expected to be phased out with the introduction of an insurance-based scheme, this is not likely to be until 2019-20 when it is forecast the NDIS will be rolled out nationally.

## Chapter 1

### 1.1 The need for an Inquiry

For the moment, CAP funding continues to be an important source of funding for people with disability. Therefore, the Committee was concerned by a number of issues highlighted publicly in relation to the CAP, including but not limited to:

- Anecdotal evidence that people have applied repeatedly for CAP funding without success.<sup>1</sup>
- Uncertainty about funding criteria and the perception that applicants must embellish their applications to have a better chance of success.<sup>2</sup>
- Lack of transparency regarding the process.<sup>3</sup>
- Insufficient funds, which means that many people with disability miss out even though they urgently need support.<sup>4</sup>

The Committee was keen to investigate these concerns in detail and construct a more complete picture of the current disability funding environment. The Committee's findings would act as a benchmark against which future systems could be compared, enabling some assessment of the impact of the NDIS or My Way. It would also provide an indication of any gaps in the current system which may assist in planning future disability services. Who is currently not being well-served by the system? What should be taken into consideration when planning an equitable system?

It was on this basis that the Committee resolved to inquire into not only the adequacy of current processes for determining accommodation and intensive family support funding, but also the level of unmet need and planning required to ensure future needs are met.

In the final stages of this Inquiry, the *Disability Services Amendment Bill 2014* was being debated in the Legislative Assembly. The primary purpose of the Bill was to make changes to the *Disability Services Act 1993* to allow for the commencement of the WA trials of My Way and the NDIS. While the Inquiry had not been concluded at this point, there is no doubt that the insights gained by Committee members during the Inquiry were able to inform the debate.

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1 Mr R.H. Cook MLA, Western Australia, Legislative Assembly, *Parliamentary Debates* (Hansard), 8 August 2012, pp4635-4656.

2 *ibid.*

3 Hon A. Xamon MLC, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 18 October 2012, pp7206-7219.

4 Hon S. Ellery MLC, and Hon H. Morton MLC (Minister for Disability Services), Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 18 October 2012, pp7206-7219.

## **1.2 Notification of Inquiry**

In accordance with its functions and powers (refer to Appendix One) the Committee determined for itself terms of reference for this Inquiry (see Appendix Two) and notified its intention to undertake the Inquiry to the Speaker of the Legislative Assembly on 13 November 2013. The Committee chose to limit its terms of reference to the investigation of Accommodation Support and Intensive Family Support funding as a means of focusing the inquiry on the two streams of CAP funding with most bearing on people with disabilities living with their families (i.e. funding relevant to living arrangements and family wellbeing).

A public call for submissions occurred in late November 2013 resulting in the receipt of 21 submissions (refer to Appendix Three). The Committee conducted nine public hearings and one closed hearing to collect evidence for the Inquiry, with the majority of hearings taking place in February and March 2014 (refer to Appendix Four). The Committee appreciated those that made submissions or gave evidence. There were, however, concerns that some felt constrained to give evidence, fearing that this might prejudice the success of their funding applications.



## Chapter 2

# Overview of disability funding in Western Australia

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**A description of the nature of disability in Western Australia, the system of determining high level funding for people with disability, and the reforms currently underway within the sector.**

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*Of the 679 applications made to the Disability Services Commission for Accommodation Support and Intensive Family Support in the latest CAP funding round, only 68 were granted.*

Approximately 1 in 5 people in Australia (4.2 million individuals) had a disability in 2012, according to Australian Bureau of Statistics figures.<sup>5</sup> This number is anticipated to increase to around 1 in 4 people in 15 years' time, mostly as a result of people developing disabilities after 65 years of age.<sup>6</sup> The proportion of people in Western Australia with "severe and profound" disability under the age of 65 is currently estimated at 3.1 per cent (or close to 70,000 individuals based on the population of WA at the time of the 2011 Census).<sup>7</sup>

The *Disability Services Act 1993* defines disability as being attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment (or a combination of those impairments) which is permanent or likely to be permanent and may be chronic or episodic, and which results in the significantly reduced capacity of the person for communication, social interaction, learning or mobility; and a need for continuing support services.<sup>8</sup>

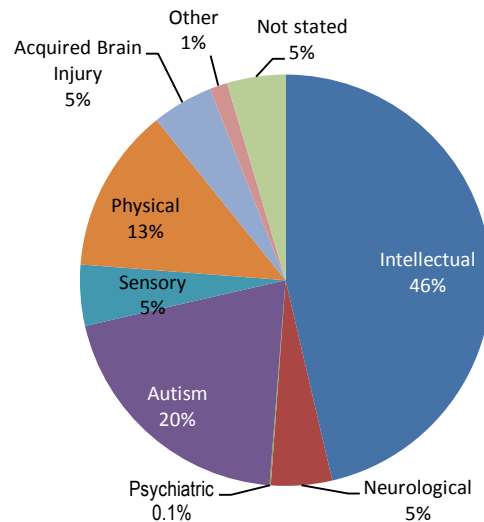
In Western Australia people with intellectual disability comprise almost half (46%) of all disability service users (see *Figure 2.1*). People with autism comprise the next biggest group (20%), followed by people with physical disability (13%).

Support for people with disability can come from a variety of sources including family members, peers, carers, community-based organisations and government and non-

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- 5 SCRGSP (Steering Committee for the Review of Government Service Provision), *Report on Government Services 2014*, Productivity Commission, Canberra, 2014, p14.10.
  - 6 Disability Services Commission, *Count Me In – a better future for everyone*, State Government of Western Australia, Perth, December 2013, p5.
  - 7 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p6. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.
  - 8 Section 3 *Disability Services Act 1993* (Western Australia).

## Chapter 2

government agencies. DSC offers supported living assistance to assist people with disability to live in their homes and communities, and this is delivered in the form of individual funding.<sup>9</sup> It must be stressed that this funding is insufficient, as this report will detail.



**Figure 2.1 Primary disability of people accessing disability supports in Western Australia 2012-13<sup>10</sup>**

As its name suggests, individual funding is allocated directly to an individual who can use the funding for any combination of support and services identified in the person's individual plan.<sup>11</sup> An individual plan is a document that describes the life a person would like to lead and what will be required to help them achieve this.<sup>12</sup>

Once allocated, funds might be paid to an organisation which manages the service with the input of the individual and his or her family/carer (organisation managed) or paid to an organisation where the individual and his or her family/carer choose the level of involvement (shared management).<sup>13</sup> The majority of DSC funding is allocated to individual funding, comprising 85 per cent of the DSC budget for services and supports.<sup>14</sup>

9 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, pp8, 13. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

10 Data sourced from Disability Services Commission, *Annual Report 2012-13*, Government of Western Australia, Perth, 2013, p56.

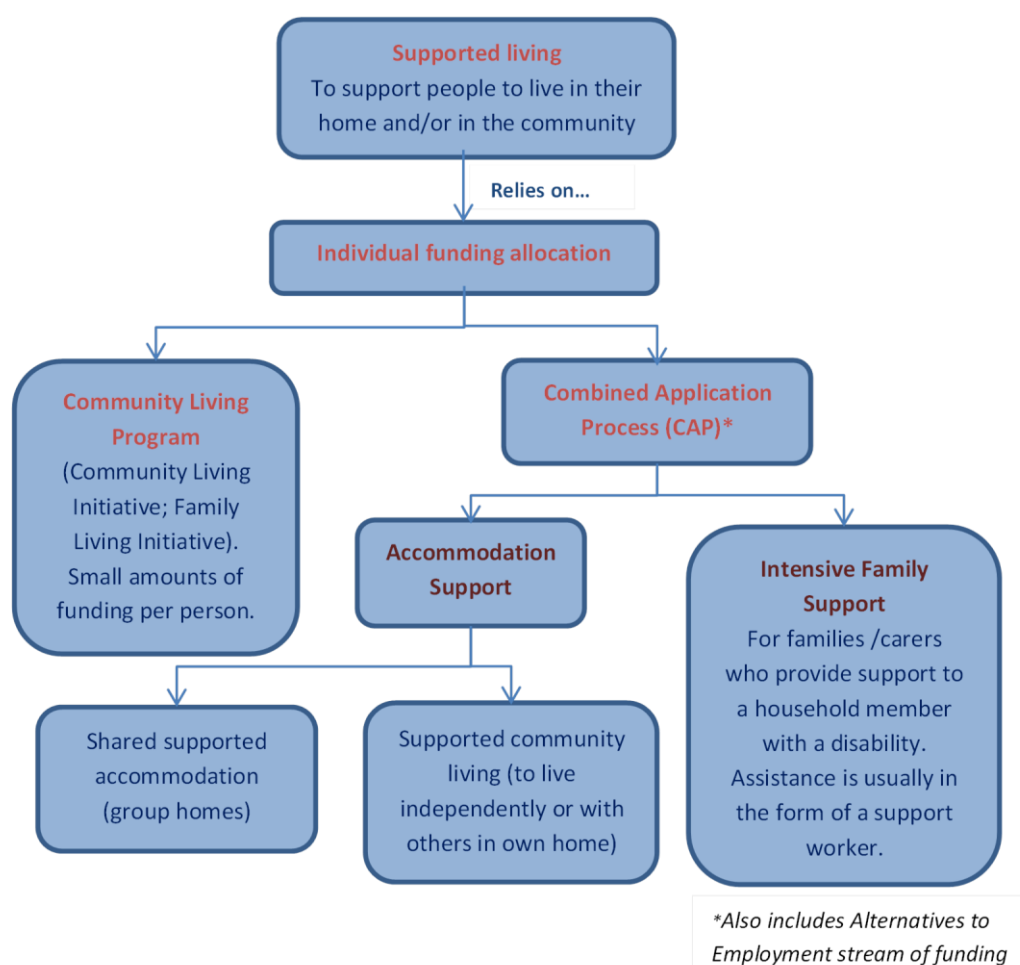
11 Submission No. 13 from Disability Services Commission, 2 January 2014, p1.

12 Disability Services Commission, *Individualised Funding Policy*, 12 August 2013, p4.

13 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, Western Australia, November 2012, p75.

14 Submission No. 13 from Disability Services Commission, 2 January 2014, p2.

DSC accommodation assistance delivered through individual funding includes Accommodation Support funding and the Community Living Program. Services and supports to assist families can also be individually funded through means such as the Family Living Initiative or Intensive Family Support (see Figure 2.2).



**Figure 2.2 Disability Services Commission supported living assistance and component programs<sup>15</sup>**

The AS and IFS funding streams allocated through the CAP have the capacity to provide a higher level of support than other programs. Young people are the major recipients

<sup>15</sup> Information sourced from Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p9. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

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of AS and IFS. In 2012-13 close to 34% of people funded for AS were 15-19 years old and close to 70% funded for IFS were school aged (5-19 years old).<sup>16</sup>

### ***Accommodation Support (AS) funding***

This is made available to people with a disability living in a number of accommodation situations, including shared care, individual arrangements and individualised accommodation options where the person lives in their family's home and support costs exceed \$30,000 per annum. Funding will cover:

- the provision of supports to individuals to carry out essential activities of daily living (for example personal care) which may vary from a few hours a week of support to 24 hours a day;
- some limited and specific (one-off) set-up funding for the accommodation option including certain furnishings.<sup>17</sup>

### ***Intensive Family Support (IFS) funding***

This type of funding recognises the additional costs of living with a disability (without subsuming the ordinary daily living costs borne by all families) and is intended to provide flexible assistance to families/carers responsible for supporting a household member with a disability. Funding may cover assistance with:

- personal care
- home help
- holiday supports
- family support
- certain one-off initiatives that are part of an integrated support strategy.

IFS can be discontinued in a number of situations, for instance if the household member with a disability receives AS funding.<sup>18</sup>

In the most recent CAP funding round (October 2013 to January 2014), the DSC received 679 applications for AS and IFS funding. Of these, only 68 people were funded. The number of new people allocated funding through CAP each year from 2009-10 to

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16 Disability Services Commission, *Disability Support Funding Bulletin Issue 2*, September 2013, pp1-5.

17 Disability Services Commission, *Accommodation Support Funding Parameters Policy*, Government of Western Australia, October 2001, pp1-9.

18 Disability Services Commission, *Intensive Family Support Guidelines*, Government of Western Australia, May 2009, pp1-6.

2012-13 is shown at Table 2.1. Numbers of people who received CAP funding for the first time in 2012-13 for AS and IFS are shown at Figure 2.3.

The number of people who receive new funding or top-up funding each year is determined by the amount of money allocated to the DSC as growth funding. This is provided by the State Government to meet expected increases in demand for services and is targeted at people who are not yet receiving funded services or who require additional services. In the 2013-14 State budget, DSC received \$32.5 million in growth funding. This is nearly \$9 million more than was allocated in 2012-13, but nearly \$8 million less than in 2011-12 (*see Table 2.1*). The DSC said that the decrease in growth funding of around \$17 million between 2011-12 and 2012-13 was to be expected, given that it followed a period of “unprecedented growth”.<sup>19</sup> (Note that the funding almost doubled between 2009-10 and 2011-12). However, demand and cost of service provision was also significant, reducing the impact of any increase in funding. (*See Chapter 3, section 3.2.7, Funding*).

**Table 2.1 Funding available for allocation through CAP\* and numbers of people who received support from 2009-10 to 2012-13<sup>20</sup>**

	2009-10	2010-11	2011-12	2012-13
Total new CAP funding allocated (in millions)	\$21.1	\$32.2	\$40.3	\$23.6
Total number of <i>new</i> people receiving funding through CAP	287	362	430	262
Total number of people receiving <i>additional funding</i> through CAP for increased supports	35	96	88	32
Total number of people receiving funding through CAP	322	458	518	294

\* Note: These figures include Alternatives to Employment as well as AS and IFS.

Of the people who received individual funding in 2012-13, 12.5 per cent accessed the funding through CAP.<sup>21</sup> That 12.5 per cent of people accounted for 66.3 per cent of the funding allocated, reflecting the large support packages made available to CAP applicants (and in particular those in the AS stream). Of the growth funding received in 2013-14, 38 per cent was allocated to accommodation support and 11 per cent was

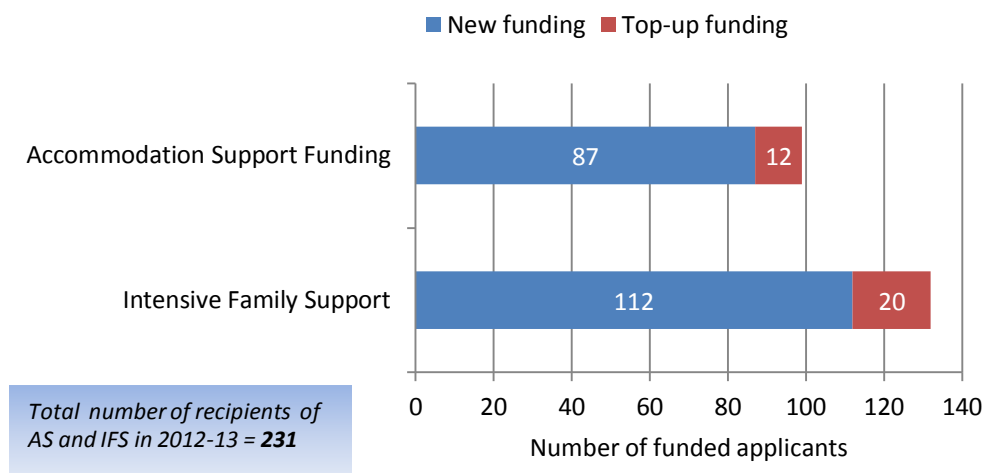
19 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – Response to questions on notice taken at hearing, 19 March 2014.

20 Disability Services Commission, *Disability Support Funding Bulletin Issue 2*, September 2013, p5.

21 11.5% accessed funding through the Community Living Program (CLP) and Family Living Initiative (FLI), and the majority (76%) accessed funding through the Local Area Resource and Post School Options allocations.

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allocated to family support services.<sup>22</sup> While a larger proportion of DSC funds are directed towards providing AS, a greater number of people receive IFS than AS. Put another way, AS funding provides a smaller number of people with larger sums of money, while IFS funding provides a larger number of people with smaller sums of money.



**Figure 2.3 Allocations of Accommodation Support and Intensive Family Support funding 2012-13<sup>23</sup>**

Until this year, there have been three CAP funding rounds per year with most unsuccessful applications (around two-thirds)<sup>24</sup> carrying over to the next round. As shown in Table 2.2, the IPAP assessed 414 applications, and there were another 265 which had been assessed previously. Nearly two-thirds (65%) of the applications were for AS. Of the 68 applications funded, half were for AS and half for IFS.

According to DSC, 60 per cent of applicants who are unsuccessful are able to access funding for alternative services (see Appendix Seven) while waiting for subsequent CAP funding rounds.<sup>25</sup> According to the DSC, the average waiting period between an initial CAP application and funding being received is two years.<sup>26</sup> However, evidence

22 Disability Services Commission, *Budget Bulletin 2013-14*, 2013. Available at: [www.disability.wa.gov.au/Global/Publications/About%20the%20Commission/corporate%20publications/Budget-Bulletin-2013-2014.pdf](http://www.disability.wa.gov.au/Global/Publications/About%20the%20Commission/corporate%20publications/Budget-Bulletin-2013-2014.pdf) Accessed on 24 October 2013.

23 Data sourced from Disability Services Commission, *Disability Support Funding Bulletin Issue 2*, September 2013, pp1-5.

24 Disability Services Commission, *Disability Support Funding Bulletin Issue 2*, September 2013, p4.

25 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p4.

26 *ibid.*

submitted to the Committee indicates that applicants may wait five or six years and even up to nine years.<sup>27</sup>

**Table 2.2 Numbers of applications and people who received support in CAP Round 2, 2013-14.**<sup>28</sup>

Funding stream	Resubmitted/ reapplied	New	Total applications	Assessed by IPAP	Assessed previously – no changes	Funded
Accommodation Support	365	73	<b>438</b>	237	201	<b>34</b>
Intensive Family Support	183	58	<b>241</b>	177	64	<b>34</b>
<b>TOTAL</b>	<b>548</b>	<b>131</b>	<b>679</b>	<b>414</b>	<b>265</b>	<b>68</b>

While the DSC maintains that applicants are informed about alternative sources of funding and services, knowledge in the disability community about these alternatives was patchy.<sup>29</sup> The Committee was perturbed that the evidence provided by the director general of the DSC in regard to alternative sources of funding and other matters relevant to the Inquiry was almost always at odds with the evidence provided by service providers, advocacy groups and clients.

### Finding 1

The director general of the Disability Services Commission presented evidence that was inconsistent with the majority of service providers, advocacy groups and clients.

## 2.1 Disability sector reforms

### 2.1.1 National reform

In 2011 the Commonwealth Government released the Productivity Commission report into a long-term disability care and support scheme. Subsequently the Council of Australian Governments (COAG) agreed in 2012 to proceed with the launch of a National Disability Insurance Scheme (NDIS). The NDIS is an entitlement-based funding

27 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p9; Submission No. 2 from Mr Paul Smale, 4 December 2013, p1.

28 Data sourced from *Combined Application Process Report from the Independent Priority Assessment Panel, 2nd Round 2013-14 (October –January 2014)*, 20 December 2013, presented to the Board of the Disability Services Commission, 7 February 2014. Supplied to CDJSC in correspondence from Ms Mary McHugh, Manager, Strategic and Executive Services, Disability Services Commission, 4 April 2014.

29 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p11; Parents/carers of people with disability, *Briefing*, 10 March 2014.

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mechanism which will provide individually tailored supports based on a uniform assessment process. It is intended to give certainty of funding based on need. In March 2013, the *NDIS Act 2013* (Commonwealth) was passed and an independent statutory agency known as the National Disability Insurance Agency (NDIA) was established to implement the NDIS.<sup>30</sup>

In August 2013, then Prime Minister Kevin Rudd and WA Premier Colin Barnett signed an agreement for disability reform in WA comprising a two-year trial to commence on 1 July 2014. The WA designed and managed My Way model, which is yet to be fully implemented, will be trialled alongside the NDIS model to allow genuine comparison of the merits of each. My Way is similar to the NDIS in that it adopts an individually tailored approach to supporting people with disabilities, but differs from the national scheme in relation to how the planning process is conducted and how services are actually delivered.

My Way has already been introduced in four locations in WA: Goldfields, Cockburn/Kwinana, Perth Hills and the Lower South-West. Participation is voluntary and people with disability are able to continue to receive the existing State services if they choose to. In March 2014, the DSC reported that of the potential 1979 participants (people already known to the DSC) across the four areas, 1798 (approximately 90%) had chosen to participate.<sup>31</sup>

From July 2014, one of the My Way launch sites (Perth Hills) will become an NDIS trial site. Two other My Way sites (Lower South-West and Cockburn/Kwinana) will become trial sites for the comparative assessment with the NDIS scheme.

**Table 2.3 My Way and NDIS trial schedule**

Location	Type of trial	Start of trial
Lower South-West	My Way	July 2014
Cockburn/Kwinana	My Way	July 2015
Perth Hills - Mundaring and Kalamunda shires	NDIS	July 2014
Perth Hills - City of Swan	NDIS	July 2015

The sites have been selected on the basis of having eligible populations of roughly the same size, which will enable genuine comparison. The combined eligible population of Cockburn/Kwinana and the Lower South West (4100) is around the same as Perth Hills (4300). People with disability within the trial sites will be assessed for eligibility in accordance with the *NDIS Act 2013* in order to receive funding for reasonable and necessary supports and services based on their individual needs. Approximately 8000

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30 National Disability Insurance Scheme, *Our history*, 2013. Available at: [www.ndis.gov.au/about-us/our-history](http://www.ndis.gov.au/about-us/our-history). Accessed on 6 January 2014.

31 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – Response to questions on notice taken at hearing, 19 March 2014.

people are estimated to be eligible. People with disability outside the trial sites will continue to receive services and supports under the existing state disability service system.<sup>32</sup>

The State and Commonwealth governments will provide additional funding to facilitate the trial sites. Ordinarily the Commonwealth provides about 20 per cent of WA's disability funding, with 80 per cent funded by the State. Under agreements reached between the former Prime Minister and the Premier in August 2013 and the current Prime Minister and the Premier on 31 March 2014, the Commonwealth will increase its funding to 40 per cent for the duration of the trials.<sup>33</sup>

## 2.1.2 State reform

### Individualised funding and services

The DSC's system for allocating funding is in transition, reflecting an over-arching move towards individualised funding and services and "person-centred" approaches. The DSC's "intended future mechanism" for allocating funds to eligible individuals will be according to the My Way model: each person with a disability will have an assessment of "reasonable and necessary supports" and an appropriate level of funding will be determined.<sup>34</sup>

This is in line with the DSC's Individualised Funding Policy,<sup>35</sup> issued in August 2013, which sets out the principles of Individual Funding and describes how a person may use funds provided by the Commission. The policy document is acknowledged as a work-in-progress,<sup>36</sup> and the DSC acknowledges that it cannot be fully implemented until My Way (or NDIS) is phased in and CAP is phased out.<sup>37</sup>

The policy has had some impact on the CAP programs, however. Previously, a person applied specifically for AS or IFS through CAP, and, if successful, received a fixed

32 Information drawn from Disability Services Commission, *Disability Reform in Western Australia Fact Sheet*, 19 August 2013 and Disability Services Commission, *WA and the National Disability Insurance Scheme Fact Sheet*, 5 August 2013.

33 Agreement between the Commonwealth and the Western Australian Governments for disability reform in Western Australia. Available from Disability Services Commission website: <http://www.disability.wa.gov.au/Global/Publications/For%20disability%20service%20providers/CEO%20Round%20Table/Agreement%20between%20the%20Commonwealth%20and%20the%20Western%20Australian%20Governments%20for%20disability%20reform%20in%20Western%20Australia.pdf>. Accessed on 2 May 2014.  
Schedule G: Bilateral Agreement for NDIS trial between the Commonwealth and Western Australia. Available from Disability Services Commission website: <http://www.disability.wa.gov.au/Global/Publications/WA%20NDIS%20My%20Way/Bilateral-Agreement-for-NDIS-trial-between-the-Commonwealth-and-Western-Australia.pdf>. Accessed on 2 May 2014.

34 Submission No. 13 from Disability Services Commission, 2 January 2014, p6.

35 *ibid*, Attachment A.

36 *ibid*, Attachment A, p5.

37 *ibid*, p6.

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amount of money which could only be used for AS (if that's what they had applied for) or IFS (if that's what they had applied for). Now, according to the Individual Funding Policy, CAP funding can be used across several programs. According to the DSC, the AS and IFS "no longer exist as programs"<sup>38</sup> – however at the time of this Inquiry the programs still existed for the purposes of allocating funds and reporting to Treasury. At the time that this report was being finalised, the DSC website was still also presenting information about the CAP.

As acknowledged in its submission, the DSC uses the CAP "to determine the level of support for the majority of Western Australians seeking individual funding"<sup>39</sup> and:

*The panel (IPAP) considers applications within program categories. While the expenditure of funding by individuals is not restricted to particular categories, its allocation, for federal reporting reasons, remains tied to Accommodation Support, Intensive Family Support and Alternatives to Employment. The panel will prioritise applications within these allocation categories.*<sup>40</sup>

From evidence presented to the Committee there is no doubt that individuals still conceptualise CAP in terms of AS or IFS and apply on this basis, even if they have the opportunity to use some of the funding for the other service types (e.g. use some of their AS funding for IFS services). There also seemed to be little awareness that the program boundaries had been relaxed. This may change in the coming years as the DSC presses ahead with the move to individualised funding (whereby money is allocated for use across a range of programs according to needs).

Already, the number of CAP rounds per financial year has been reduced from three to two as a result of the DSC supporting "alternative ways through which people can be allocated funding".<sup>41</sup> The DSC's rationale for reducing CAP rounds by a third was that there were supposedly more avenues available for people to access funding, such as Family Living Initiative, Community Living Initiative and My Way. The DSC also said that growth in Post School Options funding had also seen fewer 16 to 25-year-olds applying for CAP. Two rounds also meant a saving in administrative costs.<sup>42</sup>

### **Transition to non-government sector**

In tandem with the paradigm shift towards more self-directed support and individualised funding, there is a growing emphasis on service provision by the non-

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38 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p2.

39 Submission No. 13 from Disability Services Commission, 2 January 2014, p2.

40 *ibid*, pp2-3.

41 Ms Mary McHugh, Disability Services Commission, Letter – Answers to questions on notice from hearing, 4 April 2014.

42 *ibid*.

government sector. This is expected to provide a broad range of service providers that people can choose from, as required by the NDIS.<sup>43</sup>

The move to non-government sector service provision will occur in WA over the next few years as the State Government transitions approximately 60 per cent of DSC-provided disability accommodation services to non-government organisations.<sup>44</sup> The number of accommodation places offered by DSC will decrease over time and non-government providers will assume a greater responsibility. The aim is for DSC to maintain its places for people requiring temporary, transitional support or those with particularly complex needs.<sup>45</sup>

The DSC predicts that the cost to the DSC of supporting people in the non-government sector will be more in some cases and less in others. Dr Chalmers asserted that the objective was for families to decide what support option they wanted. In some cases the person with disability may elect to stay in their current group home, and all that would change would be the service provider. Others may take the opportunity to take up different support options.<sup>46</sup> There was no evidence before the Committee to verify whether the objective of allowing families to decide was being met.

While the State Government maintains that the transition of services to the non-government sector is in preparation for the NDIS, others have questioned the rationale for the shift, suggesting that it is not a requirement of the NDIS and that it may in fact be a cost-cutting measure.<sup>47</sup>

### Procurement reforms

The DSC has also been required to bring its procurement practices into line with the State Government's *Delivering Community Services in Partnership Policy*, implemented in 2011 to "build and support a more mature funding and contracting relationship" between the public and not-for-profit sectors.<sup>48</sup> According to the Department of Finance, one of several ways of achieving this is by "focusing on the achievement of outcomes and improving services and support for vulnerable and disadvantaged Western Australians".<sup>49</sup> According to the DSC, an outcomes-based approach "will

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43 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p11.

44 *ibid*, p1.

45 Hon Helen Morton MLC, (Minister for Disability Services), *Restructure is a step towards NDIS*, Media Statement, Perth, 11 October 2013.

46 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p11.

47 Mr Dave Kelly, Western Australia, Legislative Assembly, *Parliamentary Debates* (Hansard), 3 April 2014, p2114b.

48 Department of Finance, *Delivering Community Services in Partnership Policy*. Available at: [www.finance.wa.gov.au/cms/content.aspx?id=12662](http://www.finance.wa.gov.au/cms/content.aspx?id=12662). Accessed on 4 April 2014.

49 *ibid*.

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provide people with disability more choice and flexibility” in the way they purchase services and supports.<sup>50</sup>

National Disability Services WA (NDS WA), which represents non-government disability service providers, says that a “key challenge for services will be to respond with innovative and person-centred service responses designed to achieve those outcomes”.<sup>51</sup> Individual funding would require a tailored approach to the implementation of the new policy and procurement processes. NDS WA has been providing guidance to the sector on outcomes based contracting and individualised planning, in partnership with WA Individualised Services (WAIS).

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50 Disability Services Commission, *Procurement Reform*. Available at: [www.disability.wa.gov.au/reform1/reform/procurement-reform/](http://www.disability.wa.gov.au/reform1/reform/procurement-reform/). Accessed on 24 April 2014.

51 National Disability Services WA, *WA Disability Sector Procurement Reform*. Available at: [www.nds.org.au/projects/article/129](http://www.nds.org.au/projects/article/129). Accessed on 4 April 2014.

## Chapter 3

### The adequacy of current processes for determining funding support

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A description of how the Combined Application Process works, and an overview of the significant issues experienced by people using the process.

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*I think DSC has been seduced by CAP – it looks good; it sounds good; it looks sophisticated; it is clean and tidy; it uses fancy rating scales and it does the job; it produces a clear list of who to fund and who not to fund. I know [the Commission] is full of extremely committed people, lots of noble principles and it does a lot of very good work, but I think they have got it wrong when it comes to CAP. - Sue Harris*

#### 3.1 About the Combined Application Process

##### 3.1.1 Eligibility for funding

To be eligible for DSC funding, individuals must meet the general established criteria set out in the DSC Eligibility Policy. This details definitions of disability and impairment, specific eligibility considerations, how to request a service, specific service access considerations, and the priority indicators used. The policy refers to Disability Services Standard One which details that “each consumer seeking a service has access to services based on relative need and available resources”. As demand for supports exceeds resources available, in accordance with Disability Services Standard One, program access is provided on the basis of relative need and availability of resources.<sup>52</sup>

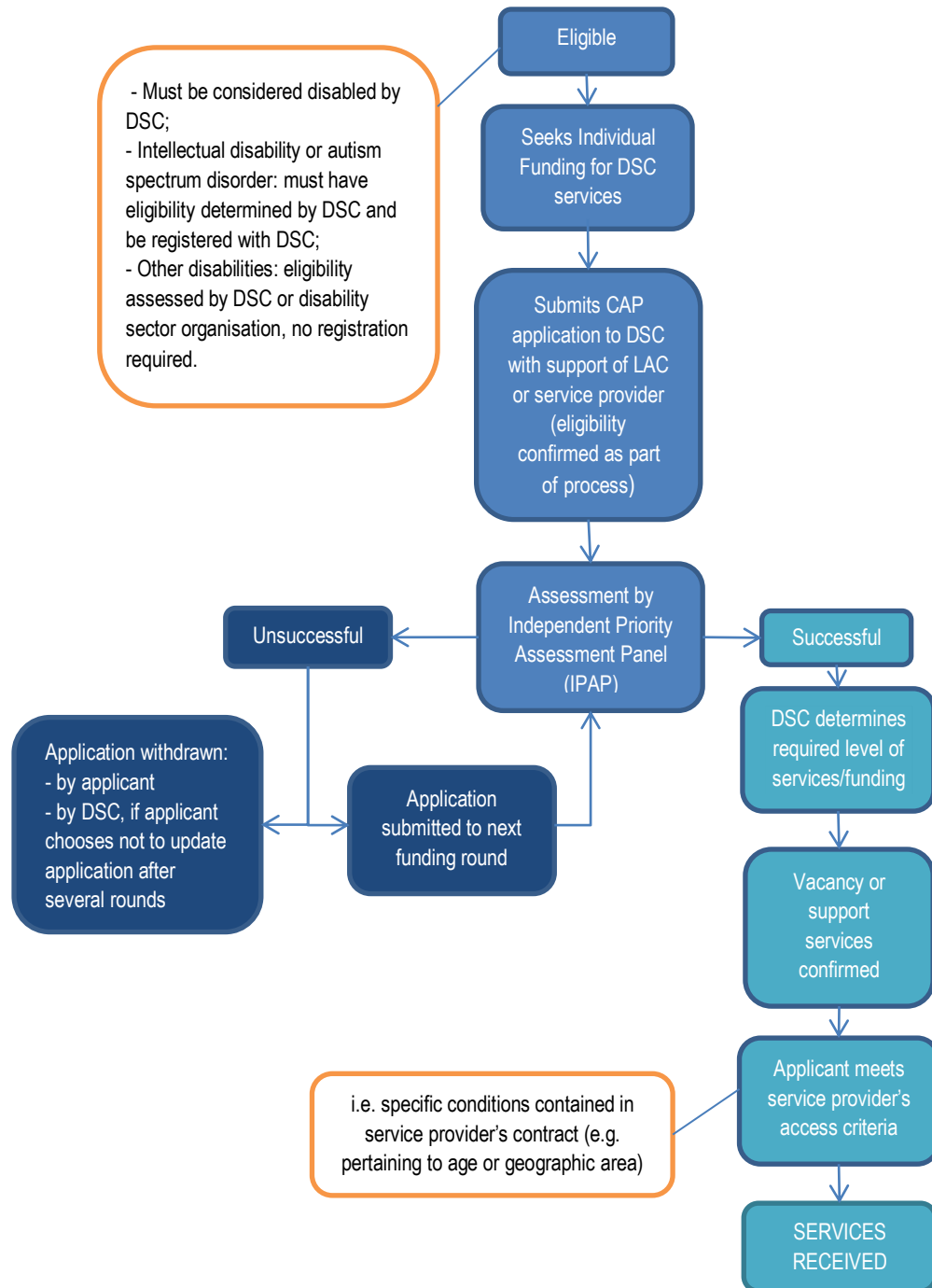
If eligible, access to Accommodation Support (AS) and Intensive Family Support (IFS) must be sought through the CAP. Under the parameters of the CAP, funding will only be allocated to individuals who can make use of it within the coming 12 months. Only permanent Australian residents with a severe or profound disability (where the disability manifests before age 65) can apply.<sup>53</sup> The process for seeking AS or IFS funding is represented by the flow diagram at Figure 3.1.

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52 Disability Services Commission, *Guidelines – Eligibility Policy for Specialist Disability Services funded or provided by the Disability Services Commission* (January 2012), Government of Western Australia, pp1-34.

53 Disability Services Commission, *Combined Application Process* (brochure), May 2013. Available at: [www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/](http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/)

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**Figure 3.1 Process for seeking DSC funding for disability Accommodation Support or Intensive Family Support.<sup>54</sup>**

<sup>54</sup> Information sourced from Disability Services Commission website and *Combined Application Process* (brochure). Available at [Funding/combined\\_application\\_process\\_brochure\\_-\\_english\\_\(id\\_372\\_ver\\_2.0.0\).pdf](#) Accessed on 24 October 2013.

### 3.1.2 The Independent Priority Assessment Panel

CAP applications for accommodation and intensive family support are assessed by the Independent Priority Assessment Panel (IPAP) twice a year (formerly three times a year). The IPAP, established by and managed by the DSC, is tasked with identifying applicants who are in most need of support relative to others in the same funding round.<sup>55</sup>

In 2010-11 DSC used a tender process to set up a panel contract for the IPAP in order to establish a “pool” of eight to twelve members, from which four would be selected for each funding round. Members sit on the panel on a rotational basis to ensure a consistent approach while sharing the overall workload. For each funding round, the five-member panel consists of a senior DSC officer plus:

- A person with a disability;
- A family member of a person with a disability;
- A representative of a non-government disability sector organisation; and
- A representative of a peak body (disability advocacy organisation).<sup>56</sup>

IPAP members are selected on the basis of their representation of one of these four key sector groups. Specific knowledge (e.g. an understanding of disability services and some analytical ability) and specific personal characteristics are also essential criteria for selection to the panel.<sup>57</sup>

The panel contract was established for a term of two years with three options to extend, each for the duration of one year.<sup>58</sup> Hence, members can remain on the panel for up to five years, however most stay two to three years.<sup>59</sup> According to Dr Chalmers, due to the sensitive nature of assessing individual applications and a desire to discourage lobbying of panel members, the identities of panel members are not publicly disclosed.<sup>60</sup>

The panel has an independent chairperson who does not assess the applications but oversees the process, ensuring consistency across panel members’ assessments and

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55 Disability Services Commission, *Request for Tender: Establishment of an Independent Priority Assessment Panel for the Disability Services Commission*, Government of Western Australia, Perth, 2010, p3.

56 *ibid*, pp3,9.

57 Submission No.13 from Disability Services Commission, 2 January 2014, Appendix B, p1.

58 Disability Services Commission, *Request for Tender: Establishment of an Independent Priority Assessment Panel for the Disability Services Commission*, Government of Western Australia, Perth, 2010, pp3,9.

59 Prof. Sherry Saggars, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p2.

60 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p19.

## Chapter 3

moderating deliberations about the merits of individual applications.<sup>61</sup> The chairperson briefs the DSC board and provides it with a report on the outcomes of each CAP round. The chairperson also acts as the public face of the IPAP and represents the panel at information sessions or workshops.

There does not appear to be any limit on the chair's tenure. The current chair, Professor Sherry Saggars, has been in the role for 10 years and has never been approached about her tenure.<sup>62</sup> An anthropologist who has worked in teaching and research for more than 40 years, Professor Saggars describes herself as having some general background knowledge about the disability sector, as well as some personal experience as the grandmother of a child with autism.<sup>63</sup> DSC director general Dr Ron Chalmers said the DSC had been happy to have Professor Saggars chairing the panel for a decade because she was "incredibly well respected and qualified in the social services area". Having been part of it for so long, she knew the process very well.<sup>64</sup> Despite Professor Saggars being an independent chair, the Committee noted that she was accompanied by a DSC staff member when she appeared before the Committee.

### 3.1.3 Assessment of applications for CAP funding

An application form for the CAP must be completed and submitted by the person with disability and/or their carer/family member. The form comprises a detailed 27-page questionnaire with the option of attaching further supporting information. In some cases the form might be completed with the assistance of a Local Area Coordinator (LAC) and/or a disability service provider. Some witnesses were aware that the application needed to be approved by an LAC prior to submission,<sup>65</sup> but others said that it was not a requirement to have the form "signed off" by an LAC although it was recommended.<sup>66</sup> Once the application is lodged and confirmed to be complete, it is presented to the IPAP for assessment.<sup>67</sup>

After each CAP round, the IPAP convenes to agree on a priority list for each funding stream within the CAP. Before the meeting, panel members individually review and score all applications (usually more than 300) using a computerised tool. Panel

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61 Disability Services Commission, *Combined Application Process Application Form*, nd, p5. Available at: [www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/cap%20application%20form%202012%20-%20final.pdf](http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/cap%20application%20form%202012%20-%20final.pdf) Accessed on 21 January 2014.

62 Prof. Sherry Saggars, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p10.

63 *ibid*, p1.

64 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, pp19-20.

65 Parents/carers of people with disability, *Briefing*, 10 March 2014.

66 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p10.

67 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, Western Australia, November 2012, p76.

members do not know what rating is attached to the scores. Panel members' scores are averaged to produce a provisional priority list for each funding stream. This process takes six to eight weeks.

The panel agrees on a final priority list by adjusting scores if necessary following group consideration. Once priority lists have been finalised, available funding is considered and allocated to individuals in priority order.<sup>68</sup> Although the panel reports funding recommendations to the director general and the board of the DSC for approval, the current director general has never over-turned any decisions made by the panel.<sup>69</sup> At the conclusion of the process, an outcome letter is sent to all applicants.

The Risk Assessment Framework used by the panel to score CAP applications takes into account risk factors including "living arrangements, support needs, harm and behaviour and impact on family and the applicability, consequence, likelihood, and timing of each risk to the individual".<sup>70</sup> Inexplicably, the criteria are unknown to the applicants. The applicant's environment and existing support network(s) are also taken into account in the assessment process.<sup>71</sup>

According to the DSC, applicants for CAP funding who are found to have the greatest need relative to other applicants in that round will be funded in priority order to the extent of the funding<sup>72</sup> that is available. The DSC describes this process as prioritising on the basis of critical and urgent need.<sup>73</sup> Each funding round is a discrete process and a priority rating assigned to an individual in one funding round may differ to the rating applied in subsequent rounds, given that there may be new applicants who are deemed to have a more critical and urgent need.<sup>74</sup>

Where applicants are unsuccessful, applications are automatically included in the next CAP round. Applicants have the opportunity to update information if required. The DSC states that applications will only be removed from the CAP process after "several unsuccessful attempts" and if there has been no change to the application, but individuals would always be given an opportunity to provide an update before this occurred.<sup>75</sup>

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68 Submission No. 13 from Disability Services Commission, 2 January 2014, pp2-3.

69 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p19.

70 Dr Ron Chalmers, Director General, Disability Services Commission, Letter, 23 December 2013.

71 Submission No. 13 from Disability Services Commission, 2 January 2014, Appendix B, p1.

72 This is the "growth funding" which is allocated to the DSC by the State Government.

73 Submission No. 13 from Disability Services Commission, 2 January 2014, p2.

74 *ibid.*

75 *ibid*, pp2-3.

## Chapter 3

The Commission operates under a *Fair Level of Funding Policy* which limits the maximum funding that can be accessed by any one individual.<sup>76</sup> As such, where the CAP application is successful, the maximum level of funding is calculated using the DSC tool known as the Estimate of Requirement for Staff Support Instrument (ERSSI).<sup>77</sup> An “options exploration process” is also initiated for recipients of AS or ISF of more than \$80,000 per year, whereby a DSC officer visits the person with disability and their carer/family to discuss funding parameters and assist in crafting an appropriate support service.<sup>78</sup>

### 3.2 The adequacy of the Combined Application Process

A degree of confusion surrounds the process of applying for funding for AS or IFS from the client perspective. The DSC asserts that these two funding programs no longer exist (as described in Chapter 2). However, the current system still requires applicants seeking a high level of funding for accommodation and at-home support services to apply through CAP. This entails completing the CAP application form.

Once the application is assessed by the IPAP, applicants are advised of the outcome in a standard letter from the DSC. If unsuccessful, the process begins again (*see Figure 3.1*). The application is automatically included in the next round unless it is withdrawn by the applicant or unless the application has not changed for some years.

People who have been through the process of finding out about how to apply for CAP funding, completing the application form, waiting for news of an outcome, receiving the news and, more often than not, resubmitting an application describe the process as complex,<sup>79</sup> secretive,<sup>80</sup> intrusive and confronting,<sup>81</sup> damaging, distressing and humiliating,<sup>82</sup> and onerous, stressful and demeaning.<sup>83</sup> Former CEO of Developmental Disability WA, Sue Harris, says “the process leaves people feeling hopeless, shattered, demoralised and helpless”.<sup>84</sup>

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76 Disability Services Commission, *Combined Application Process* (brochure), May 2013. Available at: [www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/combined\\_application\\_process\\_brochure\\_-\\_english\\_\(id\\_372\\_ver\\_2.0.0\).pdf](http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/combined_application_process_brochure_-_english_(id_372_ver_2.0.0).pdf) Accessed on 24 October 2013.

77 See also glossary at Appendix Five.

78 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, Western Australia, November 2012, pp77-78.

79 Submission No. 8 from Kalparrin, 20 December 2013, p1.

80 Submission No. 11 from CASA, 23 December 2013, p4.

81 Submission No. 21, closed submission, 3 February 2014, p4.

82 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p2.

83 Submission No. 2 from Mr Paul Smale, 4 December 2013, p1.

84 Submission No. 15 from Ms Sue Harris, 15 January 2014, p3.

## Case Study 1

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*We were running a conference in Fremantle and a lady who was having chemotherapy for the Xth time and had very limited time to live, said to us "What am I going to do?" She had an adult son with a severe disability, who simply could not look after himself and her husband was not able to look after him. "What am I going to do?" she said.*

*We spied the head of DSC at the conference, and said to her, "There is the person in charge, go and speak to her and make your case." When she went up, which she did, which was very brave for someone to do, especially in her condition, she was told, by her first name, "Hello, yes, I know your situation, all the best with the panel, it is meeting in two weeks."*

*To me, that just highlights the inhumanity of this process; you just cannot do that. With anybody in that sort of crisis, just fund them. If you run out of money, you run out of money; plead your case. But there is nothing justifiable in making those people wait to go through a formal process.<sup>85</sup>*

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### 3.2.1 Deciding to apply

While some families are new to the process of seeking support, others are long-term CAP applicants hoping their needs will finally be considered critical enough to receive funding. CAP applicants may have become aware of CAP as a funding option through their own investigations, through peers or perhaps by a service provider or LAC. However, a number of people and organisations reported that CAP was not promoted by their LAC or if they were told about it they were advised not to apply because they would not be successful,<sup>86</sup> or to apply for less funding than they actually required.<sup>87</sup>

### 3.2.2 Completing the CAP application

Applicants describe completing the CAP form as time-consuming, distressing and intrusive. The application form asks for details about the person with the disability and their family/carers, the nature of the disability, the supports currently in place, what everyday life is like, the type of disability support being sought, and what avenues of support have already been explored.

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<sup>85</sup> Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p2.

<sup>86</sup> Submission No. 6 from CPSU/CSA, 19 December 2013, p5; Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p3; Submission No. 21, closed submission, 3 February 2014, p4.

<sup>87</sup> Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p3.

### Chapter 3

The questions are presented in the first-person perspective, indicating the form is designed to be completed by the person with the disability. However, the DSC allows a parent, carer, service provider or LAC to assist the person or complete the form on the person's behalf. Since many of the questions on the form are quite complex and many of the applicants have an intellectual or cognitive disability, more often than not the form is completed by someone else on their behalf. This makes the first-person format awkward to work with:

*(My son) cannot read, so am I supposed to speak with his voice or am I supposed to speak in the third person when I make an application? It discounts the reality that a substantial proportion of these applicants have an intellectual disability.<sup>88</sup>*

CASA suggests separate application forms for people who can complete the form on their own behalf and for those who cannot.<sup>89</sup>

The form assumes a high level of literacy, including computer literacy. It is designed to be downloaded from the DSC website and completed electronically. Instructions on the form state that it "may not be as easy to complete in paper form"<sup>90</sup> and that applicants should ask their LAC or disability sector organisation for assistance.

Applicants need to work through 46 questions, some with more than one part and some requiring lengthy responses. For example:

*4. How does your primary disability affect your life? Please describe below.*

*11. If you have family and friends, do they support you on a regular basis?*

*If yes, please describe what family and friends you have in your life and how they support you.*

While the DSC acknowledges that the form is lengthy, it says it has been "trimmed down" over the years and notes that it is "less onerous" than the proposed NDIS application and assessment.<sup>91</sup> This is unlikely to offer much comfort to the time-poor applicants (generally parents) who must complete the application in between the demands of caring for disabled and other family members. Whilst acknowledging the

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88 Ms Deirdre Croft, *Transcript of Evidence*, 26 February, 2014, p7-8.

89 Submission No. 11 from CASA, 23 December 2013, p5.

90 *CAP Application Form*, 2013, p4. Available from: [www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/CAP%20Application%20Form%202013.pdf](http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/CAP%20Application%20Form%202013.pdf)

91 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p7.

reduction in length, The Centre for Cerebral Palsy (TCCP) says that the current application form is still considered too long by service users.

*The Centre strongly recommends that the length and format of the application form be made more user-friendly with the contents of the form rigorously evaluated to determine whether all the information is truly required.<sup>92</sup>*

## Case Study 2

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*The last 6 years have been such a struggle for us. We haven't had any funding or support from anywhere.*

*I looked at one of the mums in our group's IFS application, it was over 50 pages long! I don't write well like her, I don't know when I'd get the time to write all that, with a 6 year old autistic son and a 3 year old toddler and a new baby too. I hardly get any sleep, and getting through the day between all the nappies, breastfeeding, making finger foods, tantrums, and meltdowns and trying to cook dinner for us is impossible.*

*How can I get 10 minutes to start writing it, and it looks like it would take me forever to fill it all in. I'd love some help from a carer or support worker, maybe to take my little boy out while I look after the little ones, or have a sleep sometimes when they do, but I'm too worn out and too busy to even try. Isn't life hard enough already without making us do all this work.<sup>93</sup>*

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Evidence presented to the Committee suggests that some people are deterred from applying for CAP because of the application form's reputation for being time-consuming and stressful to complete:

*I can't even read or write the application because I'm either busy with the kids or worn out. I asked the LAC if they could help me write it ... but mine said that wasn't their job and it had to be written from my side of the story.<sup>94</sup>*

*The application form is complex, confronting and stressful to complete by families who are already under extreme duress.<sup>95</sup>*

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92 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p2.

93 Submission No. 21, closed submission, 3 February 2014, p10.

94 *ibid*, p11.

95 Submission No. 8 from Kalparrin, 20 December 2013, p1.

## Chapter 3

One parent said that despite her tertiary qualifications and experience in professional report and application writing, she found completing the form an “extremely difficult process” which took nearly three months, writing in “fits and starts”.<sup>96</sup>

### Case Study 3

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*I didn't have any funding for Patrick until he was 21. Because he "only" had Asperger Syndrome, Patrick wasn't eligible to join the Autism Association, but joined when he was 16. He was made eligible to join DSC in 2010. Patrick now receives Family Living Initiative funding from DSC. I used it for wages and costs of Patrick having a support worker to accompany him to TAFE and for respite for Patrick to go on short breaks with a support worker. This means he can go on holiday with a young guy (usually a uni student), and access the community like other guys his age. However, he cannot move out of home. The only options available to him are Community Living Plan and CAP funding. We recently applied for CAP but were knocked back. This is an extremely competitive process. Families are vying against each other for a limited amount of funding. The stress of writing these applications is enormous.*<sup>97</sup>

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If the process is difficult for applicants with a high level of literacy, one can only imagine the challenges for those with poor literacy skills. Articulate applicants or applicants with access to assistance from people with good writing skills were seen to have an advantage.

*This process provides an advantage to those who can articulate their case powerfully through writing. Those with lesser writing ability or whose first language is not English are unfairly disadvantaged.*<sup>98</sup>

Many individuals and organisations indicated that there was a general belief among applicants that a successful application hinged on the use of particular expressions and language. PWDWA executive director Andrew Jefferson said it was necessary

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<sup>96</sup> Submission No. 21, closed submission, 3 February 2014, p4.

<sup>97</sup> Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p2.

<sup>98</sup> Submission No. 6 from CPSU/CSA, 19 December 2013, p9.

when talking to professionals within the disability sector to use their “jargon”, the “language that they use”.<sup>99</sup>

*It requires a certain amount of skill and experience to make an application to the panel as wording in the application has to be congruent with what the panel are seeking .... my experience has been that unless you have an experienced LAC or someone who is very well versed in applying, then the application will not be considered as a strong document and consequently overlooked for a better detailed and rigorous application.*<sup>100</sup>

*We are going for Accommodation Support funding in this coming round, and I had people come out to see me and say, “This is the word we need to use, not this word” because they know the buzzwords; they know this is what is going to get them across the line. What happens to really socially disadvantaged people who can barely string a few words together, as many people with an intellectual disability come from disadvantaged backgrounds? They do not know how to play this game.*<sup>101</sup>

This was seen as one of the drawbacks of applications being accepted only in written form. Images, video footage, DVDs and observational visits are not accepted as part of an application.

*That applications for support are assessed solely on the basis of a written application form further disadvantages people (including parent carers) who are not skilled at presenting their case in writing.*<sup>102</sup>

Current CAP applications are assessed solely on the basis of a written form.... Substantial cognitive impairments are a well-recognised outcome in individuals with ABI.<sup>103</sup> These individuals have significant difficulties with attention and concentration, memory and executive functioning skills – all elements required to complete an extensive written application.<sup>104</sup> However, according to the IPAP chair allowing the inclusion of anything other than written material would be inequitable, given that it

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99 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p4.

100 Submission No. 4, closed submission, 9 December 2014, p2.

101 Ms Deirdre Croft, *Transcript of Evidence*, 26 February, 2014, p6.

102 Submission No. 11 from CASA, 23 December 2013, p6.

103 Acquired Brain Injury.

104 Submission No. 18 from Headwest, 28 January 2014, p6.

### Chapter 3

was not possible to ensure everyone had equal access to alternative forms of evidence.<sup>105</sup> Such a position is out of step with WA's policy on substantive equality. The Policy Framework for Substantive Equality, introduced by the Equal Opportunity Commission (WA) in 2005, recognises that the "one size fits all" model is not a suitable approach for public service delivery.<sup>106</sup> Government departments are encouraged to undertake needs and assessment impacts in order to identify specific systemic discrimination issues.<sup>107</sup> The CPSU/CSA recommended that current and future application process models be subjected to such an assessment.<sup>108</sup>

In addition to the practical and intellectual challenges posed by completing the application, applicants reported experiencing significant emotional distress, partly because the application required them to relate deeply personal information.

*I found this an extremely difficult process to complete... I .... had to sit down at the computer late each night and bare our family's most awful moments, challenging times, social isolation, marital stressors, mental health diagnoses and treatment, while I was exhausted and depressed... We found the process very intrusive and confronting, having to tell an unknown panel of people about our marital strain and challenges.<sup>109</sup>*

*The process requires people to outline, in writing, and in graphic detail, to strangers and to 'government', their deeply personal difficulties and inability to cope. They have to stress and elaborate on their failures, shortcomings and abnormalities, and those of their children...<sup>110</sup>*

*Families have expressed that they have to 'bare their souls', explain the depths of their despair ... share intimate family details in the application and demonstrate their failure as a family unit...<sup>111</sup>*

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105 Prof. Sherry Siggers, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p6.

106 Equal Opportunity Commission, *Substantive Equality CEO Update 2012*, report prepared by Substantive Equality Unit, Equal Opportunity Commission WA, January 2012, p3. Available from: [http://www.eoc.wa.gov.au/Libraries/Substantive\\_equality/CEO\\_Summary\\_guide\\_2012.sflb.ashx](http://www.eoc.wa.gov.au/Libraries/Substantive_equality/CEO_Summary_guide_2012.sflb.ashx). Accessed on 5 May 2014.

107 *ibid.*, p4.

108 Submission No. 6 from CPSU/CSA, 19 December 2013, p9.

109 Submission No. 21, closed submission, 3 February 2014, p4.

110 Submission No. 15 from Ms Sue Harris, 15 January 2014, p3.

111 Submission No. 16 from National Disability Services WA, 17 January 2014, p5.

Given the acute difficulties posed by the CAP application form, the Committee will observe with interest any future application forms or methods of applying for funding.

**Finding 2**

Completing the Combined Application Process application form is difficult, time-consuming and stressful.

**Finding 3**

The format and requirements of the Combined Application Process application form disadvantages applicants with poor English literacy skills and those with less ability to articulate their needs.

**Recommendation 1**

The format of the Combined Application Process application form should be reassessed for any possible reductions in length and for improvements to accessibility.

**Recommendation 2**

Alternative methods of submitting information for the Combined Application Process application should be implemented.

**3.2.3 The emphasis on crisis**

The common knowledge that CAP application assessments are based on critical and urgent need has led to applicants feeling that they have to present their circumstances in the worst possible light. While applicants are generally unsure of how the applications are scored, there is a general perception that the more desperate the case, the more likely it is to succeed. As an LAC quoted in the CPSU/CSA submission observed, “you have to be dying, threatening suicide or are homeless and destitute before you will be approved”.<sup>112</sup>

It is unclear how many people are genuinely in crisis when they apply for CAP. The DSC director general believes that “a significant number” of the 75 per cent of people who are not funded through CAP are not in critical and urgent need. In answers to questions on notice provided to the Committee, DSC manager Mary McHugh described the number of applicants who were not deemed to be in immediate critical or urgent need as “a proportion” of all applicants. Dr Chalmers said the DSC had “good advice” that some people on the list were saying “Well, maybe I do not need it now, but I’ll just put

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112 Submission No. 6 from CPSU/CSA, 19 December 2013, p4.

### Chapter 3

my name on there and we'll just see if I get lucky down the track.”<sup>113</sup> This may be a reflection of applicants' lack of certainty with the process.

Some organisations corroborate this view, saying that some people apply early fearing that the process will take years, and preferring to apply before they reach crisis point.<sup>114</sup> (See section 3.2.5 for further discussion.) However, this is a strategy destined to fail. The limited pool of funding means that only those currently in crisis or desperate need are considered and planning to avert a future crisis is a luxury which cannot be accommodated. Hence, it took the hospitalisation of one applicant before the appointed LAC suggested applying through CAP,<sup>115</sup> and the marital collapse of another, whose six previous applications had warned of the demise of the marriage if no help was forthcoming.<sup>116</sup>

Headwest chief executive officer Lee-Anne Brensell, whose organisation represents people with acquired brain injuries, was in no doubt that the people within her sphere of contact were genuinely in need:

*I am sure everyone else has said this: everyone who applies through that process is in crisis. It is critical and it is urgent. No-one is just hanging out thinking that they should apply because they are ready to go and have done some great planning in the hope that in 10 years' time they will be successful. They apply because they need it—and they need it now. If the son of one of the families I would love for you to hear from is not in the most critical of need, God I do not know who is and who will get it above him.*<sup>117</sup>

According to one parent, in an effort to convince the panel of their need, parents tried to “write about the worst day in the child's life and their most negative behaviour traits so that they can present a worst case scenario”, which was contrary to what they tried to do as carers and parents – that is, to focus on the positives.<sup>118</sup>

The strategy appears to be widespread. National Disability Services WA reported that the service providers it represents in WA<sup>119</sup> had indicated that both they (the providers) and the individuals they supported felt it was necessary “to focus on a ‘worst case

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113 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p5.

114 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p2; Ms Norelle Morris, Chief Executive Officer, Valued Independent People, *Transcript of Evidence*, 12 March 2014, p4.

115 Submission No. 21, closed submission, 3 February 2014.

116 Submission No. 10 from Ms Neeva Stephen, 22 December 2013, p1.

117 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p5.

118 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p2.

119 NDS WA has 77 members.

scenario' as a strategy to have their application stand out from the many others".<sup>120</sup> Carers WA reported similarly that its members had stated that they needed to "drop the bundle" to demonstrate the level of support required.<sup>121</sup> Developmental Disability WA's comments are almost identical to those of NDS WA and Carers WA.<sup>122</sup>

#### Case Study 4

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*Late in 2004, after 6 years of regularly requesting more support, I finally lodged for CAP funding under the Intensive Family Support stream. I was requesting the equivalent of 33 hours support per week. Every one of the 6 times I was knocked back (over 2 years), I struggled with the amount of help we already had, which equated to approximately 10 hours care per week. The theme of ALL the applications was the imminent demise of my marriage.*<sup>123</sup>

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#### Case Study 5<sup>124</sup>

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*Esme is eighty years of age and is the full time carer of her 57 year old daughter Lisa. Esme's health is in decline, she has suffered two strokes and is concerned what would happen to Lisa should she pass away or is incapacitated. Esme has approached her Local Area Coordinator to request funding for accommodation support so that Lisa can be transitioned into alternative accommodation. This will allow Esme to support Lisa in her move and Lisa will not have to contend with the trauma of moving out of home on top of losing her mum.*

*Strictly speaking the case is not critical or urgent as the daughter still has a roof over her head, the mum is there as a primary carer and until such time Lisa is out on the street or her mum is dead the application is unlikely to succeed.*<sup>125</sup>

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120 Submission No. 16 from National Disability Services WA, 17 January 2014, p5.

121 Submission No. 19 from Carers WA, 31 January 2014, p4.

122 Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

123 Submission No. 10 from Ms Neeva Stephen, 22 December 2013, p1.

124 The names in the case study have been changed to protect the identity of the individuals. The case study is a real scenario provided by an LAC.

125 Submission No. 6 from CPSU/CSA, 19 December 2013, p4.

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### 3.2.4 Receiving news of the outcome

Disability organisations and families/carers report that many CAP applicants are dissatisfied with the feedback they receive when their application is unsuccessful. Applicants receive a standardised letter stating that they were unsuccessful and that there were others judged to be in greater need.<sup>126</sup>

DSC director general Dr Chalmers says that the content of the outcome letter has been refined many times, but regardless of how the letter is written there is always an impact when people receive bad news.

Dr Chalmers says that DSC has a “far more sophisticated mechanism for people to get feedback on their applications” than in the past, sometimes by way of a formal communication and sometimes through the LAC network. This was demonstrably at odds with client submissions and evidence. Applicants’ families consistently expressed a desire for more information rather than less, to assist them in making even the most rudimentary decisions about the future.

According to the IPAP chair, if panel members are concerned about the particular circumstances of an unsuccessful applicant, they might request a personal meeting between the panel and the family. However, she said it would be too difficult to provide personalised feedback to several hundred applicants.

Of all the people/groups who made submissions and witnesses who appeared before the Committee, only one mentioned having received feedback on an application. This was a service provider manager (providers often submit applications on behalf of clients) who described the feedback as inconsistent.

*Sometimes we have had feedback that said that we did not express enough need for the person. Sometimes we have had feedback that we actually needed to provide supporting documentation. Sometimes we have had feedback that we have provided too much documentation. When we have gone back and asked what was wrong with this, usually, to the frustration of my staff, the answer we get quite often is contradictory to the one from the round before.<sup>127</sup>*

Many submissions made complaints that feedback was lacking in detail<sup>128</sup> and abrupt and perfunctory,<sup>129</sup> and one contributor, Sue Harris, was incredulous that “life-

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126 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p8; Submission No. 8 from Kalparrin, 20 December 2013, p2.

127 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, p3.

128 Submission No. 8 from Kalparrin, 20 December 2013, p2.

129 Submission No. 11 from CASA, 23 December 2013, p6.

devastating news” would be delivered in a formal rote letter.<sup>130</sup> Ms Harris said that people in critical need of help were further stressed and demeaned by what was a “seemingly callous and unprofessional disregard” for their difficulties.<sup>131</sup> This is supported by several advocacy organisations, who say that they receive many calls from distressed families immediately following a CAP round outcome.<sup>132</sup> (See also section 3.3, *Impacts and consequences*.)

Sometimes even when people approach the DSC for feedback (instead of just waiting for it to come to them) the result is not satisfactory. The CEO of Headwest related the case of an applicant who contacted the DSC for feedback after missing out in the latest CAP round, and was asked how many years she had been in the system. “She is into the second year and there was the notion that she probably had another year or two to go before she would be successful.”

Another couple in their 70s, who have been applying for CAP for their daughter for more than five years, had met with DSC board members at what are termed Reference Network meetings on five occasions. The Reference Network meetings enable people with disability, their families/carers and sector organisations to raise concerns and views directly with board members for “appropriate follow-up” by the DSC executive. They are held three times a year.<sup>133</sup> While the DSC says that the meetings have been very effective and inclusive,<sup>134</sup> this couple described it as a waste of time. “All they say is, ‘Yeah, thanks for that. We’ll put it in the file’ and that’s it.”<sup>135</sup>

Despite the potential difficulty of providing more detailed and/or personalised feedback to a large number of applicants, the overwhelming dissatisfaction with the outcome letter and lack of follow-up expressed by applicants indicates the need for change.

#### Finding 4

Combined Application Process applicants are overwhelmingly dissatisfied with the outcome letter and feedback following a funding round, regarding it as callous and lacking in detail.

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130 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p3.

131 Submission No. 15 from Ms Sue Harris, 15 January 2014, p3.

132 Submission No. 8 from Kalparrin, 20 December 2013, p3; Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p10; Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p11.

133 Disability Services Commission, *Reference networks*. Available at: [www.disability.wa.gov.au/about-us1/about-us/our-structure/disability-services-commission-board/reference-networks/](http://www.disability.wa.gov.au/about-us1/about-us/our-structure/disability-services-commission-board/reference-networks/). Accessed on 7 April 2014.

134 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – response to questions on notice taken at hearing, 19 March 2014.

135 Mr Robert Ryle and Mrs Lesley Ryle, parents/carers, *Transcript of Evidence*, 26 February 2014, p8.

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### Recommendation 3

The Disability Services Commission should revise the method by which news of an unsuccessful funding application is conveyed, to ensure: a) applicants have a better understanding of how the decision was reached; and b) it is delivered in a timely and compassionate manner.

#### Deciding whether to update an application

In most cases unsuccessful applications are automatically included in the next CAP round. Applicants do not have to update their application before it is resubmitted; however, applicants reported feeling that unless their application was updated it may be “perceived as coming from a family that was not well-motivated”.<sup>136</sup> There is a perception that an unsuccessful application requires improvement if it is to have a better chance of success: “The process is one that if you are going to have a successful outcome, you have to put forward a case that results in more points.”<sup>137</sup>

Consequently, many applicants resubmit lengthy applications repeatedly in the hope of maximising their chances. One parent reported submitting a 50-page application 15 times over a period of five years.<sup>138</sup> However, for others, the prospect of updating the application is daunting (one parent/carer said a recent update had taken three days to complete<sup>139</sup>) and after multiple knockbacks they refuse to do any more.<sup>140</sup>

#### 3.2.5 Waiting and weighting and the inability to plan

There are two features of the CAP process that make it impossible for applicants to plan their care/the care of the person with disability with any certainty:

- The prioritisation of those with urgent and critical needs
- Discrete funding rounds

As alluded to previously, the system simply does not cater for families/carers to anticipate the future care needs of a person with disability. Applications made in anticipation of what will be needed within the next months or year or two are not successful because the need is not deemed to be urgent.

But reaching the point of critical and urgent need (a subjective concept in any case) is no guarantee of success either, due to limited funds. As PWdWA’s Mr Jefferson put it, it

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136 Submission No. 2 from Mr Paul Smale, 4 December 2013, p1.

137 Mr Andrew Jefferson, Executive Director, People with Disabilities (WA) Inc, *Transcript of Evidence*, 4 December 2014, p2.

138 Submission No. 2 from Mr Paul Smale, 4 December 2013, p1.

139 Parents/carers of people with disability, *Briefing*, 10 March 2014.

140 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3.

is pointless for a parent to try to have the same sort of conversation about leaving home that he/she might have with a child without a disability.

*... you start up a conversation about, "Is it time for you to think about maybe leaving the family home, maybe sharing a house with some mates, and start that next stage of your life?" You cannot have that conversation with any confidence because you would not know when you could achieve funding.*<sup>141</sup>

Headwest sums up the dilemma perfectly:

*When considering age-appropriate life stages such as moving out of home, extensive financial planning needs to be considered. For individuals with a disability, there is even greater consideration required, having to factor in out-of-home assistance for self-care, activities of daily living and community participation. However, using a needs-based approach, an application such as this would result in significant delay before achieving funding, as this would not be considered an application of crisis. This makes planning for the future extremely difficult for those caring for a family member with a disability.*<sup>142</sup>

A parent of a person with an intellectual disability said that the system was all about "how long we can keep these carers functioning".<sup>143</sup> People who are determined by the IPAP to be able to cope a little longer are made to wait. For those with intellectual disabilities, waiting until a crisis had occurred – for example, the death of the parent who had been caring for them – was the worst possible time to be implementing change.

*... the definition of intellectual disability is that you have difficulty adapting to change. (They) are saying, "We are going to make you change your living environment when your whole family is in crisis, when your parents die, when your health fails, and off you go to any bed that is available" rather than, "Let us make this transition work for you and work for your family."*<sup>144</sup>

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141 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, pp3-4.

142 Submission No. 18 from Headwest, 28 January 2014, p8.

143 Ms Deirdre Croft, *Transcript of Evidence*, 26 February, 2014, p5.

144 *ibid.*

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Kalparrin, a support organisation for parents of children with special needs, reported that there was a belief among its membership that the CAP process rewards people who do not plan and punishes people who self-care.<sup>145</sup>

### Case Study 6

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*One of the families includes an older set of parents in their early 70s. They have been working with the Local Area Coordination program through the Disability Services Commission for approximately 10 to 12 years. They both have ailing health and physical conditions. Their daughter has cerebral palsy and extreme and complex support needs, physical and otherwise. They were finding that whilst they were happy for her to be at home and they wanted her to remain part of the family unit, they were provided with some intensive family support funding over the years to help them with in-home support, particularly around the hoisting and transferring and things like that. They could cope with the rest of the care, but there were certain things that they were obviously not able to do.*

*Obviously the promotion of individualised service models is around planning. This family had been planning for 10 years saying their health had been getting worse, their physical capacity to care for their daughter had been decreasing year after year, and that they would be going into retirement and selling their house. That has now happened. I have been involved in their particular process for over two years. They have not been successful in the CAP round. They have reams of evidence and paper around the planning, what the timeframes are from the beginning to the end, and they are still not up. Now they are moving in two weeks and their daughter has nowhere to go at this stage.<sup>146</sup>*

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Despite seemingly widespread understanding that the CAP meets only urgent and critical need, some people still applied before they reached this stage, knowing there would be a delay. But there was a sense that being on the list was a move in the right direction, “a bit like getting on the housing list,” as Mr Jefferson put it. “...you have to

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<sup>145</sup> Submission No. 8 from Kalparrin, 20 December 2013, p1.

<sup>146</sup> Ms Norelle Morris, Chief Executive Officer, Valued Independent People, *Transcript of Evidence*, 12 March 2014, pp2-3.

put your name down at some point or you are never going to achieve a house, even though you know it may be many years in advance.”<sup>147</sup>

However, the CAP list does not function like a housing waiting list. There is no queue. Applicants do not move up the list just by staying on it. As described previously, for each CAP funding round, a new list is formed, based on the prioritisation of all applicants by the IPAP. While the reasons for this have been made clear – that is, that someone with genuinely critical need who had not applied previously must be considered a priority rather than being put at the bottom of a very long list – there is still a very strong sense of inequity and resentment.

Some submissions and witnesses have discussed the possibility of some kind of waiting list being considered so that people can have some hope at least that they will eventually get the help they need.<sup>148</sup> One parent, who was eventually funded, said it would have been a much less stressful process had he been given some indication of how many years he would have to wait. Applicants should be given an estimate.

*In that way the family can organise their lives for that period and plan accordingly. Not knowing when or if the application will be granted is extremely stressful... if I had known that it would have been 5 years before (my son) was likely to be funded I would have saved the hassle and stress of submitting fifteen 50 page submissions and getting the associated letters of support. More importantly I could have planned my own life in the knowledge of how much longer I would need to care for (my son).*<sup>149</sup>

Whilst no one was able to say exactly what they thought a waiting list would look like, there were some suggestions as to what features it might have, including the ability to apply a weighting to reflect how long someone had been waiting or how many times they had applied. This might help to overcome the perceived unfairness of missing out on funding because, despite being just past the cut-off in one round, in a subsequent round a surge of new urgent applications would push the applicant further down the list. It might equally be the case that given different circumstances – that is, that there were no or few new applications that were more urgent – the person in that same position on the list might advance on the list and be funded. This is why the system has often been referred to as a cruel lottery.<sup>150</sup>

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147 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p4.

148 Submission No. 15 from Ms Sue Harris, 15 January 2014, pp3-4; Parents/carers of people with disability, *Briefing*, 10 March 2014.

149 Submission No. 2 from Mr Paul Smale, 4 December 2013, p1.

150 Submission No. 6 from CPSU/CSA, 19 December 2013, p3; Submission No. 15 from Ms Sue Harris, 15 January 2014, p3; Parent/carer of people with disability, *Briefing*, 10 March 2014.

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Former disability sector executive Ms Harris felt that people who were deemed to be in extreme need should just be funded, without entering the CAP process and having to wait several months. A separate pool of emergency funding for these few extreme cases would mean that the CAP priority list would be unaffected by them. The Committee embraces this suggestion.

Other suggestions were that the applications be categorised according to disability type, so that assessors were not trying to compare apples with oranges. There is a perception among parents/carers that the applications of people with physical disabilities are scored very differently from those with intellectual disabilities because there are more criteria by which to attract points. Professor Saggars confirmed that panel members often articulated a concern about comparing different disability types, and conceded that there was a “strongly perceived need” for the distinction to be made.

*It is like comparing apples and oranges, particularly with respect to disabilities acquired through accidents, for instance, brain injuries and things of that kind or neurological conditions and disabilities of that kind. It is exceedingly difficult to compare the circumstances of those people alongside people who have birth-related defects and things of that kind.<sup>151</sup>*

The Committee has been unable to verify whether applications for certain types of disabilities might attract a higher score, since it has not been provided with the details of the Risk Assessment Framework and the method of scoring, despite several requests.

There have also been suggestions that age be taken into account – that is, applications from parents over 70 who are still caring for their children should be given a higher weighting; and that the applications for those with changed need (who have previously been funded) be considered as a separate list.

The Committee also suggested that there be a maximum waiting period for people who have qualified for support to give people some level of certainty and spare them the stress of completing application updates.

Ms Harris said that a waiting list might be more appropriately called a register of need. This would result in a bigger pool of people from which living companions could be sourced. According to Ms Harris, at present living companions must be drawn from a

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151 Prof. Sherry Saggars, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p7.

limited pool of people who have received CAP funding, which makes it difficult if not impossible to find suitable living companions in a share home situation.<sup>152</sup>

Someone who had not yet received funding but was registered as being in need might be the perfect companion for someone who had received funding, and it would make sense to allow this person to be funded ahead of some others on the list, in order to facilitate a better and more cost-effective living option for both applicants.

The NDIS will of course overcome the problem of a waiting list since everyone who is determined to require support will receive funding. However, in the meantime, people who are in need now and who have, perhaps, already been waiting a few years, are daunted by the prospect of waiting until 2019-20 for the NDIS. There do seem to be workable options for facilitating advancement in the queue and these should be explored.

#### **Finding 5**

The lack of a waiting list for people who apply for Combined Application Process funding makes it impossible for people to plan how they will care for themselves/their disabled family member.

#### **Recommendation 4**

The Disability Services Commission should explore options for weighting applications according to how long people have been waiting and the age of the carer.

#### **Recommendation 5**

That the Disability Services Commission considers implementing a maximum waiting period for Combined Application Process applicants.

#### **Recommendation 6**

Consideration be given to establishing a separate pool of funding for urgent, extreme cases, independent of Combined Application Process funding, thereby facilitating the establishment of a waiting list for all other cases.

### **3.2.6 Transparency**

A 2007 Auditor General report into home-based services in Western Australia found the CAP to be lacking in transparency and accountability. Deficiencies identified by the Auditor General included:

- non-disclosure to applicants of the criteria used by the IPAP to assess applications;
- lack of meaningful feedback provided to unsuccessful applicants; and

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152 Submission No. 15 from Ms Sue Harris, 15 January 2014, pp3-4.

### Chapter 3

- limited documentation on how the IPAP has rated applicants, preventing independent validation of assessments.

At the time the Auditor General stated:

*...cumulatively, these factors give the assessment process an air of secrecy that is out of step with modern public administration.*<sup>153</sup>

In response to the Auditor General's findings regarding feedback to those who had unsuccessfully applied for CAP funding, DSC conducted a number of consumer information sessions to assist applicants to gain a better understanding of processes and to express issues of concern. DSC also indicated at the time that unsuccessful CAP applicants in need of support were visited by local area coordinators who would continue to provide this form of assistance.<sup>154</sup>

Despite this, evidence received by the Committee indicates that seven years later, many of the issues highlighted by the Auditor General relating to transparency persist.

#### **Lack of transparency surrounding the assessment panel and criteria**

As stated previously in this chapter (section 3.1.2), the identities of the IPAP members are not publicly disclosed because of a concern that this will lead to lobbying of members by applicants. However, the public perception is that the IPAP is shrouded in secrecy and important decisions about people's futures are being made by "faceless, nameless people"<sup>155</sup>

There are also concerns that the panel may not be representative of all disability groups, despite the DSC endeavouring to provide assurance that this is not the case by way of its website information and CAP Implementation Policy. The policy states that the CAP uses clearly defined, transparent and consistent processes and ensures, "through the terms of reference of the IPAP, that decision making regarding allocation is underpinned by balanced perspectives and enhanced by the inclusion of stakeholder representatives".<sup>156</sup>

Many in the sector, however, are either not aware of this or are not convinced.

*You do not know what sort of background they come from, so if there is a panel there ... of a couple of parents with autism and then you*

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153 Auditor General of Western Australia, *A Helping Hand: Home-based Services in Western Australia* (Report 6, 2007), Western Australia, June 2007, pp22-24.

154 Public Accounts Committee, *Review of the Reports of the Auditor General 2008-2009*, Parliament of Western Australia, Perth, 26 November 2009, pp70-71.

155 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p8.

156 Disability Services Commission, *Combined Application Process Implementation Policy*, Government of Western Australia, November 2012, pp1-4.

*have got service providers from Autism Association ... they know autism. So, what are they going to pick? Autism.*<sup>157</sup>

*... it almost totally lacks transparency. People do not know who is making the decision, on what basis and they have no opportunity to appeal.*<sup>158</sup>

*It lacks transparency and we do not know who is involved in the process, what the attrition rate looks like and where they get them from. We do not know much about who they are and what they know or do not know.*<sup>159</sup>

The head of one disability advocacy organisation, who had served as a panel member, noted that ideas in the community about how the panel worked did not reflect her experiences of the panel.<sup>160</sup> She attributed this to a lack of information.

*Unfortunately there is very little information available to the community about how the CAP panels work, how they assess the information that is provided to them, and what things guide their decision making.*<sup>161</sup>

The assessment framework is also a closely guarded secret. Although there is information available about the broad areas which will be assessed (largely reflecting the headings of the CAP application form), people do not know how the scoring works. The DSC has made a conscious decision not to release the inner workings of its risk assessment framework, believing it may lead to people tailoring their applications to generate a higher score. Dr Chalmers expressed the view that the framework would never be publicly released:

*Whenever this gets raised, successive governments look at the issue and say, "No way; don't release the inner workings of the risk assessment side of things." We looked at what the Auditor General said and we understood where it was coming from, but we did not change.*<sup>162</sup>

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157 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p8.

158 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p2.

159 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p5.

160 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p3.

161 Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

162 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p14.

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The refusal to make the process open leads to doubt about the efficacy of the process and a belief that there must be something to hide.

*... there is a lack of transparency in the manner in which assessments are made with a view in the sector that the process is DSC driven without proper criteria guiding decision making.*<sup>163</sup>

Numerous submissions, from parents/carers and from organisations, called for the criteria to be made available or at least clarified.<sup>164</sup> This would help applicants to determine their chances of success and potentially save them from wasting time on their applications.<sup>165</sup>

The Committee understands the frustration of applicants unable to access the assessment criteria. These were not made available to the Committee either, despite several requests. This hampered the Committee's ability to assess the efficacy of the current system. The Committee finds it implausible that making the criteria known even to the Committee would enable persons to tailor their applications to maximise the likelihood of success. Further, if the criteria were generally available, everyone would still be on the same footing and could be judged on their merits.

Given the position taken by the director general of the DSC, the Committee felt compelled to call on IPAP chair Professor Saggars to give evidence on the criteria. Whilst Professor Saggars was frank and helpful in her evidence and the process, she too refused to disclose the criteria on instruction from the director general. Given that Professor Saggars is an independent chair this interference was unwarranted and reflects badly on the director general.

There is clearly a public perception problem, brought about by lack of information about the process. A number of organisations and individuals questioned why the DSC would not make the process more transparent.

*It is not clear why the Government does not go to greater lengths to provide this kind of information to the community. While this knowledge would give little comfort to those individuals and families whose calls for supports and services go unanswered, it might give people a broader understanding as to why current system works as it does.*<sup>166</sup>

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163 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p3.

164 Submission No. 15 from Ms Sue Harris, 15 January 2014, p4; Submission No. 16 from National Disability Services WA, 17 January 2014, p6; Submission No. 18 from Headwest, 28 January 2014, p7.

165 Submission No. 19 from Carers WA, 31 January 2014, p5; Submission No. 21, closed submission, 3 February 2014.

166 Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

### Lack of information regarding how funding decisions are made

Organisations and individuals have noted a change in the nature of the information provided to applicants after a CAP round, and in the DSC's Funding Bulletins, which are published annually. The DSC concedes that the information provided now is different from several years ago.<sup>167</sup> However, while the DSC maintains that the information provided is more comprehensive than in the past,<sup>168</sup> most say the opposite. It seems that the information the DSC no longer provides is the information that applicants and organisations want the most: the number of successful and unsuccessful applicants; and the applicant's relative ranking in the priority list.

The DSC's rationale for no longer providing the ranking is that each funding round is discrete, which means that the ranking could drop in subsequent rounds if people with greater need entered the system and were ranked above them. IPAP chair Professor Sagers is concerned about giving false hope to people by providing their ranking.<sup>169</sup> The DSC also no longer publishes the number of unsuccessful applicants or demographic data about the successful applicants. Dr Chalmers says this is because it was giving people a "skewed picture":

*... they were just looking at CAP and a program in CAP and saying, "Oh, there are still 300 people missing out there." They were not seeing the full picture of what was available to them, so we felt it was misleading.*<sup>170</sup>

This information is provided in the IPAP report to the board after each round. (The Committee obtained a copy of the report, which is why statistics regarding numbers of unsuccessful applicants are quoted elsewhere in this report.) The DSC also provides a "confidential briefing document" to organisations sponsoring CAP applicants, listing the number of people applying for support and the number of people recommended for funding under each service category. CASA says it is not clear why agencies are bound to secrecy, "especially when this information was previously freely supplied to applicants".<sup>171</sup>

Numerous submissions comment that the information provided now is less useful than in the past.

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167 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p10.

168 *ibid.*

169 Prof. Sherry Sagers, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p2.

170 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p11.

171 Submission No. 11 from CASA, 23 December 2013, p6.

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*All letters of rejection received since December 2012 have had no explanation given as to why they were not successful. This contrasts with letters of rejection received prior to December 2012 which included a graph showing the rating DSC had given the assessment (from "Super Urgent" through to "Can Wait") and would indicate how the application stood in relation to all applications received. Under this older system Parents/Carers felt reassured that their applications had actually been read and considered.<sup>172</sup>*

*Originally, we used to get statistics of how many were in our band because we were applying for full-time support, and even ages of carers. Now they have disbanded that, so we have no knowledge.<sup>173</sup>*

Applicants, service providers and advocacy organisations are keen to know how many people applied, how many people were successful, their ages, their type of disability and how long people have been waiting. This type of information helps applicants to understand the context in which their application was considered and assists providers and advocacy groups in planning and allocating resources.

The Combined Application Process Implementation Policy states that the CAP “uses communication processes that are clear and consistent to inform individuals, their families and carers of the outcome of their application”.<sup>174</sup> They may be consistent, but they are consistently lacking in the detail that witnesses have said they would find useful.

A number of submissions observed that not providing information – especially information that was once available – gives the impression that DSC has something to hide<sup>175</sup> and causes people to “doubt that the processes are as they should be”.<sup>176</sup> As such, some were at pains to understand why the DSC would not release more information and make the process more transparent.<sup>177</sup> When asked directly whether the IPAP would be able to adequately perform the functions required of it if some of the information it uses was made public, panel chair Professor Saggars replied that it was “possible to have greater levels of transparency”,<sup>178</sup> given an appropriate level of

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172 Submission No. 8 from Kalparrin, 20 December 2013, p3.

173 Mr Robert Ryle, parent/carer, *Transcript of Evidence*, 26 February 2014, p3.

174 Disability Services Commission, *Combined Application Process Implementation Policy*, Government of Western Australia, November 2012, pp1-4.

175 Submission No. 11 from CASA, 23 December 2013, p10; Submission No. 15 from Ms Sue Harris, 15 January 2014, p5.

176 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p15.

177 *Ibid*; Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

178 Prof. Sherry Saggars, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p4.

administrative support. “I do not see any point in not broadcasting the numbers of unsuccessful applicants, for instance.”<sup>179</sup> This confirms the Committee’s view that the release of more information would not hamper the operation of the IPAP, subject to the provision of additional administrative resources.

#### **Finding 6**

The release of more information would not hamper the operation of the Independent Priority Assessment Panel, subject to the provision of additional administrative resources.

#### **Finding 7**

The lack of availability of the Combined Application Process assessment criteria is at the heart of applicants’ dissatisfaction with the system.

#### **Finding 8**

There is a lack of transparency surrounding the operation of the Combined Application Process and a lack of publicly accessible information about the outcome of each Combined Application Process round.

#### **Recommendation 7**

The Combined Application Process application assessment criteria should be made available to applicants.

### **3.2.7 Funding**

There is consensus across the sector that demand out-strips available funding for disability services. However there are competing views regarding the degree to which dollar increases in funding in recent years have translated to real increases in funding and services.

The DSC says that there has been average growth in funding of 14 per cent per year over the past five years.<sup>180</sup> This is acknowledged by others in the disability sector; however, the following points were made:

- While the level of funding has increased, demand has also grown<sup>181</sup>
- After taking indexation into consideration, the growth from this year onwards will be closer to “maybe one and a half per cent”<sup>182</sup>

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179 *ibid.*

180 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p6.

181 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p5; Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, pp4-5.

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- As funding has increased, so have the costs of providing accommodation and family support<sup>183</sup>
- Much of the 14 per cent growth is catch-up funding to deal with previous under-funding of individuals and organisations<sup>184</sup>
- The increased funding is dealing with a backlog resulting from the system now funding people with all types of disability, rather than just intellectual disability.<sup>185</sup>
- Viability and sustainability funding from the State Government in the past two years was intended to bolster wages of care workers, but this does not equate to more service delivery.<sup>186</sup>

The point was also made that given the complex nature of the disability funding system, it was sometimes hard for people in the industry to see where the money was actually going.<sup>187</sup>

There were a number of other anomalies in relation to the distribution and use of disability funding.

As Dr Chalmers pointed out when he appeared before the Committee, many people who may have applied for CAP are offered smaller packages of funding through other programs, including the LAC network.<sup>188</sup> But one parent wonders whether repeatedly receiving small amounts of money for a short term fix is actually more economical than awarding CAP funding in the first instance, since it “wastes peoples time, resources and money in finding such sources every few months” for a problem that is ongoing. She points out that her daughter’s intellectual disability will never be cured and wonders what will happen if/when she can no longer attract any short-term funds.<sup>189</sup>

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182 Mr David Granville, Director, Service Development and Strategic Relations, The Centre for Cerebral Palsy, *Transcript of Evidence*, 12 March 2014, p5.

183 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p10.

184 Mr David Granville, Director, Service Development and Strategic Relations, The Centre for Cerebral Palsy, *Transcript of Evidence*, 12 March 2014, p5.

185 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p4.

186 Department of Treasury and Curtin University, *Sustainable Funding and Contracting with the Not For Profit Sector Initiative and Associated Procurement Reforms – 2012 Evaluation*, Government of Western Australia, December 2012, pp15,27.

187 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p6; Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p6.

188 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, pp6-7.

189 Submission No. 3 from Ms Lesley Pascoe, parent/carer, p1.

On a similar theme, Valued Independent People CEO Norelle Morris points out that the longer people are in the system, the greater their need will become.<sup>190</sup> Someone who has been applying for CAP funding for five years is likely to need a greater amount of assistance now than they would have when they first applied – hence the demand for funds continuously snowballs.

Several parents/carers and organisations felt that they did not get the full value of funding received because so much money was lost in paying “inefficient service providers” and in “unnecessary processes”.<sup>191</sup> (See section 3.3.4 for further discussion on procurement.)

### 3.2.8 Complaints and/or appeals

Matters which can be subject to complaint are defined by the *Disability Services Act 1993*. This includes instances where DSC acts “unreasonably in making or not making a grant to the complainant”.<sup>192</sup> In relation to the CAP, DSC guidelines advise that complaints may be lodged through the formal DSC complaint channels.<sup>193</sup> There is no avenue for appealing decisions of the IPAP unless there has been a failure in the process. Given the lack of transparency, it is difficult to comprehend how applicants would be able to identify any failure in the process.

DSC complaints are handled in accordance with a Consumer Complaints Management Policy and Procedure. This involves an internal complaint handling process in the first instance and includes internal review and/or investigation. If the complaint cannot be resolved internally then it may proceed to external independent review by the Health and Disability Services Complaints Office (HADSCO), which is an independent statutory authority tasked with investigating complaints about health and/or disability services.

Alternatively, complaints may be referred to the Ombudsman who investigates complaints relating to administrative matters involving state government departments.<sup>194</sup> However, the Ombudsman has no power to compel remedial action.

In 2007 the Auditor General found that unsuccessful CAP applicants were not fully informed about avenues for complaints.<sup>195</sup>

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190 Ms Norelle Morris, Chief Executive Officer, Valued Independent People, *Transcript of Evidence*, 12 March 2014, p4.

191 Submission No. 21, closed submission, 3 February 2014, p7; Parents/carers of people with disability, *Briefing*, 10 March 2014; Submission No. 20 from People with Disabilities WA, 3 February 2014, p8.

192 Section 33 *Disability Services Act 1993* (Western Australia).

193 Disability Services Commission, *Combined Application Process Implementation Policy*, Government of Western Australia, November 2012, p3.

194 Disability Services Commission, *Consumer Complaints Management Policy and Procedure*, Government of Western Australia, December 2011, pp2,8,13.

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The bottom line, as Developmental Disability WA makes clear, is that there is no mechanism for an appeal. “So if you do not get funding, you have nowhere to take that.”<sup>196</sup>

### **Fear of making a complaint**

Carers WA points out that some family carers fear making a complaint to HADSCO because they are concerned about maintaining positive relationships with DSC staff, who they rely upon for continued funding and access to information.<sup>197</sup>

Others also alluded to people being afraid to speak out in case they jeopardised their chances of funding.<sup>198</sup> Mrs Brensell was concerned that some families represented by Headwest were unwilling to appear before the Committee because they were “fearful of what it might mean for their place or position in the process”.<sup>199</sup>

*... it is very sad when people tell you that they really do not want to talk because they fear jeopardising their CAP application.*<sup>200</sup>

### **3.2.9 Issues with LACs**

Local Area Coordinators are part of a local area coordination program which has operated across the State since 1988. The underlying philosophy of the program is that LACs use their local knowledge to help people with disability and their families access the support and services they need.<sup>201</sup> According to the DSC website, each LAC works with between 50 and 65 people, but there has been some suggestion that some may work with higher numbers than that. LACs support people across a range of DSC programs and services, not just the CAP program.

The DSC provides LACs with initial and ongoing training, which includes:<sup>202</sup>

**Core training:** an intensive program for new LACs which focuses on the LAC role and informs recruits about the “person-centred, strengths based and partnership approach that frames all interactions”; people with disability meet with LACs twice throughout

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195 Auditor General of Western Australia, *A Helping Hand: Home-based Services in Western Australia* (Report 6, 2007), Western Australia, June 2007, p25.

196 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p4.

197 Submission No. 19 from Carers WA, 31 January 2014, p7.

198 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p5.

199 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p1.

200 *ibid*, p2.

201 Disability Services Commission, *Local Area Coordination*. Available at: [www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/](http://www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/). Accessed on 11 April 2014.

202 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – response to questions on notice taken at hearing, 19 March 2014.

the program to give their perspective on how LACs can establish and maintain effective working relationships with them.

**Communication skills:** a new program “developed in response to awareness that LACs require targeted skills to navigate often complex relationships with individuals, families, carers and other organisations”.

**Community development:** another new program to support LACs in building inclusive communities “through partnerships and relationship building”.

**Planning module:** new program, due to be launched at the end of April 2014, to help LACs in developing skills “to plan effective strategies with individuals and families that support their needs and goals”.

Despite the training offered, the Committee heard many complaints about LACs, including that they lacked training and the necessary skills to do their job. Other complaints revolved around: LACs discouraging people from applying for CAP; and the high turnover/lack of continuity.

There were many comments similar to the two provided here:

*My LAC told me this week that I "shouldn't bother applying for IFS" because I "won't get it", that things aren't "bad enough" for our family.<sup>203</sup>*

*She has had three goes at the CAP application and has been unsuccessful every time. This round they did not put in because they were told by their Local Area Coordinator that they would not get funding and it was a bit of a waste of time.<sup>204</sup>*

LACs are probably being realistic (and following DSC directives) when they advise people that an application for CAP will not be successful. However, the result is that people feel their rights are being eroded. They also feel that their situation, no matter how desperate, is of no consequence. One parent referred to LACs as the gatekeepers,<sup>205</sup> an appropriate term considering that in many cases they determine whether an application is submitted. While it seems that bypassing the LAC is still possible in some cases, the Committee was told that having the LAC sign off on an

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203 Submission No. 21, closed submission, 3 February 2014.

204 Ms Sandy Komen, Manager, At Home Services, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p3.

205 Parent/carers of person with disability, *Briefing*, 10 March 2014.

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application was “recommended”<sup>206</sup> and a DSC staff member said it was a requirement.<sup>207</sup>

When dealing with such sensitive matters as a family’s capacity to cope and the likelihood that their needs will not be met, good communication skills are surely of paramount importance. The DSC seems to have recognised this with the implementation of a training program focussing on communication skills. But perhaps the program is too recent to have had an impact. A number of disability service users reported that these skills were less than satisfactory.

It was suggested that more training be provided to ensure that LACs knew how to provide support and guidance to a diverse array of families, and that they are encouraged to recognise that it was “a potentially stressful period” for them.<sup>208</sup>

Parents of children with autism requested that the DSC provide a “better-trained, more informed, less biased” network of LACs who would not offer their opinion on the likelihood of success of the application, but instead help them to write the application and/or help them to access funding or support from alternative sources.<sup>209</sup> IPAP chair Professor Saggars said that there were differences in the abilities of LACs as in any line of work, with “terrific” LACs as well as “less-than-terrific” LACs. She also said that on occasions the IPAP had asked that LACs be given feedback that the assistance they had provided was not good enough.

The Committee’s findings in this area are reminiscent of the findings of a DSC-commissioned report on LAC client satisfaction prepared by PricewaterhouseCoopers (PWC) in 2010. While the report found that most people interviewed were satisfied with the service they had received from their LAC, at least one-third were not satisfied. One of the key issues driving dissatisfaction was lack of confidence in individual LACs.<sup>210</sup>

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206 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p10.

207 Ms Mary McHugh, Manager, Strategic and Executive Services, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p6.

208 Submission No. 19 from Carers WA, 31 January 2014, p5; Submission No. 16 from National Disability Services WA, 17 January 2014, p6.

209 Submission No. 21, closed submission, 3 February 2014.

210 Disability Services Commission/PricewaterhouseCoopers, *Local Area Coordination Consultation Project*, PricewaterhouseCoopers, 2010, p8. Available at: [www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/](http://www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/). Accessed on 11 April 2014.

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*The current system of applying for support is generally poorly promoted by the Local Area Coordinators (if you have one) if it is raised at all with families. Our own LAC did not tell me about CAP (IFS) funding, I found out through another parent. I was not encouraged to apply.*

*Many families are told “your family situation isn’t bad enough”, “you won’t qualify so there’s no point applying”, “it’s a really hard process and you probably won’t get it”, “thousands of people apply so your chances aren’t good”.<sup>211</sup>*

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Evidence presented to the Committee indicates that the attrition rate of LACs is high, a significant disadvantage to service users considering that submitting a convincing application is dependent on the LAC knowing the family’s situation well. PWDWA’s executive director said that his organisation had dealt with a family whose LAC had said, “Well, I have just become your LAC. I really don’t know your family that well, so I cannot realistically sign it off.”<sup>212</sup> Similarly, another parent said:

*I had no support from our LAC as our previous one had retired and it took three months to replace her. The new LAC started in his role the day before my application was due and read it briefly before giving me useful but very limited feedback.<sup>213</sup>*

One parent had had four LACs in 12 months<sup>214</sup>, another said her LAC had left in February and would not be replaced until July,<sup>215</sup> and another claimed that she could count the number of useful LACs she had had on one hand and still have fingers left over.<sup>216</sup> One parent said that if LACs perceived you as intelligent and articulate you would tend to be ignored, to the point of not even receiving mail-outs about services.

Again, these findings reflect those of the PWC report:

*One of the most common complaints about the Program pertained to turnover of LACs. This seemed to have affected certain geographical areas more than others. In general, the greater the level of turnover, the greater the level of dissatisfaction with the Program ... Clients were*

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211 Submission No. 21, closed submission, 3 February 2014, p4.

212 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p10.

213 Submission No. 21, closed submission, 3 February 2014.

214 Mrs Lesley Ryle, parent/carer, *Transcript of Evidence*, 26 February 2014, p3.

215 Parent/carer of people with disability, *Briefing*, 10 March 2014.

216 *ibid.*

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*often frustrated with the high turnover as they disliked having to retell their story to each new LAC. Clients also did not like the uncertainty associated with getting a new LAC.*<sup>217</sup>

Having an LAC does not seem to be a guarantee that a family will get the information and support that it needs. Given that the My Way project is “building on the strengths of the Local Area Coordination program”,<sup>218</sup> it is critical that problems with the program are noted and addressed. It would be unwise to build a new program upon one which is flawed.

### Finding 9

While many Local Area Coordinators act as an effective conduit between families and the Disability Services Commission, feedback from submissions and evidence suggests some lack training and communication skills.

### Finding 10

The high attrition rate of Local Area Coordinators means that many do not get to know a family sufficiently well to provide quality advice and support.

### Recommendation 8

Close attention should be paid to the inadequacies of the Local Area Coordinator model, given that a similar model of individual coordination will be used for NDIS/My Way.

### 3.2.10 Evaluation of the CAP

DSC states that many refinements have been made to the CAP over its 13 years of operation “based on consumer feedback”.<sup>219</sup> However, it is unclear whether there has been any formal evaluation of the process, other than independent reviews of the Risk Assessment Framework used by the IPAP to assess CAP applications.<sup>220</sup>

When asked whether there had been any evaluation to assess whether the CAP application assessment process might be biased towards well-written applications, a DSC staff member and the IPAP chair both said they were not aware of any

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217 Disability Services Commission/PricewaterhouseCoopers, *Local Area Coordination Consultation Project*, PricewaterhouseCoopers, 2010, pp11-12. Available at: [www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/](http://www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/). Accessed on 11 April 2014.

218 Disability Services Commission, *Local Area Coordination*. Available at: [www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/](http://www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/planning/local-area-coordination/). Accessed on 9 April 2014.

219 Submission No. 13 from Disability Services Commission, 2 January 2014, p2.

220 *ibid*, Attachment B.

evaluations.<sup>221</sup> PWdWA executive director Mr Jefferson was also unaware of any evaluations. However, he said if there was an evaluation process, it should be made publicly available.

*You have to have access to the detailed workings of it. You want to know who else is sweeping behind, providing an evaluation of that process, an independent evaluation of that process ... I think the commission are very good at consulting outside consultancies when they want to have a look at something. I would have thought that certainly with the CAP process they could have done something similar. They may well have done and they may well know what the outcomes are—we do not.*<sup>222</sup>

The DSC engaged KPMG to undertake reviews of the Risk Assessment Framework in 2007 and 2009. Using non-identified data extracted from the CAP database, the evaluations assessed the inter-rater reliability (i.e. the degree of agreement between ratings) of the risk factor scores assigned to application criteria by panel members.<sup>223</sup>

#### Recommendation 9

Any evaluations of the Combined Application Process and the Risk Assessment Framework commissioned by the Disability Services Commission should be made available to the public.

### 3.3 Impacts and consequences

A system with many imperfections will inevitably result in a series of related negative impacts and consequences.

#### 3.3.1 The pitfalls of operating in a competitive environment

Intense competition for a limited pool of funds means that in providing the evidence of criticality that the IPAP requires, applicants may be tempted to exaggerate their circumstances. In the same way that desperate job-seekers might over-state their qualifications or experience when applying for a desirable job in a tight employment market, CAP applicants desperate for help might overplay the negatives.

221 Ms Mary McHugh, Manager, Strategic and Executive Services and Prof. Sherry Saggars, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p3.

222 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p9.

223 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – response to questions on notice taken at hearing, 19 March 2014.

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### Case Study 8

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*I have got a son with multiple disabilities. When he got to 18 or 19, I thought, "My other son has moved out of home; it's right for Stephen." So we put in an application. That first application was solely on Stephen's right to move out of home. It was the right time and everything. We never got it. Nine years later, after I do not know how many applications, we managed to get the funding, but that application was on my inability to care for him. The actual process is so soul destroying for families. I do not want to paint my son in a terrible picture. Yes, he has some behaviours that we need to acknowledge, but he is a lovely kid. If I read my application back today, I would think I would not want to know this child. That is what it does to families.<sup>224</sup>*

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People may seek out ways by which they can improve their rating, such as enlisting the help of an experienced LAC or skilled advocates "who are able to ... load an application in a way that could be favoured by the scoring process that is in place".<sup>225</sup> Mr Jefferson, from PWdWA, said that the process encouraged people to exaggerate their situation and it was difficult for advocacy organisations not to collude with that.

*It is very difficult when you are working with people who are quite clearly in desperate crisis, I guess, to not work in a way that is going to help them achieve the outcome that is going to work for them. So what we find is that people who have made applications and seen the result and changed their next application and received a better outcome have then learned perhaps there is some value in using a similar technique.<sup>226</sup>*

Desperation could lead to extreme behaviour such as threatening suicide, or making a child homeless. Anything that might make an application more competitive is fair game (which is the justification for the details of the scoring process and the identities of the panel members not being disclosed).

*... if you are homeless, you have got much more chance of receiving accommodation support funding. Most parents do not want to put their son or daughter on the street to be able to achieve a positive CAP outcome, but if you were prepared to do that—if you were prepared to*

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224 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p5.

225 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p2.

226 *ibid.*

*say, “You can’t live here anymore; off you go”—then it is highly likely that if that was indicated in your CAP application, you would receive more points as a result of that. As a result of that, with certain people, you could imagine that that knowledge could lead to, I guess, some very deliberate acts to try and affect the outcome.”<sup>227</sup>*

*I have heard many stories from families who talk about the fact that they have to go in there and totally exaggerate the amount of dysfunction in their family and their lives to give themselves a chance. People talk about threatening suicide as a way of elevating their situation up the priority list.”<sup>228</sup>*

Whilst acknowledging that it was a competitive environment, Dr Chalmers was doubtful that applicants were “gilding the lily” and suggested that people were more likely to be reluctant to put forward a true reflection of the pressures that they were under.<sup>229</sup> If this is the case, the reasons stated by Dr Chalmers for not publicising the CAP criteria would seem to lack foundation. However, the Committee noted that the overwhelming majority of evidence presented was that people did not down-play their circumstances or plight.

#### **Finding 11**

Because only the most critical and urgent cases are funded, Combined Application Process applicants feel compelled to emphasise the negative aspects of their lives, and in some cases to exaggerate.

#### **3.3.2 Impact on family health and wellbeing**

*We are just at our wits’ end. We have been applying for CAP for six years I think. They give you a short time to put in your application, you wait for months and then you just get a note that says, “Bad luck.” We just do not know where to go. It is like being in jail for 40 years and you have done no crime; nobody wants to help. You do not know what to do.”<sup>230</sup>*

The weeks following the outcome of a CAP round are a busy time for disability advocacy and support groups. PWdWA said that the group took a lot of angry and upset phone calls after the CAP round from people who had missed out, and spent

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227 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p3.

228 Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p4.

229 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p8.

230 Mrs Lesley Ryle, parent/carer, *Transcript of Evidence*, 26 February 2014, p3.

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time counselling them or directing them to counselling services and peer support groups.<sup>231</sup> CASA also provided support to people following the CAP round,<sup>232</sup> as did Kalparrin.<sup>233</sup>

The Committee has been left in no doubt as to the destructive effect of the application process on families. One parent said that after being knocked back it often took weeks to recover, and many families were so traumatised by multiple knockbacks they refused to do any more applications.<sup>234</sup> Having bared its soul throughout the process, the family was then expected to “put itself together and move on”.<sup>235</sup>

While this is an immediate impact of the CAP process, the longer term impact of repeatedly not receiving support is that families find they cannot contribute productively to the community. People begin to suffer mentally and physically from the strain of applying for support, sleep deprivation, exhaustion from never taking a holiday and lack of fulfilment as a result of having given up a career. As spelt out by PWdWA:

*People with disabilities living at home and their family carers are often damaged by the strain, isolation and sense of hopelessness. The risk of physical and mental ill health is very real. The personal and financial costs associated with this can be considerable.*<sup>236</sup>

The irony is that the lack of support for the person with a disability may result in the carer also becoming a burden to the community. If provided with enough support, the carer is able to hold down a job, contribute taxes, maintain a sense of their own identity, and remain healthier. This is consistent with one of the expected benefits of the NDIS – that is, that better funding of the disability sector will have an economic benefit to the nation by allowing carers back into the workforce.

Parents also had to cope with the shame and guilt of putting a child into care when they were unable to cope. A disability sector worker who works closely with families said it was very distressing to see families and individuals reach crisis point and give up hope that their needs would ever be addressed, which in some cases “led to people abandoning their loved one to state care”.

Mr Jefferson said that older parents in particular, who had spent most of their lives caring for a child without any outside help, would not cope well with “the shame of

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231 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p10.

232 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p11.

233 Submission No. 8 from Kalparrin, 20 December 2013, p3.

234 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3.

235 Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p4.

236 Submission No. 20 from People with Disabilities WA, 3 February 2014, p10.

having put their son away” if it got to a point where they could not cope. In fact they may not even make an application to do so, leading to the possibility of the parent dying at the home and the person with disability not knowing what to do.

But it is not just the older generation who feel this keenly. One young parent at a forum the Committee attended was visibly distressed when speaking of the fear that she may one day have to hand her son over to the government because she would not be able to cope. Becoming a ward of the state was one way of getting a place. Again, according to Mr Jefferson, it was more likely that younger parents would be prepared to do this than a 70-year-old mother, who would perceive it as totally shameful. Of the 4223 children in the care of the CEO of the Department for Child Protection and Family Support (as at 31 March 2014), 317 were recorded as having a disability or were registered with the DSC.<sup>237, 238</sup>

### **Finding 12**

The continual stress of applying for Combined Application Process funding has an adverse impact on the health and wellbeing of carers, who may also end up needing support.

#### **Impact on siblings**

A number of witnesses spoke of the impact of having a child with disability on other children in the family. These children often missed out on things that their peers had because their parents simply did not have the time to dedicate to them.<sup>239</sup> They could suffer anxiety and depression as a result of being exposed to a sibling with severe behavioural issues.<sup>240</sup> They were often called upon to help look after the child with the disability, although later in life, they may choose to have nothing to do with the sibling.

Many spoke of wonderful siblings who loved and supported the child with disability; others spoke about how the family had been torn apart by the stress of caring for a child with disability.<sup>241</sup>

Many spoke of parents wanting to make sure their child had appropriate care before anything happened to them (the parents), because they did not want the child/adult to become the 24-hour a day responsibility of other children in the family. They felt this was an unreasonable expectation.<sup>242</sup>

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237 Helen Morton, MLC, Minister for Child Protection, Letter, 28 April 2014.

238 This figure may be an under-estimation since details of a child’s disability are not always formally recorded by the Department for Child Protection and Family Support.

239 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p5.

240 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p1; Submission No. 21, closed submission, 3 February 2014.

241 Submission No. 4, closed submission, 9 December 2014.

242 Parents/carers of people with disability, *Briefing*, 10 March 2014.

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### Case Study 9

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*We receive CAP/IFS funding for our severely autistic child who has no speech and severe behavioural problems include extreme violence towards myself, my husband and our other teenage child (not autistic). Before IFS (2 years ago), we were all feeling like life wasn't worth living anymore. Now we have regular respite every 6 weeks for most of the weekend, we can take our other child on short trips twice a year to give some small amount of "normal" time with us, my husband (who is FIFO) and I can spend some time talking and actually enjoying life for a while instead of doing constant, exhausting behaviour management with our autistic child. Our marriage was very rocky, we were on the brink of separating, our family was miserable, every day we felt overwhelmed and had no fun, no enjoyment, no pleasure in our lives.*

*Our other child has been amazing with the autistic child but in truth her life was nothing like it should have been. I really don't know where we'd be now if it wasn't for IFS and the fantastic people at our IFS service provider, they are wonderful. We are so grateful. All of our families need this type of help.<sup>243</sup>*

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### Case Study 10

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*Lisa is a forty year old lady who has Downs Syndrome. She lives with her parents who are ageing and would love to see her settled before their health deteriorates further. Lisa is one of three daughters. Her sisters are married and have their own families. One lives in Sydney and the other lives in Perth but is always on call if her parents are unwell. Lisa has been accessing respite with the same agency for many years. This is paid for by her parents as she has no funding.*

*She enjoys going as she has a lot in common with the other ladies and she has the use of a spare room in the house. Her parents always thought that this would be good for her to move in permanently when they received some funding for permanent accommodation. They have been applying for four years without success. The agency has told them that they have to fill that vacancy. They are not allowed to use it as a respite bed any longer. Lisa has set her heart on moving in with her friends but if she is not successful in this next round her dreams will be shattered. Her parents would not be able to relax and enjoy time together without having to build their lives around Lisa's life.<sup>244</sup>*

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243 Submission No. 21, closed submission, 3 February 2014, p7.

244 Submission No. 11 from CASA, 23 December 2013, p12.

### 3.3.3 Lack of transparency leads to lack of trust

The lack of transparency which was discussed in section 3.2.6 results in “conflicting perceptions of the process”<sup>245</sup> and people second-guessing the reasons for their lack of success and for other people’s success. NDS WA said that:

*... some suggest that people with challenging behaviour fare better than those with significant physical support needs; some applicants believe that under-estimating the need and applying for less support than the person actually needs is more likely to meet with success ...*<sup>246</sup>

In an environment in which one family has to pitch effectively against another family who is affected by disability, this fostering of misinformation and resentment is destructive. One parent described it as “a degrading race to the bottom”.<sup>247</sup> Carers WA said that some people reported feeling that others who were less needy were getting more than them. The lack of transparency in the decision making process added to people’s sense of feeling unfairly treated.<sup>248</sup>

*I know one family and the mother got on TV and shouted and whatever and they got their funding three or four years ago. I think sometimes it is the squeaky wheel*<sup>249</sup>

*I know other families ... who receive IFS funding. What's not "bad enough" about our situation that they should be eligible and we aren't?*<sup>250</sup>

DDWA said that people did not understand how decisions were made about who received funding, how much and why that amount.<sup>251</sup> There was also a sense that information was being deliberately withheld,<sup>252</sup> which leads to suspicion about who is making decisions and even whether there may be the opportunity to influence or manipulate the system. It led one parent to ponder whether the DSC was “running a system based on the personal bias of LACs against the people they exist to serve and

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245 Submission No. 16 from National Disability Services WA, 17 January 2014, p5.

246 *ibid.*

247 Parent/carer of person with disability, *Briefing*, 10 March 2014.

248 Submission No. 19 from Carers WA, 31 January 2014, p5.

249 Mrs Lesley Ryle, parent/carer, *Transcript of Evidence*, 26 February 2014, p7.

250 Submission No. 21, closed submission, 3 February 2014, p9.

251 Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

252 *ibid*; Submission No. 15 from Ms Sue Harris, 15 January 2014, p5; Submission No. 18 from Headwest, 28 January 2014, p8.

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support”,<sup>253</sup> and another wondered whether it was “who you know as to what you get”.<sup>254</sup>

DDWA notes that while LACs are the most common source of information about funding supports, they are not the most trusted source of information more generally. The most trusted sources of information were advocacy and support organisations and other families “and there is a huge level of trust that exists there”.<sup>255</sup>

Mr Jefferson said he did not know who was doing the scoring process (the identities of those on the IPAP panel) and how many were employed by the DSC “and therefore would have the potential for a vested interest or could be influenced”.

As Ms Harvey points out, greater transparency would make all the difference:

*Because there is a lack of transparency and confidence, it sort of creates this sense of competition with people when people start comparing themselves with each other. If people had the opportunity to understand that system and that assessment process better ... people could have a greater level of trust and confidence in that process and how the people who are part of it conduct those assessments. That would be helpful to our system.*

### Finding 13

A lack of factual information about how the Combined Application Process works and how decisions are made leads to dissatisfaction with the system.

#### 3.3.4 Consequences of the WA procurement reforms

The pool of CAP funding available from year to year remains relatively constant unless there is an injection of growth funds. PWdWA suggests that in light of the finite nature of this resource, recent State Government procurement reforms may be adversely affecting people with disability and placing the CAP under even more pressure.

In the 2011-12 budget, the State Government allocated \$600 million over four years to facilitate sustainable funding and contracting with the not-for-profit sector in accordance with the *Delivering Community Services in Partnership Policy*. The funds were rolled out in two tranches: the first (Component I) from July 2011 represented a 15 per cent price adjustment across the board on all eligible not-for-profit community service contracts; and the second (Component II) represented an average increase of

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253 Submission No. 21, closed submission, 3 February 2014, p9.

254 Parent/carer of person with disability, *Briefing*, 10 March 2014.

255 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p5.

10 per cent across eligible contracts to be rolled out over a two-year period from July 2013.

The initiative was designed to achieve a fairer and more appropriate price for services provided by the not-for-profit sector; ensure contracts are outcomes focused for the benefit of end users; and improve procurement processes.<sup>256</sup>

PWdWA indicated that while the underlying principles of the initiative were sound, in reality it had only benefited organisations claiming to serve the interests of people with disability. PWdWA had information from a service provider indicating it would charge significantly more for the support service it delivers under the new arrangements. This would mean that disability clients would not be able to afford the same amount of care.

In an example provided by PWdWA, if a client who had received CAP funding of \$100,000 had been charged a 15 per cent administration fee by the service provider, the client would have had \$85,000 remaining to spend on his/her care (usually spent on paying support staff). However, with some providers increasing administration fees to 25 per cent, the same client would have only \$75,000 to spend on support staff, which would mean a reduction in support staff hours.

As a consequence, in order to maintain the same level of service, the person with disability would require top-up funding which may place more pressure on an already limited pool of CAP funds.<sup>257</sup> Professor Sagggers acknowledges in the most recent IPAP CAP funding report that the increase in applications for changed needs “may have been as a result of new unit process arrangements” following new service agreements.<sup>258</sup>

Disability sector organisations (compared to other community sector providers) have been the beneficiaries of the majority of the State Government funding, receiving more than half of the total allocation.<sup>259</sup> It is true that organisations have benefited most from the injection of funds with a 2012 evaluation finding that 73 per cent of Component I funds went towards staff salaries or benefits. That said there also

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256 Department of the Premier and Cabinet, *Partnership Forum Fact Sheet 4: Sustainable Funding and Contracting with the Not-For-Profit Sector*, June 2012. Available at: [www.partnershipforum.dpc.wa.gov.au/CurrentProjects/Pages/FundingContracting.aspx](http://www.partnershipforum.dpc.wa.gov.au/CurrentProjects/Pages/FundingContracting.aspx) Accessed on 4 February 2014.

257 Submission No. 20 from People with Disabilities WA, 3 February 2014, p8.

258 *Combined Application Process Report from the Independent Priority Assessment Panel, 2nd Round 2013-14 (October –January 2014)*, 20 December 2013, p7. Presented to the Board of the Disability Services Commission, 7 February 2014. Supplied to CDJSC in correspondence from Ms Mary McHugh, Manager, Strategic and Executive Services, Disability Services Commission, 4 April 2014.

259 Dr Ron Chalmers, Director General, Disability Services Commission, Legislative Council Estimates Hearing *Transcript of Evidence*, 27 September 2013, p12.

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appeared to be improvements to service quality, range and number of people served.<sup>260</sup>

Reinforcing the PWdWA claim, the evaluation found some early evidence to suggest that the quantity of service would decline as a consequence of the reforms. Some agencies surveyed believed that given the quality of service is fixed and the price would be determined by agency budgets, the only thing not-for-profit organisations could change would be the quantity of service provided. The evaluation noted that two agencies had already observed a decline in the amount of service provided. Overall however, it was still too early to tell what impact the new policy had on service to end users.<sup>261</sup>

### Finding 14

Procurement reforms may be putting more pressure on funding for people with disabilities.

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260 Department of Treasury and Curtin University, *Sustainable Funding and Contracting with the Not For Profit Sector Initiative and Associated Procurement Reforms – 2012 Evaluation*, Government of Western Australia, December 2012, pp7,11.

261 Department of Treasury and Curtin University, *Sustainable Funding and Contracting with the Not For Profit Sector Initiative and Associated Procurement Reforms – 2012 Evaluation*, Government of Western Australia, December 2012, pp15,27.

## Chapter 4

### The level of unmet need

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**An exploration of the difficulty of determining unmet need, the ways in which it can be hidden, and the disability needs that are currently not being adequately met.**

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*In Western Australia, there is a lack of a true understanding of the level of unmet need in individuals with disabilities and their families. It is essential we have an accurate understanding of this to enable the appropriate provision of services and service evaluation. - Headwest*

When the Productivity Commission inquired into the disability care and support system in Australia in 2011 it observed that there was significant unmet need for disability services throughout Australia.<sup>262</sup> Evidence presented to the Committee suggests that nothing has changed – unmet need is a significant factor in Western Australia in 2014,<sup>263</sup> and has a detrimental impact upon people with disabilities and their families.<sup>264</sup>

#### 4.1 The difficulty of measuring unmet need

Anecdotally, the level of unmet need in Western Australia is high.<sup>265</sup> However it is difficult to quantify due to the lack of data available.<sup>266</sup> Good data is, according to the Productivity Commission, the “lubricant of a well-functioning system”.<sup>267</sup> A key prerequisite for proper planning, according to one former disability sector executive, is the availability of “the best possible data on who needs what now and who is likely to need what, and when”.<sup>268</sup>

While it is possible to obtain broad indications of need using Australian Bureau of Statistics data on disability, State level data showing how many people with disability there are and how many are receiving assistance is hard to come by. While some<sup>269</sup>

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262 Productivity Commission, *Disability Care and Support* (Report No. 54), Commonwealth of Australia, Canberra, 31 July 2011, p111. Available at [www.pc.gov.au/projects/inquiry/disability-support/report](http://www.pc.gov.au/projects/inquiry/disability-support/report). Accessed on 14 April 2014.

263 Submission No. 18 from Headwest WA, 28 January 2014, p8.

264 Submission No. 20 from People with Disabilities WA, 3 February 2014, p9.

265 Submission No. 18 from Headwest WA, 28 January 2014, p8.

266 *ibid.*

267 Productivity Commission, *Disability Care and Support* (Report No. 54), Commonwealth of Australia, Canberra, 31 July 2011, vol. 2, p564. Available at [www.pc.gov.au/projects/inquiry/disability-support/report](http://www.pc.gov.au/projects/inquiry/disability-support/report). Accessed on 14 April 2014.

268 Submission No. 15 from Ms Sue Harris, 15 January 2014, p5.

269 Submission No. 11 from CASA, 23 December 2013, p10; Submission No. 15 from Ms Sue Harris, 15 January 2014, p5.

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believe that the DSC would have this data and are choosing not share it, Dr Chalmers has said that the DSC does not have a record of every person in the State with a disability.

*Ours is an enabling and voluntary service. We do not, in any way, try to identify every person with a disability across WA. It very much relies on individuals stepping forward and using the mechanisms to seek support from the commission. We just do not have that population-based overview; in fact, the Productivity Commission's report was the closest we have come to an overview of that a couple of years ago.*<sup>270</sup>

The Productivity Commission report referred to by Dr Chalmers draws on ABS data, and it seems to be these two sources that are frequently quoted. However, people in the sector in WA, particularly advocacy and support groups, want more detailed data that will identify the number of people in the State that require supports and services to enable the appropriate provision of services and service evaluation.

While some have said that not enough data is collected in the first place, many contributors to the Inquiry said that the amount of data being released by the DSC had decreased. According to Mrs Brensell, not only is good data not collected, "it is certainly not shared responsibly and effectively across sectors and across services".<sup>271</sup>

The DSC publishes a *Disability Support Funding Bulletin*<sup>272</sup> showing the outcomes of CAP funding each year and makes this available on its website.<sup>273</sup> However, the Committee was told by stakeholders that these statistics are not comprehensive<sup>274</sup>. According to one group, the bulletin "appears to serve only to confuse and concern" and "is not helpful in understanding the extent of unmet need across the State or in identifying any demographic hotspots of priority need, or systemic failings".<sup>275</sup>

*People should know how the different subgroups in disability are faring, not so that they can war with each other, just so that we have a picture of what is going on.*<sup>276</sup>

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270 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p15.

271 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p8.

272 Latest Disability Support Funding Bulletin, Issue 2 (September 2013) p2. Available at [www.disability.wa.gov.au/about-us1/about-us/corporate-publications/](http://www.disability.wa.gov.au/about-us1/about-us/corporate-publications/). Accessed on 14 April 2014.

273 Submission No. 13 from Disability Services Commission, 2 January 2014, p2.

274 Submission No. 17 from Developmental Disability WA, 21 January 2014, p5.; Submission No. 11 from CASA, 23 December 2013, p6.

275 Submission No. 20 from People with Disabilities WA, 3 February 2014, p10.

276 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, pp4-5.

Hence, a degree of “guesstimating” occurs when counting unmet need in the current CAP process.<sup>277</sup> Despite the unreliability of using unsuccessful CAP applications as an indication of unmet need, in the absence of anything else, this measure is frequently relied upon according to the CPSU/CSA.<sup>278</sup> Using this methodology “dramatically under-reports the extent of the problem”.<sup>279</sup>

*It does not provide useful data—the sort of data that is essential for planning—rather it provides broad, general data that seems more designed to shine a light on the number of people being helped.*<sup>280</sup>

The DSC no longer publishes bulletins after each CAP funding round as it did previously.<sup>281</sup>

As DDWA states, gaining accurate measures of need is a complex process. Measures of need should seek to anticipate the nature of that need during the course of a lifetime, recognising that people’s need for supports and services could change over time.<sup>282</sup>

It is also worth noting that quantitative measures only tell part of the story. The Committee appreciates that gaining an accurate measure of need is multifaceted.

*Two individual people living with the same functional disability can experience entirely different needs for supports and services based on a range of factors in their lives. Population based measures of ‘need’ often don’t capture those elements of people’s lives and so a range of underpinning supports and services that can support the capacity and resilience of individuals and families is often missed, with the likely impact of increasing people’s risk of developing urgent and critical needs.*<sup>283</sup>

The Committee recognises the importance of accurate and informative data about the nature and level of service needs in communities, in order to understand need, and to plan for the provision of such services.

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277 Parent/carers of person with disability, *Briefing*, 10 March 2014.

278 Submission No. 6 from CPSU/CSA, 19 December 2013, p5.

279 *ibid*.

280 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p2.

281 Submission No. 11 from CASA, 23 December 2013, p6; Submission No. 18 from Headwest, 28 January 2014, p8.

282 Submission No. 17 from Developmental Disability WA, 21 January 2014, p4.

283 *ibid*, p7.

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### Finding 15

Major deficiencies in collection and sharing of data in relation to the unmet need of people with disability in WA make it impossible to plan future services.

### Recommendation 10

That in order to better inform public debate and service provision, the Disability Services Commission augments and makes publicly available, in a variety of formats, its data and analysis relating to the levels and types of unmet need after each Combined Application Process funding round.

## 4.2 Types of unmet need

Unmet need can take a variety of forms. It might be that the very specific needs of a particular disabling condition are not being met, or it might be that the needs of a particular age group are being masked. Unmet need can also be hidden.

### 4.2.1 Hidden need

The Inquiry has identified two main types of hidden need: people who have given up on CAP and withdrawn from the system; and people who have never applied for CAP, for one reason or another, and are not registered in the system.

#### People who give up on CAP

The Committee heard about the prevalence of situations where people had simply given up hope of ever getting CAP funding.<sup>284</sup> Coping with the trauma of missing out on funding was cited by many people as a major factor in withdrawing from the CAP process. As discussed in Chapter 3, many families chose to remain in crisis owing to the stress attached to submitting an application and the duress it placed the entire family under.<sup>285</sup> Applicants already in the pool from previous funding rounds who failed to secure funding often became disheartened and withdrew their submissions.<sup>286</sup>

*Out of pure frustration and heartbreak some choose to withdraw from the process.*<sup>287</sup>

One submission noted that after unsuccessfully applying for out-of-home accommodation for five years, they had given up.<sup>288</sup> Inherent flaws in the CAP process were said to have discouraged applicants.<sup>289</sup>

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284 Ms Sue Harris, *Transcript of Evidence*, 19 March 2014, p3.

285 Submission No. 8 from Kalparrin, 20 December 2013, p4. ; Submission No. 17 from Developmental Disability WA, 21 January 2014, p9.

286 Submission No. 6 from CPSU/CSA, 19 December 2013, p4.

287 *ibid.*

288 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p4.

289 Submission No. 17 from Developmental Disability WA, 21 January 2014, p7.

**Finding 16**

People who give up on applying for Combined Application Process funding are lost from the system and mask the true nature of unmet need.

**People who are not in the system**

Unsuccessful CAP applications are an unreliable measure of unmet need because of the sizeable cohort of people not registered in the disability system.<sup>290</sup> NDS WA noted that “many people do not apply for CAP funding because they are not aware of the option, are advised not to by LACs, find the process emotionally challenging or for other reasons”.<sup>291</sup> Little was known about individuals (and their families) that were not registered with the DSC.<sup>292</sup>

Somewhat alarming was the claim that LACs get a “pat on the back” for retaining funds,<sup>293</sup> which may mean they discourage people from applying. How widespread this practice is has not been determined, but the evidence of one parent that her LAC signed off on a collection of applications (which had previously not been submitted) just before leaving the job lends some weight to the claim.<sup>294</sup>

Ageing carers can also have unmet needs that remain hidden within families until such time as acute intervention is required. With carers becoming older and often carrying a disability themselves, the situation in which an aged carer is no longer able to look after the person with a disability that they have looked after long-term<sup>295</sup> is likely to occur more frequently.<sup>296</sup> According to TCCP, over the next 30 years the number of carers is projected to rise by 57 per cent while the number of aged people needing care will rise by 160 per cent.<sup>297</sup> As Mr Jefferson said:

*We know anecdotally that in those situations where you have got a particularly elderly parent, the carer role changes, so that we have got situations where we have got people with an intellectual or cognitive disability effectively supporting mum, who has looked after them for years ...*<sup>298</sup>

Mr Jefferson reminded the Committee of the “horror stories” of the parent who had died and the person with the disability had not been able to alert anyone.

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290 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p4.

291 Submission No. 16 from National Disability Services WA, 17 January 2014, p7.

292 Submission No. 18 from Headwest, 28 January 2014, p8.

293 Parent/carers of person with disability, *Briefing*, 10 March 2014.

294 *ibid.*

295 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, pp6-7.

296 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p5.

297 *ibid.*

298 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, pp6-7.

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*We do not really know how many people are out there where mum has done this forever and has not actually had any direct contact with the Disability Services Commission because mum and maybe an aunty have provided that support.*<sup>299</sup>

Advances in health care have meant that unlike previous generations, people with disability increasingly outlive their parents. This means that an increasing number of families are facing the dilemma of what will happen to their child when they pass away.<sup>300</sup>

While it is difficult to predict how many ageing carers may need support in the future, figures from the IPAP give some indication of the current situation (bearing in mind that this is not a true reflection of anticipated need because it includes only those who have made an application). IPAP chair Professor Sagggers said that there was no research conducted on the data to indicate trends, but certainly in every CAP round there were a number of ageing carers – people 70-plus – who did not get funded.<sup>301</sup>

The IPAP's most recent report to the DSC board, reporting on the outcome of the CAP funding round completed in January 2014, shows that there were 13 applications for AS from carers aged 80 or over, and 26 from carers aged 71 to 79. Nine carers aged 80 or more had applied for IFS, while five IFS applicants were in the 71 to 79 age group.

Hidden need can also manifest itself in other ways. Carers WA stated that some families were reluctant to use formal services as they were not confident that the service providers would deliver appropriate services to meet the needs of the person with disability.<sup>302</sup>

*Individuals and families with concerns about the appropriateness of formal services are less likely to apply and hence will not be captured in measures of unmet need ... Specific reasons for not using formal services include a lack of confidence that service providers will adhere to values that are consistent with those of the family*<sup>303</sup>.

This could include values relating to particular cultural practices, judgements about allowing sexual activity by younger teenagers, and the need for same sex care workers to provide intimate personal care. The changing of sanitary pads and showering of young women with physical and intellectual disability by male support workers was not

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299 *ibid.*

300 Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p7.

301 Prof. Sherry Sagggers, IPAP Chair, Disability Services Commission, *Transcript of Evidence*, 19 March 2014, p8.

302 Submission No. 19 from Carers WA, 31 January 2014, p7.

303 *ibid.*

acceptable to some individuals and family members and yet occurred in disability accommodation settings.<sup>304</sup>

The Committee was made aware that figures relating to unmet need may be skewed because of people being redirected into alternative funding streams. Dr Chalmers acknowledged that DSC “has been actively involved in assisting people through re-referral to more appropriate funding streams”.<sup>305</sup> One such referral stream is the aged-care system. People with disability re-directed from the State system into an aged-care facility in the Federal system are not recorded by the DSC as an unmet need.<sup>306</sup> In evidence, the Committee heard that this cohort poses a challenge in being recorded as an unmet need.

*The challenge is when people are ACAT-ed.<sup>307</sup> The way the system works at the moment is that if somebody is in hospital and they have high needs and it is evident that they are not going to get funding through the CAP round, they will then talk to the aged care coordinator in the Disability Services Commission, who will then write a letter to the hospital saying that this person is unlikely to receive funding through them in the immediate future and therefore should be eligible for an ACAT. Then the hospital arranges to have the person ACAT-ed and then they move into a nursing home. But there is no record, apart from that initial letter from DSC, of that person within that system, so all those people who have received that letter are actually not recorded in those CAP figures; they do not even know they exist basically.<sup>308</sup>*

The Committee heard that the Commonwealth-State interface is problematical for those navigating the CAP process. Once an applicant is the recipient of any Commonwealth funding they are ineligible for the State-based aids and equipment program. This is best highlighted by an example brought before the Committee by the Brightwater Care Group:

*Even though they are getting some low levels of support maybe through the aged-care system, that lowers their priority for care because they are seen as already getting some service. With this young woman with MS, prior to going into hospital, she had been assessed as*

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304 Submission No. 19 from Carers WA, 31 January 2014, p7.

305 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p8.

306 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p4.

307 This refers to being assessed by the Aged Care Assessment Team.

308 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p4.

## Chapter 4

*requiring an electric wheelchair; she had applied under the aids and equipment program. She was told, yes, she would get an electric wheelchair and had been measured up for it, but before it was delivered, she had the exacerbation of some medical conditions associated with her MS. She could not come home without a package and then had to be assessed for an aged-care package. As soon as she was assessed for an aged-care package, she was no longer eligible for that electric wheelchair. So she had to come home without an electric wheelchair, which would have made a huge difference to her quality of life—just being able to be mobile independently around her home and around the neighbourhood. Fortunately, the MS Society eventually fundraised and got her an electric wheelchair.*<sup>309</sup>

### Finding 17

There is a significant cohort of people with disability unknown to the system because they have never applied for disability support funding.

#### People in Aboriginal and CALD communities

Another area of unmet need relates to people with disability in Aboriginal and culturally and linguistically diverse (CALD) communities. The Committee was told about the lack of knowledge of known need within Aboriginal populations, particularly in rural and remote areas. Aboriginal people with disability were not engaging with the sector as it was not perceived to be accommodating their needs. This in itself understates the needs of this cohort.<sup>310</sup>

*We know historically that Indigenous people often do not engage with services at any level... Indigenous people are often loath to engage with government. So although we know a little about the need in remote areas, as well as metro areas, the extent of known need has not been captured at all. In addition to that, where we do know the need, we also know that historically there has been a limited sector response to Indigenous people with disability. There is also a limited engagement of Aboriginal people as employees to provide services.*<sup>311</sup>

Their understanding of, and accessibility to, the system and/or the processes, and their lack of independent advocacy particularly, were noted by Mrs Brensell as reasons

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309 Ms Sandy Komen, Manager, At Home Services, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p4.

310 Ms Frances Buchanan, Operations Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p5.

311 *ibid.*

Aboriginal and CALD communities do not interface with the disability sector.<sup>312</sup> Nevertheless, 6.9 per cent of all CAP applications are from Indigenous people, which is greater than the representation of Indigenous people in the total WA population (3.5 per cent). However, it may be the case that the need is even greater than that reflected by the CAP.

#### 4.2.2 People whose needs have changed

A common theme emerged from submissions in relation to the changing needs of people with disabilities and represents a major area of unmet need:<sup>313</sup> that is, that the CAP process is crisis-driven and lacks a lifetime approach to care for people with disability.

*Measures of need must not only identify the number of people that will require supports and services, they must also seek to anticipate the nature of that need during the course of a lifetime, recognising that people's need for supports and services can change over time.*<sup>314</sup>

The Committee was greatly concerned at repeated complaints of the inflexibility of the CAP funding model which prevented it from being responsive to the changing needs of individuals.<sup>315</sup>

*Once a person is funded, they should be regarded as being 'in the system'. As their needs change, they should receive more, or less, or no, funding, according to their changing circumstances. Apart from responding more flexibly and appropriately to people with disabilities and families, this will remove the current incentive to ask for as much as you can and cling onto it regardless of what you need, and the strong disincentive of the system as it stands to return funding that is not currently needed.*<sup>316</sup>

More flexibility in CAP funding may go some way towards removing the perceived incentive for requesting more funding than is actually required. NDS WA noted that

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312 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p8.

313 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p3.; Submission No. 16 from National Disability Services WA, 17 January 2014, p5; Submission No. 17 from Developmental Disability WA, 21 January 2014, p8.

314 Submission No. 17 from Developmental Disability WA, 21 January 2014, p4.

315 Submission No. 10 from Ms Neeva Stephen, 22 December 2013, p2.; Submission No. 15 from Ms Sue Harris, 15 January 2014, p4.; Submission No. 16 from National Disability Services WA, 17 January 2014, p6.; Submission No. 20 from People with Disabilities WA, 3 February 2014, p7.

316 Submission No.15 from Ms Sue Harris, 15 January 2014, p4.

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people who are competing against someone who has no funding are perceived as less likely to be successful.<sup>317</sup> The IPAP report made the same observation.<sup>318</sup>

According to Carers WA, planning processes for a person with disability should identify and address the needs of family members in a caring role in order to support the changing needs of the person with disability and the changing needs of the family members.<sup>319</sup> NDS WA highlighted that at present there is no flexibility in the CAP to deal with extraordinary life events between funding rounds. Should an unexpected death of the principal carer or a significant deterioration of the person's condition occur, service providers were expected to fill in the gaps until the next round of funding without additional resources.<sup>320</sup>

NDS WA recommended that a separate allocation of funding be retained for changed need and that the move towards more individualised and flexible responses to individual's needs be reflected in funding processes so that needs could be reviewed when significant life changes occurred.<sup>321</sup> However, PWdWA cautioned that a specific allocation for "changed need" appeared to best serve the interests of service providers and their clients and would severely disadvantage people with disabilities who currently lived at home with family carers who wanted to access long term funding, along with the people trying to vacate health service facilities.<sup>322</sup> According to a parent/carers there was no provision in the current system to say "now we need more".<sup>323</sup>

*I have always said my son was born with a disability. He was registered with DSC from a very early age. They knew he was there. When he was born, I think there should be planning at different life stages for what he needs when he needs it. And the worst thing is when your child gets to 18, you can fall off the perch; nobody seems to know.*<sup>324</sup>

### Finding 18

The changing needs of people with disability throughout their lives is not sufficiently recognised or catered for, resulting in an under-estimation of the number of people in need.

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317 Submission No. 16 from National Disability Services WA, 17 January 2014, p6.

318 *Combined Application Process Report from the Independent Priority Assessment Panel, 2<sup>nd</sup> Round 2013-14 (October –January 2014)*, 20 December 2013, presented to the Board of the Disability Services Commission, 7 February 2014. Supplied to CDJSC in correspondence from Ms Mary McHugh, Manager, Strategic and Executive Services, Disability Services Commission, 4 April 2014.

319 Submission No. 19 from Carers WA, 31 January 2014, p8.

320 Submission No. 16 from National Disability Services WA, 17 January 2014, p6.

321 *ibid.*

322 Submission No. 20 from People with Disabilities WA, 3 February 2014, p7.

323 Parent/carers of person with disability, *Briefing*, 10 March 2014.

324 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p8.

### 4.2.3 People with autism spectrum disorders

The unmet needs of people with autism spectrum disorders (ASD) are said to be growing rapidly with increasing rates of autism diagnosis and reduced government spending.<sup>325</sup> The number of people in Western Australia currently being diagnosed with ASD is approximately 1 in 120, with girls being notoriously under-diagnosed or undiagnosed.<sup>326</sup>

*The government ... needs to become involved with individuals, carers and organisations in the autism community to plan for the “tsunami of individuals with ASD” who will be requiring supported accommodation now and in the future. The human cost of failure to plan now cannot be measured.*<sup>327</sup>

Dr Chalmers said the DSC had invested heavily in WA Autism Diagnosticians’ Forum (WAADF) over the last decade and was mindful that they were under pressure to keep pace with the demand for assessments.<sup>328</sup> Additional funds had been allocated to this area of unmet need in the past couple of years.

*The rigour that is in our process actually requires three different specialists to be doing their stuff and then combining their views: therapists, psychologists and neurologists. That takes time, so it pushes out time frames again waiting for that to happen. We are under pressure. We are conscious of that and we are doing our best to keep pace.*<sup>329</sup>

In the meantime, families are still struggling to find appropriate support for children with ASD.

*Patrick’s support needs are too great to be able to choose CLP [Community Living Program]. CAP is our only option. He is “too high-functioning” for a group home, but not high-functioning enough for CLP. CAP funding for him to live in the community and house share with a support worker is the only option open to him.*<sup>330</sup>

### 4.2.4 Young people in aged care

The Committee gathered evidence from a number of sources relating to the lack of adequate accommodation facilities and age-appropriate supports for young people

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325 Submission No. 21, closed submission, 3 February 2014, p6.

326 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3.

327 *ibid.*

328 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p16.

329 *ibid.*

330 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3.

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with disability.<sup>331</sup> The unmet needs of younger people in aged care are of great concern to the Committee. There is considerable angst in the community about the inappropriate settings young people with disabilities are subjected to, simply because of a lack of suitable alternatives.<sup>332</sup>

Headwest said that appropriate services for adolescents and young adults should be addressed as an urgent priority. The current state of service provision for this age group was severely lacking. Funding opportunities, accommodation facilities, respite care and community activities needed to be developed to ensure there was opportunity for positive long term outcomes of this age group.<sup>333</sup>

Mrs Brensell said that the Australian medical model was good at keeping people alive and getting them back out of the hospital system and into the community. However, after this point, rehabilitation and care needs were generally not met. Accommodation in an aged care facility was not appropriate; staff at aged care facilities did not have the ability or the skills to best support them and provide the caring and nurturing environment that younger people needed.<sup>334</sup>

*Experience shows us that most aged-care settings are simply not suited for younger people ... particularly with complex care needs, especially those with acquired disability due to accident or degenerative neurological conditions. Most people with MS and a lot of other conditions will tell us that they would rather die than go into aged-care.*<sup>335</sup>

TCCP highlighted the plight of people with disability who age prior to their chronological age (showing signs of disabilities that are usually associated with people who are ageing). Services available to them were extremely limited, with many having no option other than to be accommodated inappropriately by the aged care system.

*It is generally known that traditionally disability services are not well equipped to manage the conditions and symptoms of ageing any more than aged care services can meet the specific needs of people with disability. As a result people are forced to fit in with available services rather than services being tailored to meet their needs. Service users*

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331 Submission No. 16 from National Disability Services WA, 17 January 2014, p7; Submission No. 18 from Headwest, 28 January 2014, p9; Submission No. 20 from People with Disabilities WA, 3 February 2014, p11.

332 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p3.

333 Submission No. 18 from Headwest, 28 January 2014, p11.

334 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p3.

335 Ms Susan Shapland, General Manager, Member Services, Multiple Sclerosis Society of WA, *Transcript of Evidence*, 12 March 2014, p9.

*have stated that the process for transferring between one sector and the other is neither transparent nor easily manoeuvrable.*<sup>336</sup>

In the absence of disability-wide sector capacity to respond the situation also arises where young people end up in aged care facilities by “default”,<sup>337</sup> often leaving many of them in a “state of limbo”.<sup>338</sup> Dr Chalmers reported that about 80 young people were affected by this.<sup>339</sup>

Younger people living with disability had to fit in with available services, rather than having the opportunity to choose from a selection of tailor made solutions, according to a submission from Young Onset Parkinson’s Disease (YOPD).<sup>340</sup> A concerned parent told the Committee that sometimes younger people are placed in an aged-care facility because they are resourced to have “medical staff on duty 24 hours a day”<sup>341</sup>. This is also supported in the YOPD submission.

*When the person with YOPD reaches the advanced stages of the disease (stage 4) they will require ongoing 24-hour assistance with the activities of daily living: overseeing medication schedules that can range from every 1-3 hours, dressing, toileting and eating. Of particular concern at present is obtaining urgent access to disability support services, respite care and long-term supported accommodation outside the aged-care system.*<sup>342</sup>

The Committee heard many references to the Younger People in Residential Aged-care (YPIRAC) program. A COAG initiative, YPIRAC was a five-year (2006-2011) intergovernmental agreement jointly funded by the State and Commonwealth governments.<sup>343</sup> The program’s overall objective was to reduce the number of younger people in residential aged care.<sup>344</sup> Since the Commonwealth Government program funding ceased in 2011, the onus has been on the States to self-fund this cohort. The

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336 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p5.

337 Ms Susan Shapland, General Manager, Member Services, Multiple Sclerosis Society of WA, *Transcript of Evidence*, 12 March 2014, p9.

338 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p5.

339 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p10.

340 Submission No. 7 from Young Onset Parkinson’s Disease, 20 December 2013, p2.

341 Parent/carers of person with disability, *Briefing*, 10 March 2014.

342 Submission No. 7 from Young Onset Parkinson’s Disease, 20 December 2013, pp1-2.

343 A copy of the bilateral agreement is available at [www.dss.gov.au/sites/default/files/documents/06\\_2012/combinedbilat.pdf](http://www.dss.gov.au/sites/default/files/documents/06_2012/combinedbilat.pdf). Accessed on 14 April 2014.

344 Disability Services Commission, Annual report, 2011-2012, Government of Western Australia, 2012, p30. [www.disability.wa.gov.au/about-us1/about-us/corporate-publications/previous-annual-reports/](http://www.disability.wa.gov.au/about-us1/about-us/corporate-publications/previous-annual-reports/). Accessed on 14 April 2014.

## Chapter 4

DSC had tried to treat that group as a high priority within the CAP process however Dr Chalmers concedes that “we are still losing ground on that”.<sup>345</sup>

*In our experience, cared for in the right environment, age appropriate and with staff with the right skill sets, younger people age-in-place and die with dignity. Growth funds need to be ongoing or we continually try to play catch-up.*<sup>346</sup>

### Case Study 11

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*Bob was diagnosed with MS in 1998 at the age of 36. His disease was progressive and by 2008, he had lost his relationship, his job and his mobility. In a wheelchair and experiencing the embarrassment of double incontinence, fatigue and difficulties with his activities of daily living, we lodged a CAP application for a care package, requesting \$37 000. HACC and the MS Society services were in place but becoming increasingly inadequate.*

*Bob continued to deteriorate and develop the trigeminal neuralgia, an extremely painful condition of the face, triggered by eating and drinking. He also experienced significant side effects from the medications he used to treat that condition. From 2009 to 2012, he had numerous hospital admissions and we were able to place him in and out of our residential respite home because his poor nutritional status and immobility were leading to diminishing health.*

*In late 2012, the CAP was updated, seeking funding for a high-support accommodation option as he clearly needed access to 24-hour care and support. If support failed to turn up, he was found sleeping in his wheelchair and often sitting in faeces. Bob was admitted to hospital for surgical cleaning of a pressure sore and with no funding through CAP, had an ACAT assessment and was transferred to a nursing home in July 2013. He became increasingly depressed and teary, wanting to go home. Sharing a four-bed room with elderly men was distressing for him. Sadly, Bob died in October 2013, aged 50.*

*We withdrew his CAP application.*<sup>347</sup>

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345 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p9.

346 Ms Susan Shapland, General Manager, Member Services, Multiple Sclerosis Society of WA, *Transcript of Evidence*, 12 March 2014, p9.

347 Ms Susan Shapland, General Manager, Member Services, Multiple Sclerosis Society of WA, *Transcript of Evidence*, 12 March 2014, p9.

## Case Study 12

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*An 18-year-old that an aide used to support had a very sad accident on holidays and went straight from hospital into nursing care. He was 21 when he moved into a nursing home. He could not do anything for himself. To say "yes", he was able to open his mouth slightly to indicate a "yes", and to say "no", he would cry, and that was the only control he had over his body.*

*Sadly, in the nursing home there are a number of other people very different to young Kell who needed support. A number of those people, sadly, had a degree of dementia. One of the ladies with dementia developed a soft spot for this young man and felt that she could ... care for him.*

*With her condition, she did not understand that the young man could only swallow food that has been pureed to almost a thick liquid. He could not chew; he had no chewing muscles. So he existed on a diet of slop, basically. But, like all young men, the lady thought that young Kell would love chips from the canteen, so she would go and buy potato crisps and give them to him, and he cannot chew. So he was often getting pneumonia because the pieces of chip that she crushed up and put in his mouth will go straight to his lungs.*

*The only way to keep him safe from a very well-meaning co-resident was to lock him in his bedroom. This guy, he cannot call out, he cannot unlock his bedroom, he cannot say, "Hey, I need the bathroom now" or "Hey, I'd like to watch telly" or "Can you change a channel" or "I have an itchy head." So he would stay locked in his bedroom between meals where someone will go in and give him his slops for his meal, and he really existed in his bedroom with the door locked.*

*Sometimes someone would remember to put the telly on. I do not know whether he wanted to watch The Morning Show or not but that is what he would get. And that was his existence, because he did not have any alternatives for funding. There is many a sad story like that of younger people with disabilities living in aged-care facilities.<sup>348</sup>*

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348 Ms Frances Buchanan, Operations Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, pp9-10.

## Chapter 4

Finding a solution to appropriately supporting and accommodating younger people with disabilities continues to pose a challenge for the DSC.<sup>349</sup> The State Government has committed \$6 million over three years starting in 2014–15 in support of this.<sup>350</sup> The DSC has expressed its intention to provide purpose-built housing or enhance current support arrangements for younger people with disability who are about to enter or currently live in residential aged-care facilities.<sup>351</sup> This is welcome news to the disability sector which has high hopes that this funding boost will be invested into finding viable support solutions for younger people inappropriately institutionalised in nursing homes.<sup>352</sup>

### Finding 19

The highly inappropriate accommodation of younger people with disabilities in aged care facilities is still occurring.

### Recommendation 11

While the Committee supports the funding commitment for housing for younger people currently in aged care facilities, further initiatives in this area of unmet need should be encouraged. Securing positive, long term outcomes to divert adolescents and young adults from aged-care residential facilities should be made a priority.

#### 4.2.5 People with catastrophic and/or brain injuries

There are many people in Western Australia living with acquired brain injuries (ABI). Individuals who acquire significant and catastrophic injuries represent a significant amount of unmet need in the CAP process.<sup>353</sup> Headwest estimates that approximately 57, 500 people in Western Australia have an ABI.<sup>354</sup>

*We know that the commission only supports – or has registered with it or is known to it – maybe 23 000 people in Western Australia. I used the figure of 57 500 just for ABI, let alone the number of people in our*

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349 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p9.

350 Government of Western Australia, 2013-14 Budget, Economic and Fiscal Outlook, Budget paper No.3, 8 August 2013, pp151-1. Available at: [www.treasury.wa.gov.au/cms/uploadedFiles/State\\_Budget/Budget\\_2013\\_14/bp3.pdf](http://www.treasury.wa.gov.au/cms/uploadedFiles/State_Budget/Budget_2013_14/bp3.pdf). Accessed on 24 April 2014.

351 Disability Services Commission, Annual report, 2012-2013, Government of Western Australia, 2013, p59. Available at [www.disability.wa.gov.au/about-us1/about-us/corporate-publications/#Annual Report](http://www.disability.wa.gov.au/about-us1/about-us/corporate-publications/#Annual%20Report). Accessed on 14 April 2014.

352 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p3.

353 Submission No. 16 from National Disability Services WA, 17 January 2014, p8.; Submission No. 18 from Headwest, 28 January 2014, p8.

354 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p7.

*community who have intellectual disabilities, ASD, physical disabilities and sensory disabilities.*<sup>355</sup>

Headwest stated that brain injury has profound effects on the entire family unit, with family strain, depression, psychological distress, and burden well documented.<sup>356</sup> Supporting family cohesion and connectedness was an important priority for all concerned when working with individuals with an ABI and their families.<sup>357</sup> However, the Committee heard that the CAP process does not always support this.

DDWA recounted anecdotal evidence of people with acquired injuries struggling with unmet need. Of particular concern were “bottlenecks” in the system caused by people remaining in institutional care because they were not able to get support.<sup>358</sup> This was a concern voiced by Headwest also. Mrs Brensell alerted the Committee to instances of “bed-blocking” by people aged 18 years and younger as they generally had “nowhere to go”.<sup>359</sup> Similarly, Janet Wagland from Brightwater Care Group told the Committee that “the hospital system is starting to see a bedding crisis”.<sup>360</sup>

The Committee heard that options available to persons in the 16-18 age bracket who had sustained catastrophic injuries were very limited.<sup>361</sup> The unmet needs of people with injuries was also raised by PWdWA:

*PWdWA is aware of many people who have worked through long, painful recovery and rehabilitation processes only to become stuck inappropriately and unnecessarily in an expensive medical/rehabilitation resource due to the inability of other people, assessed as ready to leave a rehabilitation facility, being unable to achieve funding through the CAP process. These people often describe their situations as hopeless and say that they have resigned themselves to permanently residing with groups of other similarly affected people in health-funded institutionalised care.*<sup>362</sup>

Many saw the introduction of a no-fault injury scheme as alleviating the issue of unmet need for individuals following catastrophic injury. This is discussed in Chapter 5.

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355 *ibid.*

356 Submission No. 18 from Headwest, 28 January 2014, p7.

357 *ibid.*

358 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p5.

359 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p4.

360 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, pp2-3.

361 *ibid.*

362 Submission No. 20 from People with Disabilities WA, 3 February 2014, p11.

## Chapter 4

### Case Study 13

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*The young man was 16 when he was hit by a bus and received catastrophic injuries. He was deemed to be at fault. He has multiple disabilities. That happened January two years ago, so it is just two years post trauma.*

*He spent a year in RPH at Shenton Park in the adult stream even though he was 16. He was ineligible for Brightwater services at that point in time because he was under age. He has had a CAP in for at least four rounds. The family were extremely concerned about where he would go and what he would do.*

*His mum and dad separated during that time and were living in different locations. The dad gave up his professional business as an architect to stay home and be full-time carer. The mum is a senior public servant who now has to work reduced hours in a part-time capacity in a substantive role to also share care.*

*There was nowhere for him to go. He was technically bed-blocking—that is, medically able to leave. The family did not want him to go to a nursing home and the young man himself was fearful. He communicates through a communication aide. It is a device that talks for him. Whether or not it is because of his brain injury, manipulative behaviours became evident and quite strong and he was very fearful. Given that he did not go into a facility, the dad agreed to take him home. Not only is dad and the family dealing with the grief and loss of a son, they are now his full-time carers. They have to maintain his therapy and drive him to Shenton Park every day where he is an outpatient. He has numerous medical operations that are ongoing. He needs intensive therapy.<sup>363</sup>*

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### Finding 20

The Disability Services Commission currently supports only about half of all people in WA known to have acquired brain injuries, representing a large unmet need.

#### 4.2.6 People with genetic/degenerative diseases

The Committee received evidence from Young Onset Parkinson's Disease (YOPD) about the impact of unmet needs on people with degenerative disease. According to their submission there is a lack of awareness across the health sector about the complex

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363 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, p6.

nature of Parkinson's disease and the daily challenges faced by those suffering its debilitating physical, cognitive and emotional effects.<sup>364</sup>

Parkinson's disease was uniformly treated as a condition of the elderly with most services geared towards that belief; however there were many people with YOPD hidden in the community, coping as best they could until a crisis situation occurred. When crisis care was required it had not been available, resulting in long hospital stays with nowhere else to go as their families/carers were no longer able to cope.<sup>365</sup>

#### Case Study 14

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*I spoke last night to a family of a young woman with MS who is now 40—she was 33 when she was diagnosed—and it is quite a rapidly progressing MS. She has had three goes at the CAP application and has been unsuccessful every time. This round they did not put in because they were told by their local area coordinator that they would not get funding and it was a bit of a waste of time.*

*Since then her mother, who is caring for her, now has health issues of her own. We are providing support to this young woman through an aged-care home care package, which is a level 4 package. I guess that is probably where it destroys some of those people who are not successful in CAP applications; sometimes they do not manage to get an aged-care package. It is a level 4 package that is around \$45 000 a year, and you can get that only if you have been deemed ineligible numerous times for other packages.*

*However, that is a Commonwealth-funded package and the Commonwealth is tightening up on that, so the ACATs have been told that they cannot make people under 65 eligible anymore.*<sup>366</sup>

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The biggest fear amongst those with YOPD was the progression to a total loss of independence and being placed in an aged care facility.<sup>367</sup> According to the YOPD submission, in 2011 there were 188 people with YOPD residing in aged care facilities in Australia.<sup>368</sup>

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364 Submission No. 7 from Young Onset Parkinson's Disease, 20 December 2013, p1.

365 *ibid.*

366 Ms Sandy Komen, Manager, At Home Services, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p3-4.

367 *ibid.*

368 Deloitte Access Economics (2011) *Living with Parkinson's Disease: Update*. Cited in Submission No. 7 from Young Onset Parkinson's Disease, 20 December 2013, p1.

## Chapter 4

Brightwater Care Group also provides care for people with degenerative or genetic diseases.

*We have got probably about 10 people at the moment who we are supporting at home who are younger people with some sort of neurological condition, people who have had a stroke, people with younger onset dementia—people in their 50s with dementia—and people with motor neurone disease and things like that. People like that with rapidly progressing conditions and people with Huntington’s disease often find that their condition is deteriorating so quickly that the CAP round is not going to meet them in time.<sup>369</sup>*

### 4.3 Unmet needs beyond the disability sector: a shared responsibility

CAP-related unmet need – and more generally, the “inter-connectedness of people’s needs” – encroaches into policy areas outside of the disability sector.<sup>370</sup> It has become obvious during the course of this Inquiry that meeting the needs of people with disabilities is beyond the capacity of any one agency.

*There is also no doubt that the effectiveness of other non-disability support systems have a flow-on effect on the nature of people’s need for disability supports. Where people with disabilities have poor access to high quality services and outcomes in areas like education, employment, health and housing for example, this will have flow-on effects to their demands for specialist disability supports and services.<sup>371</sup>*

*Our health system is almost funding the deficits in our disability system, and that will continue even under an NDIS model unless there is some effective interface between the systems.<sup>372</sup>*

#### 4.3.1 Bricks and mortar accommodation

There is considerable unmet need in appropriate “bricks and mortar” accommodation. The issue of insufficient housing options for people with disability is not new. In its 2011 inquiry into affordable housing the *Community Development and Justice Standing*

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369 Ms Sandy Komen, Manager, At Home Services, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, p4.

370 Submission No. 17 from Developmental Disability WA, 21 January 2014, p7.

371 *ibid.*

372 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, p7.

*Committee* of the 38th Parliament found that a significant shortfall existed in Western Australia in relation to accommodation and other support services for people with moderate, severe and profound disabilities. The Committee found that only a small number of people with disability were able to access supported housing services despite significant funding increases over the last 20 years.<sup>373</sup>

This scenario remains unchanged. Evidence proffered to this Committee reinforces the Committee's 2011 finding. Matching disability support funding with adequate housing is an essential aspect of successfully meeting the needs of people with disability.<sup>374</sup>

*There has been a three-year funding program of disability housing, which concludes at the end of this financial year.... There is no point, if someone can finally get through the vagaries of the CAP process and actually get some funding to support them in independent accommodation, but then they cannot get housing".*<sup>375</sup>

*The human cost of failure to plan now cannot be measured.*<sup>376</sup>

The 2011-12 State budget allocated \$95.7 million over three years for social housing to support people with a disability.<sup>377</sup> In a joint initiative with the Department of Housing, 169 dwellings accommodating 340 people with disability were to be built.<sup>378</sup> Approximately \$14 million is to be spent in the final year of the program (2013-14),<sup>379</sup> but it is uncertain whether there will be further funding for housing at the conclusion of the program.

### 4.3.2 Mental health services

According to TCCP, mental health services, including psychiatric services is another major area with a considerable unmet demand. The Committee was told that these

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373 Community Development and Justice Standing Committee, *A Fading Dream – Affordable Housing in Western Australia*, Parliament of Western Australia, 3 November 2011, p186.

374 Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p11.

375 *ibid.*

376 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3.

377 Disability Services Commission, *Annual Report 2012-13*, Government of Western Australia, September 2013, p60. Available at [www.disability.wa.gov.au/about-us1/about-us/corporate-publications/#Annual Report](http://www.disability.wa.gov.au/about-us1/about-us/corporate-publications/#Annual%20Report) . Accessed on 22 April 2014.

378 Government of Western Australia, *2011-12 Budget Statements, Budget Paper No.2, Vol. 2*, 19 May 2011, p892. Available at: [www.treasury.wa.gov.au/cms/uploadedFiles/State\\_Budget/Budget\\_2011\\_12/2011-12\\_bp2\\_v2.pdf](http://www.treasury.wa.gov.au/cms/uploadedFiles/State_Budget/Budget_2011_12/2011-12_bp2_v2.pdf). Accessed on 24 April 2014.

379 Government of Western Australia, *2012-13 Budget Statements, Budget Paper No.2, Vol. 2*, 17 May 2011, p680. Available at: [www.treasury.wa.gov.au/cms/uploadedFiles/State\\_Budget/Budget\\_2012\\_13/2012-13\\_budgetpaperno2\\_v2.pdf](http://www.treasury.wa.gov.au/cms/uploadedFiles/State_Budget/Budget_2012_13/2012-13_budgetpaperno2_v2.pdf)

## Chapter 4

services are “overstretched” and are “struggling” to keep pace with the needs of those with a mental illness.<sup>380</sup>

The State’s mental health strategy, Mental Health 2020, acknowledged the challenge associated with dual diagnosis. As people with a disability are more likely to experience mental health problems and/or mental illness, Mental Health 2020 stated that “development and implementation of shared approaches between mental health and services for people with disability and acquired brain injury” was necessary, as was joint planning to better assist people with co-occurring problems and complex needs.<sup>381</sup>

A 10-year Mental Health Services Plan is currently being developed under the joint sponsorship of the Mental Health Commission and Department of Health. This will support the directions identified in Mental Health 2020<sup>382</sup> and will also address recommendations from the review into referral and discharge practices of public mental health facilities conducted by Professor Bryant Stokes. The review conducted in 2012 similarly highlighted the need for programs which associate mental health with disability.<sup>383</sup> The Mental Health Services Plan is due for completion by mid-2014.<sup>384</sup> While it will take some time to implement changes on the ground it is promising that steps are being taken to address mental health services for people with disability.

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380 Submission No. 14 from TCCP, 14 January 2014, p6.

381 Mental Health Commission, Mental Health 2020: Making it personal and everybody’s business, Government of Western Australia, 2011, p36. Available at [www.mentalhealth.wa.gov.au/Libraries/pdf\\_docs/Mental\\_Health\\_Commission\\_strategic\\_plan\\_2020.sflb.ashx](http://www.mentalhealth.wa.gov.au/Libraries/pdf_docs/Mental_Health_Commission_strategic_plan_2020.sflb.ashx) Accessed on 22 April 2014.

382 Mental Health Commission, Western Australian Mental Health Services Plan: Communique 1, nd, p1. Available at: [www.mentalhealth.wa.gov.au/Libraries/pdf\\_docs/Western\\_Australian\\_Mental\\_Health\\_Services\\_Plan-Communique%201.sflb.ashx](http://www.mentalhealth.wa.gov.au/Libraries/pdf_docs/Western_Australian_Mental_Health_Services_Plan-Communique%201.sflb.ashx) . Accessed on 12 February 2014.

383 Department of Health/Mental Health Commission, Review of the admission or referral to and the discharge and transfer practices of public mental health facilities/services in Western Australia, report prepared by Professor Bryant Stokes AM, Government of Western Australia, Perth, July 2012, p9.

384 Hon Helen Morton MLC, Minister for Mental Health, Western Australia, Legislative Council, Parliamentary Debates (Hansard), 12 December 2013, p7704.

## Chapter 5

### Planning required to meet demand for disability support services

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Consideration of the planning requirements that should be taken into account for the implementation of NDIS/My Way, what planning is required for the intervening years, and needs within the sector (staff, housing, an injury insurance scheme) which require government attention.

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*Given that there is already unmet need, within the existing population, NDS WA is concerned that planning for future services does not become de-prioritised and valuable work completed to date set aside.*

*— National Disability Services WA*

As discussed in Chapter 4, determining future need is a complex and inexact science. One thing that is expected, however, is that the number of people who identify themselves as having a disability will increase (NDS WA suggests there will be an increase of 38 per cent by 2024).<sup>385</sup> The number of people who apply for funding is also expected to increase under NDIS.<sup>386</sup> There is also expected to be an increase in people with particular types of disability – for example people with ASD.<sup>387</sup>

The DSC is currently preparing for the NDIS and My Way trials, and it is hoped that the evaluation of these will provide some indication of how much support and what type of support will be needed in the future. Evidence presented during this Inquiry has also given the Committee an insight into where the gaps are and hence, what sort of planning should be taking place from this point on.

#### 5.1 Planning for the NDIS/My Way

DSC has indicated that as the State moves to align with NDIS/My Way, funding will increasingly take the form of individualised packages and self-directed support, and many of the other existing forms of funding will be actively phased out. According to DSC, more people with disability will use My Way and fewer will use CAP until the entire State has transitioned to the My Way mechanism.<sup>388</sup>

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385 Submission No. 16 from National Disability Services WA, 17 January 2014, p9.

386 Submission No. 6 from CPSU/CSA, 19 December 2013, p7.

387 Submission No. 1 from Ms Melissa Kelly, 3 December 2013, p3; Submission No. 21, closed submission, 3 February 2014.

388 Submission No. 13 from Disability Services Commission, 2 January 2014, p6.

## Chapter 5

Although CAP and My Way are both methods of individualised funding, these two funding allocation methods differ significantly in relation to focus, decision making and evaluation of needs. Whereas CAP is geared to fund the most urgent and critical need and relies on a centralised panel to assess funding applications, My Way is underpinned by a more holistic planning philosophy.

This person-centred approach uses My Way coordinators to work through goals and desired outcomes with the person with disability with a view to identifying needs and purchasing supports before a crisis point is reached. Funding decisions are based on what is “reasonable and necessary”<sup>389</sup> to support the individual and are devolved to a local DSC representative rather than determined by a remote central panel.<sup>390</sup>

The NDIS and My Way trials beginning in July 2014 are intended to provide an opportunity to assess how well the systems will work and to make necessary adjustments before final implementation. Given that the trials last for two years, evaluation is likely to be several years away and the system will not commence in full until 2019-20.

In the meantime, disability sector organisations and individuals are keeping a close watch on the evolution of the NDIS/My Way to ensure it delivers what is needed – and that it is in fact delivered at all. While uncertainty about the nuts and bolts operation of the NDIS makes it somewhat difficult to comment definitively on planning, contributors to this Inquiry have nevertheless provided the Committee with their observations, concerns, suggestions and hopes.

### 5.1.1 Resources

An obvious concern raised several times during the Inquiry is whether the DSC will have enough resources to oversee the NDIS/My Way trials without having to divert resources from the areas where the trials are not operating.

DSC director general Dr Chalmers acknowledged that it would be “a tricky time” because from July 1 DSC would effectively be working in three environments: with the My Way model in the lower south-west; with the NDIS model in the Hills (despite not being run by DSC they would need to be mindful of what was happening because the participants were still West Australians with a disability); and with the 83 per cent of people who would continue to be covered by current arrangements.<sup>391</sup> The Committee noted that many people were concerned that their access to funding would be reduced if they were not part of the NDIS or My Way trials.

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389 The same terminology as is used in the National Disability Insurance Scheme Act 2013.

390 Submission No. 13 from Disability Services Commission, 2 January 2014, p6.

391 Dr Ron Chalmers, Director General, Disability Services Commission, *Transcript of Evidence*, 19 February 2014, p16.

Dr Chalmers said the Commission had been preparing for the past year, but acknowledged that the trials would put additional strain on staff. The team in the lower south-west had been expanded to cope with an expected trebling of the number of people who would potentially access support. He said that if this expected demand was replicated across the State, “we have a lot of work ahead of us”.<sup>392</sup>

Future planning would also have to take into account support for people with mental health, which was currently not provided by DSC. Dr Chalmers said that if the NDIS was to be operationalised through the DSC, they would need “teams of people on the ground to be able to make that happen”.<sup>393</sup> In the short term, however, for the impending trial, he was confident that DSC would be ready:

*The reality is that the Commonwealth had a small army of people working on this for two years. We were given eight months to gear up for this, but I would have to say that we are good to go on 1 July, and we are very confident that it is going to roll out well. I cannot comment on the Perth Hills because I have no control over how the national agency is going to roll that out.*<sup>394</sup>

Dr Chalmers said the DSC had also been working closely with the Department of Housing to ensure there would be suitable accommodation for newly-funded individuals who had received support to live away from the family home.

The Committee also raised with Dr Chalmers the issue of ensuring that there are enough service providers primed to cope with the increase in demand and that they will meet required standards.

Dr Chalmers said that when the DSC knew it would be going ahead with the trials it identified a need to increase the rigour of its quality assurance (QA) system. While he did not see any serious issues with the existing QA system, the regularity of independent monitoring meant that there would need to be more of a focus on analysing self-assessments done by organisations, intervening appropriately to deal with particular issues and serious incident reporting. More money would be invested into “the whole raft of machinery within all of that” in the lead-up to July 1. He did not think there was any basis for worrying that services in a non-government organisation would “pale in terms of rigour” when compared with the government service.<sup>395</sup>

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<sup>392</sup> *ibid*, p17.

<sup>393</sup> *ibid*.

<sup>394</sup> *ibid*, p16.

<sup>395</sup> *ibid*, p18.

## Chapter 5

### 5.1.2 The move to individualised services

The DSC has already begun migrating people to an individualised system similar to that of the NDIS, and as such some issues have already been identified. Because an individualised system operates on the basis of individual planning and self-directed care, many of the concerns have been around planning support and capacity – for both service providers and individuals.

Planning processes needed to be suited to the needs of the service users.<sup>396</sup> Headwest believed this could mean the inclusion of interviews or some way for individuals to express and communicate their needs in a way that is suitable for them.<sup>397</sup> Carers WA said that feedback from NDIS launch sites in other States indicated that developing plans that truly reflected the needs of an individual and their family were taking longer than allowed for in funding models. This should be factored into future planning.<sup>398</sup>

At this point it is unclear exactly what role service providers will play in the individual's planning process. According to TCCP and NDS WA, the original intention of the NDIA was that planning would be done by an individual coordinator outside the service provider organisation. This was for reasons of equity and impartiality, ensuring that the service user was not being influenced to use the services of any particular agency.

However, according to NDS WA a high proportion of plans needed to be redone because they were based on insufficient information.<sup>399</sup> The service providers had since applied some pressure on the NDIA to be included, maintaining that they are the ones with the expertise and knowledge that can help inform the process. There had since been some flexibility from the NDIA, allowing service providers to be involved so long as it was with the consent of the service user.

TCCP said that the benefits of relationships built over many years between service users and long term staff who had supported them would have been lost. For some service users, paid support workers were the only family they had known and it was not necessarily in their best interests to have these relationships compromised for the sake of impartiality and equity.<sup>400</sup> NDS WA said relying on the knowledge and capacity of one individual in planning someone's life was "fraught with risk".<sup>401</sup>

TCCP said that while service providers employed experienced support workers who knew their clients well, it was unlikely that they would have the skills required for

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396 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, pp6-7.

397 Submission No. 18 from Headwest, 28 January 2014, p7.

398 Submission No. 19 from Carers WA, 31 January 2014, p8.

399 Mr Terry Simpson, State Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p10.

400 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p7.

401 Ms Frances Buchanan, Operations Manager, National Disability Services WA, *Transcript of Evidence*, 12 March 2014, p10.

developing plans. Planning skills training would need to be provided. It was also important for service providers' financial and IT systems to be reviewed and upgraded so that the funds attached to the plans and the information related to each plan could be stored, easily accessed and be a "dynamic document" as directed by the service user.

Most planning thus far had followed a "tick box" approach rather than being an open, all-inclusive process where the service user and those close to him/her had directed the development of the plan.

TCCP believes that the new planning process will increase accountability and make service provision more transparent. Service monitoring would play a critical role in ensuring that the goals and outcomes outlined in the plan were being achieved, or at least provide reasons for why they were not progressing as well as expected.<sup>402</sup>

Service providers would also need training in how to avoid conflict between people with disability and family members when moving towards greater self-direction.<sup>403</sup> The wishes of the person with the disability did not always align with those of the family or carer – but it was the wishes of the person with disability that needed to take precedence and providers and advocacy groups needed to ensure that their voice was heard.<sup>404</sup>

As the ones in control of their care, service users and/or their carers would also likely need training in employing and managing staff, taxation arrangements, service planning and coordination, and supported decision making.<sup>405</sup> Family members in the decision-making role needed to feel confident that the decisions made reflected the wishes of the person with disability. CASA is also concerned that self-directed care will disadvantage those who are already especially disadvantaged due to their own personal limitations and/or their family or social circumstances.<sup>406</sup> CASA quotes an article by Anglicare Australia CEO Kasy Chambers which suggests that in the "highly contested and growing marketplace of disability and aged care, the most obvious business models are likely to privilege the privileged"; the poorest and least capable might not do so well because they were more "complicated, demanding and distracting" and would not look like a good business opportunity.<sup>407</sup>

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402 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p7.

403 Submission No. 19 from Carers WA, 31 January 2014, p8.

404 Mr Andrew Jefferson, Executive Director, People with Disabilities WA, *Transcript of Evidence*, 4 December 2014, p14.

405 Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, pp6-7.

406 Submission No. 11 from CASA, 23 December 2013, p1.

407 Kasy Chambers, "Is Australia becoming comfortable with inequality?" *The Drum*, 18 October 2013. Available at [www.abc.net.au/news/2013-10-15/chambers-anti-poverty-week/5022920](http://www.abc.net.au/news/2013-10-15/chambers-anti-poverty-week/5022920). Accessed 23 April 2014.

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### Recommendation 12

That the Minister for Disability Services ensures that adequate training is provided to ensure disability service providers and disability service users are equipped to negotiate and manage the terms of individual plans and employment relationships.

#### 5.1.3 What happens in the interim

While there is a groundswell of support for the NDIS and optimism around the prospect of its introduction, there is also concern at what will happen to disability services in the meantime. If introduced, the NDIS is still six years away – too long to wait for many families who need assistance now. The issue of unmet demand will continue.

While the DSC has been moving toward an NDIS type of model through My Way, and would continue to do so with or without the NDIS, the critical difference between the two models is the system of funding and eligibility. Lack of funds is recognised as the biggest impediment to meeting need in the current system. As such, maintaining and preferably increasing disability funding in the years leading up to the NDIS was the most common recommendation made by people in the sector, along with the need for vigilance.

*The main point I would like to make is that between now and when the NDIS eventually gets going, if it does—around 2020—we still have people in critical need. We seem to have taken our eye off the ball. We have all been working for the NDIS to get it up and going, but we seem to have just taken that bit of pressure off what is needed now. People cannot wait until 2020.*<sup>408</sup>

As PWDWA says:

*No matter what the process of applying for funding is, the lack of available funding between now and the full rollout of the NDIS in 2019 is a most serious and pressing problem ... committing time and resources to reforming the current processes is secondary to the urgent need for greater resourcing. PWDWA considers that the provision of significantly greater funding levels is the only meaningful way to address the crisis in unmet need.*<sup>409</sup>

NDS WA was planning to keep a close eye on the State Budget:

*... that will be the test: the extent to which there is growth funding that is quite separate and distinct from the funding under the*

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408 Mrs Carol Franklin, CASA, *Transcript of Evidence*, 26 February 2014, p2.

409 Submission No. 20 from People with Disabilities WA, 3 February 2014, p7.

*Commonwealth-State agreement for the trial sites ... to continue to cater with just the enormous and growing unmet need across the entire State, otherwise we will have enormous inequity between the trial sites and the rest of the population.*

And a parent/carer put the case even more plainly:

*Clearly more funding applications need to be granted, so the State Government needs to find a way in the budget to make it happen. More individuals with disabilities and their families being supported will directly lead to more people – with and without disabilities – in the workforce, thereby flowing through to the budget. I just don't understand the short-sightedness of State Government after State Government not realising that adequately and appropriately supported people with disabilities and their families are the answer to the future of this State (and country, for that matter).<sup>410</sup>*

DDWA urged the Committee to call for “significant funding increases for disability supports and services to continue to address unmet need until the resolution of the final NDIS/My Way outcome”.<sup>411</sup>

Others, as well as acknowledging the necessity of funding, called for a more equitable system of allocating funds.

*While the NDIS promises that the needs of all people will be met, it could be up to six years before the Scheme is fully implemented. Until this time, there needs to be an accessible and equitable funding application process to ensure individuals with disabilities and their families have the support, service provision and quality of life that is their right.<sup>412</sup>*

But not everyone was supportive of modifying the system during a period of change. Ms Harvey thought it would be difficult.

*To go through a change process within CAP when there is so much reform happening at the moment, and trying to make too many changes in CAP while this other system is happening, might be quite difficult to manage ... I would probably caution against trying to tinker too much with the system while we are watching what is happening*

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410 Submission No. 10 from Ms Neeva Stephen, 22 December 2013, p2.

411 Submission No. 17 from Developmental Disability WA, 21 January 2014, p3.

412 Submission No. 18 from Headwest, 28 January 2014, p4.

## Chapter 5

*here, but I certainly think we need to continue the growth in funding for those supports and services.*<sup>413</sup>

### Recommendation 13

The level of growth funding for disability support must be maintained at the current level (including indexation) or increased in the intervening years from now until the introduction of a national disability insurance scheme.

#### 5.1.4 Misgivings and cautionary words

Despite the generally positive sentiment towards the NDIS, those in the industry have some misgivings – in some cases because of what they know it will not deliver, in other cases because they are not certain of what it will deliver. Some words of caution are also offered. DDWA is concerned about the way in which “reasonable and necessary” supports will be negotiated.<sup>414</sup> DDWA is particularly interested in the expectations of the level of informal support to be provided by families, and what support is also available to those families to provide the informal support that is expected of them.

According to NDIS principles, informal, family and community supports should be explored and supported in the planning process prior to consideration of any funded supports (a principle adopted by the DSC and enshrined in its Individualised Funding Policy). These are sometimes also called “natural supports” – family, friends, neighbours or organisations (for example, volunteer networks) that surround and support a person.

DDWA is concerned that the current system tells people with disabilities and their families that they should seek out formal supports and services as a last resort only, and that informal and community-based connections must play a greater part in meeting needs,<sup>415</sup> without necessarily investing in empowering and supporting people to build and maintain those networks. If this is also the way the NDIS is destined to operate, there will need to be greater investment in early intervention and in support for the informal network. Ms Harvey said that while the NDIS model acknowledged the

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413 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p9.

414 This terminology, which is also used in the National Disability Insurance Scheme Act, was also queried during parliamentary debate on the Disability Services Amendment Bill 2014 – see Dr Tony Buti and Ms Andrea Mitchell, Western Australia, Legislative Assembly, *Parliamentary Debates* (Hansard), 8 April 2014, p2260b-2266a.

415 See DSC Individualised Funding Policy, 5. Principles – Individual Planning: “Any informal, family and community supports should be explored and supported in the planning process prior to consideration of any funded supports” and 5. Principles – Individualised funding scope: “Any formal supports are complementary to, and supportive of, the primary role of family, friends, networks and community in ensuring a good life for the person and will not replace these more natural supports.”

need to provide more capacity-building support, there was no explanation of how this would be achieved.<sup>416</sup>

Brightwater Care Group's Janet Wagland was also concerned about the lack of vision for early intervention programs under the NDIS.

*... at the moment anecdotally we are hearing that most of that early intervention is just random packages – so handing somebody some funding for six weeks' worth of physiotherapy or another bit of funding for six weeks' worth of speech pathology. There is no integrated early intervention approach to support people in achieving long-term outcomes that will ultimately reduce their cost of care.*<sup>417</sup>

My Way also had no framework to support early intervention strategies, according to Mrs Wagland. Likewise, neither system provided for funding to improve the capability and independence of someone with an injury disability, even though this would ultimately mean less intensive support would be needed in time, freeing up dollars for other people coming into the system.

Mrs Wagland was also concerned that the interface between the NDIS and other government departments was not optimal. Other government departments were often relevant to people with brain injuries and degenerative diseases – for example the health system, the justice system, the education system and the mental health system.

*The NDIS, as it has been presented to us at this point in time, is not so much looking at interface but more gatekeeping as to who will pay for what. For a group of people who are spread across a number of services, if you do not have an effective interface, you are not going to be picking (them) up ...*<sup>418</sup>

Someone who did not nominate themselves for disability care would not necessarily be referred if they came into contact with the other systems. Mrs Wagland wondered how it would be possible to determine the numbers of people who required support if there was no connection between the government departments, which was “a huge concern for this particular group”.

Expanding on the problem of self-nominating for support for people with cognitive disabilities, Mrs Wagland said that people with neurological disabilities who had acquired a disability from a disease process such as Huntington's disease, MS or motor

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416 Ms Taryn Harvey, Chief Executive Officer, Developmental Disability WA, *Transcript of Evidence*, 26 February 2014, p7.

417 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group, *Transcript of Evidence*, 12 March 2014, p5.

418 *ibid*, p6.

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neurone disease, or who had acquired a brain injury, often had a cognitive disability. Features of cognitive disability included lack of initiative and lack of insight which would make it extremely difficult to obtain support in a system that required people to self-nominate and describe their care needs.

There was also a suggestion that some private sector service providers may be less than enthusiastic in their support for the NDIS because, with funding delivered to the client rather than the agency/provider, they feared a loss of revenue and control.<sup>419</sup> Under the NDIS, the client will choose his/her own service provider, and the service provider will be paid after delivering the service, rather than before. Service providers who want to deliver services under the Scheme must register with the NDIA.

At present, according to the head of one support group, larger service providers were able to wield influence with the DSC and even the Minister for Disability Services. Even with the start of the transition to My Way, which is based around individualised funding, certain groups were able to “heavily influence” what happened and maintain connections with the DSC.<sup>420</sup>

*There are probably a handful of the bigger players that are at the table every single time and they do have first and foremost their businesses as their primary concern.... We could call it a purple circle, we could call it a circle of security – we could call it a lot of things. I suggest it does exist.*<sup>421</sup>

### 5.1.5 Evaluation

Many in the disability sector are looking forward to the evaluation of the NDIS and My Way trials, but stressed the importance of an independent and thorough evaluation. While the NDIS evaluation in other states is being undertaken by the National Institute of Labour Studies from Flinders University, the evaluation of WA’s NDIS trial (and the My Way trial) will be conducted by a consultant appointed by the DSC. Tenders to conduct the evaluations closed at the end of April 2014.<sup>422</sup>

NDS WA said WA was in a unique position in being able to trial both My Way and NDIS, and hoped for an “independent and thorough, evidence-based evaluation and comparison of both pilots” so that the best model could be selected for the future. It

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419 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, pp4-5.

420 *ibid.*

421 *ibid.*

422 At the time of tabling this report the successful tenderer had not been announced.

also recommended that a quality of life assessment be included for both so that there is a comparison of difference made to the life of the person with a disability.<sup>423</sup>

CASA said that the WA Government's assertions that its approach to disability service provision was superior to that of other jurisdictions (including a nationally controlled and governed scheme) would need to be backed up with "rigorously and independently tested data and analysis". Careful monitoring would also be required to assess whether NDIS outcomes differed between people with different disabling conditions (especially those with intellectual disability compared to other disabilities) and/or according to the severity of the condition and complexity of needs that result.<sup>424</sup>

NDS WA also recommended that planning processes seek input from the disability services organisations and acknowledge their significant expertise, experience and relationships with people with disability and their families.<sup>425</sup>

The DSC's Joint Steering Committee<sup>426</sup> will be overseeing the evaluation. Given that the DSC is also responsible for appointing the evaluator, the Committee expects that the evaluation will be closely scrutinised for signs of any bias.

### Finding 21

The Committee is concerned that genuine comparison of the WA NDIS and My Way trials with those of the NDIS trials in other States may be compromised due to the evaluations being conducted by different bodies.

### Recommendation 14

That the Minister for Disability Services ensures that evaluations of the NDIS and My Way trials are independent and compatible.

## 5.2 Other planning needs to meet future demand

### 5.2.1 Sector-wide planning

The DSC has been working on a Sector Development Plan which was intended to guide the long-term sustainable development of the disability services sector and ensure services continued to meet the needs of people with disability. While the plan was expected to focus on funded services it would also promote better understanding of, and investment in, community-based supports. As the plan was also designed to be a

423 Submission No. 16 from National Disability Services WA, 17 January 2014, p10.

424 Submission No. 11 from CASA, 23 December 2013, p8.

425 Submission No. 16 from National Disability Services WA, 17 January 2014, p9.

426 This consists of "senior officials from First Ministers' departments, disability departments and other disability stakeholders". Disability Services Commission, A comparative evaluation of the two Western Australian trial site models, 19 February 2014, p1. Available at: [www.disability.wa.gov.au/Global/Publications/WA%20NDIS%20My%20Way/WA-Comparative-Evaluation-Terms-of-Reference-February-2014.pdf](http://www.disability.wa.gov.au/Global/Publications/WA%20NDIS%20My%20Way/WA-Comparative-Evaluation-Terms-of-Reference-February-2014.pdf). Accessed on 24 April 2014.

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resource document for government/funding bodies, service providers, people with disabilities and their families/carers, it would also contain information on disability services in the broader context, including “workforce, training and development, quality assurance and housing”.<sup>427</sup>

The process so far has involved a geographically based assessment of the current service system with a view to identifying current and future demand, service gaps and areas for development.<sup>428</sup> The DSC has applied population data from various sources as well as CAP data on unmet demand to compile area profile consultation documents for seven metropolitan areas, eight regional areas and a state-wide overview document.<sup>429</sup> DSC invited written feedback on the profile documents and conducted focus groups/interviews to inform strategies to address the priorities identified in each area.

The Sector Development Plan was due to be published at the end of 2013. The Community and Sector Development directorate, which was responsible for coordinating development of the plan, was recently decommissioned and its functions transferred to other parts of DSC.<sup>430</sup> This has concerned NDS WA, which said that the directorate’s work on the sector development plan had not yet been translated into a plan for the future. It was also concerned for the future of the Count Me In strategy, which established 13 priorities for shaping a positive future for people with disabilities and their families/carers in WA.<sup>431</sup>

Several other groups (TTCP, Therapy Focus and DDWA) also expressed hope that the Sector Development Plan, which had collected valuable data, would not be neglected. In a recent communication, DSC said the plan was still in the process of being finalised. The DSC was considering which initiatives within the plan to prioritise in order to ensure the sector was equipped to meet “the short-term requirements” of disability reform initiatives and current commitments, including the NDIS My Way trial, the National Disability Strategy and Count Me In.<sup>432</sup>

### 5.2.2 Staffing

Concerns about having sufficient disability care workers to meet growing demand are being fuelled by the cutting of government disability services. Some in the sector are

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427 Disability Services Commission, *Sector Development Plan – Disability Services. Concept Paper*, Government of Western Australia, nd, pp1-7.

428 *ibid.*

429 Disability Services Commission, *Sector Development Plan – Area Profile Documents*, nd. Available at: [www.disability.wa.gov.au/reform1/reform/sector\\_development/sector\\_development\\_plan/sector-development-planarea-profile-consultation-documents](http://www.disability.wa.gov.au/reform1/reform/sector_development/sector_development_plan/sector-development-planarea-profile-consultation-documents) Accessed on 6 February 2014.

430 Disability Services Commission, *Sector e-Bulletin*, Government of Western Australia, September 2013, pp2-3.

431 Submission No. 16 from National Disability Services WA, 17 January 2014, p9.

432 Dr Ron Chalmers, Director General, Disability Services Commission, Letter – response to questions on notice taken at hearing, 19 March 2014.

not convinced that workers leaving the government sector will take up positions in the private sector, mainly because the wages and conditions offered are said to be inferior. The CPSU/CSA claims that many DSC employees have reported to the union that they will leave the disability sector if they are obliged to change employer.

The DSC said that the injection of government viability and sustainability funding in the past two years had made a huge difference to wages in the non-government sector. Dr Chalmers said that while he may have had some concerns a couple of years ago at the differential between government and non-government services, feedback from the non-government sector was that they were in a much better position now and were able to provide attractive packages to staff. However, the Committee was unable to verify that this was the case.

According to the CPSU/CSA, the not-for-profit sector would continue to struggle to attract and retain staff. The union quotes a report by PricewaterhouseCoopers and the Centre for Social Impact<sup>433</sup> that found that not-for-profit providers were already struggling to satisfy demand, casting doubt on their ability to absorb future increases in demand.

The CPSU/CSA argued that the cutting of government direct service delivery and the consequent loss of well-qualified and experienced workers would potentially decrease the capacity of the disability sector overall. It argued that a robust public service could work closely with the not-for-profit sector to address the demand for services and provide a stable workforce in the areas where not-for-profits have difficulty. “A service delivery model with complementary Government and NFP sectors will provide better outcomes than a heavily burdened NFP sector operating in isolation.”

Several organisations and individuals – including parents – have called for remuneration for support workers to be adequate. One parent was concerned that families would not be able to find people willing to care for their disabled children if they are paid less than \$23 an hour – but did not expect that they should do the job for less.<sup>434</sup>

#### **Recommendation 15**

That the Minister for Disability Services ensures that contract arrangements for disability services contain a commitment that wages and conditions for disability care workers in the non-government sector are at least equal to those of disability care workers in the government sector.

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433 PricewaterhouseCoopers and The Centre for Social Impact, *PwC-CSI Community Index: Not-for-profit sector survey results*, May 2013.

434 Parent/carer of people with disability, *Briefing*, 10 March 2014.

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### 5.2.3 Housing and appropriate accommodation

As discussed briefly in Chapter 4, the lack of universal housing is a significant unmet need. In looking to the future, consideration should be given to not only housing construction (as mentioned previously) but to the different types of accommodation that should be offered. There is widespread dissatisfaction with the accommodation models currently in place. The Committee repeatedly heard grievances from dissatisfied families, carers and advocacy groups about the dearth of suitable supported accommodation that exists for people with disability of all ages, but in particular those under 65 years of age.<sup>435</sup>

Several contributors noted the difficulty of maintaining family connections when a member of the family – perhaps a husband and father – was in an institutional facility with no allowance for privacy.

*Say, for example, it is a 40-something-year-old male who has a wife and two children. That is not only not a grand environment for young kids to be hanging out in, but also it is not an acceptable environment for that younger person to have intimate moments with his wife, nor is it conducive to him having his friends over for a barbecue, to have a beer or to do all those things that a 40-something-year-old person might naturally be doing. I do not think that disability or a brain injury excludes people from having a good life, or at least having an opportunity to experience those things.*<sup>436</sup>

The Committee advocates better consumer-choice in accommodation settings for people with disability. Empowering people with disability to be able to make choices as to where they would like to live or who they would like to live with is not a characteristic of the CAP process. It limits group living options<sup>437</sup> (as mentioned previously – see section 4.3.1) and there are limited opportunities for cluster living.<sup>438</sup> This was a particular complaint of one parent and long-time advocate who maintains that a cluster living arrangement – whereby people live in their own unit/home alongside other people with disabilities with their own unit/home – is financially and socially sensible.

*The purpose of cluster living as opposed to single homes in the community is the family atmosphere. Birds of a feather- flock together!*

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435 Submission No. 5 from Mr William Booth, 18 December 2013, p1.; Submission No. 12, closed submission, 23 December 2013, p.4.; Submission No. 14 from The Centre for Cerebral Palsy, 14 January 2014, p4.; Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, p2-3.

436 Mrs Lee-Anne Brensell, Chief Executive Officer, Headwest, *Transcript of Evidence*, 19 March 2014, pp3-4.

437 Submission No. 15 from Ms Sue Harris, 15 January 2014, p3.

438 Submission No. 5 from Mr William Booth, 18 December 2013, p1.

*Is this lifestyle successful? Well, just ask the residents who don't want to move. And when mum and dad fall off the perch they will be family to each other.*<sup>439</sup>

It was unrealistic to think that integration with the general community would mean that people with intellectual disability would be looked after. A clustered community would provide greater support.<sup>440</sup>

Greater investment in disability-specific accommodation facilities should also be considered, to ensure that the care and support provided reflects the specific needs of the person. Carers within aged care facilities were not trained to care for people with Parkinson's disease, according to a parent/carer.

*The accommodation in a nursing home is clearly inappropriate for people with Parkinson's, whether they are under 65 years or over. WA needs specific facilities for people with Parkinson's where trained staff know about the importance of receiving the pills on time, the impact of protein on pill uptake and the variability of the symptoms of the disease. These are very important factors in optimising the ongoing wellbeing of a Parkinson's sufferer.*<sup>441</sup>

PWdWA maintains that cultural and lifestyle preferences of a person with disability should be given greater emphasis,<sup>442</sup> and this could be realised through more appropriate accommodation. The existing disability standards (as part of DSC's overall quality assurance system) should assist continuous sector-wide improvement and encourage service providers to offer the most appropriate care. The standards, developed collaboratively by Australian and state governments, consumers and service providers, have been in place since 1993 and DSC promotes their implementation within all services it funds or provides. In particular the standard pertaining to individual needs specifies that services should be provided "in a manner sensitive to the age, sex, and the cultural, linguistic and religious background of each person with disability".<sup>443</sup>

Updated National Disability Standards for disability service providers were published in December 2013 and endorsed by all Australian jurisdictions. The national standards comprise even more extensive indicators of practice relating to individual outcomes, and require service planning and delivery to be "responsive to diversity including

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439 *ibid.*

440 *ibid.*

441 Submission No. 12, closed submission, 23 December 2013, p.4.

442 Submission No. 20 from People with Disabilities WA, 3 February 2014, p9.

443 Disability Services Commission, *Disability Services Standards*, Government of Western Australia, June 2011, p11.

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disability, age, gender, culture, heritage, language, faith, sexual identity, relationship status, and other relevant factors”.<sup>444</sup>

### Finding 22

There is a lack of accommodation to appropriately meet the cultural and lifestyle preferences of people with disability.

#### Recommendation 16

That the Disability Services Commission’s quality management framework focuses on providing accommodation services appropriate to gender, age, cultural and lifestyle values.

#### Recommendation 17

That the Disability Services Commission and Department of Housing provide a greater variety of accommodation options for people with disability, such as cluster living arrangements.

### 5.2.4 Status of the no-fault injury insurance scheme

In 2011 the Productivity Commission recommended the implementation of a National Injury Insurance Scheme (NIIS) to complement the NDIS. The NIIS is a no-fault insurance scheme intended to cover all medical, rehabilitation and ongoing care costs arising from newly acquired catastrophic injury. The care needs of people with existing catastrophic injury would be met through NDIS. It is envisaged that the NIIS will primarily be funded from insurance premiums and operate as a federation of state-based schemes.<sup>445</sup>

Some states (New South Wales and Victoria) already have no fault insurance schemes, however this is not available to people in Western Australia and there is no timetable for a scheme to be introduced in this State.<sup>446</sup>

The State Government has not committed to the NIIS but supports it in principle and is considering how it might be applied to WA.<sup>447</sup> An increase of \$87 to vehicle registration premiums to cover the no-fault motor vehicle accident insurance scheme was

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444 Department of Social Services (Commonwealth), *National Standards for Disability Services*, Australian Government, December 2013, p16.

445 Productivity Commission, *Disability Care and Support* (Report No. 54), Commonwealth of Australia, Canberra, 31 July 2011, pp851-852, 913.

446 Submission No. 20 from People with Disabilities WA, 3 February 2014, p12.

447 Hon Helen Morton, MLC, Minister for Disability Services, Western Australia, Legislative Council, *Parliamentary Debates* (Hansard), 6 August 2013, p2564.

suggested in December 2012.<sup>448</sup> Adopting the State scheme would be a key step towards establishing a national scheme.

### Case Study 15

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*We have one young gentleman—this speaks to both the Insurance Commission and our court system as well—who was travelling in a car. He was a young person from Albany. He was a passenger in the car. The vehicle hit a horse that had escaped from a farmer's paddock. He is not deemed as being eligible for motor vehicle [accident] compensation because the liability actually lies with the farmer for letting the horse out. Therefore, he is not getting any funding.*

*He has got extremely high disability—a high physical disability, a high cognitive disability. He has very low awareness of what is happening around him. His family have in fact sold their property in Albany and have moved to Perth. They have bought a property in Perth, and they have renovated it, expecting him to eventually come home to them. He has been in the round for at least two years and he has not received any funding at all. He is still living in what is supposed to be a transitional service.*

*He has been badly done by due to the lack of a no-fault system to begin with, and that means that he is then not able to actively look at, apart from our transitional service, additional therapy and support because he is not receiving that level of compensation funding, that early intervention-type of funding, but also he is not getting any funding for long-term permanent care.<sup>449</sup>*

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NDS WA, PWDWA and Headwest have called on the State Government to introduce the scheme as soon as possible. Mrs Brensell said she would be concerned if the May State budget did not show any commitment towards the introduction of a no-fault accident insurance scheme. She said the cost savings would be massive, and NDS WA said the scheme would take pressure off the CAP.

*I am not convinced that anyone, should they face this situation or should they know someone in this situation, would not agree to pay a little bit more if it means that someone with a catastrophic injury is cared for the rest of his or her life.*

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448 A. Probyn and S. Wright, '\$87 car rego rise: WA accepts need for no-fault crash insurance scheme', *The West Australian*, 18 December 2012, p1.

449 Mrs Janet Wagland, Manager, Services for Younger People, Brightwater Care Group *Transcript of Evidence*, 12 March 2014, p3.

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In the short-term, the State Government asserts it will meet the care and support costs for people who sustain a catastrophic injury within the NDIS/My Way launch sites in WA, in accordance with agreements with all other governments.<sup>450</sup>

### Recommendation 18

That the State Government expedites a timetable for the adoption and implementation of the National Injury Insurance Scheme.



MS M.M. QUIRK, MLA  
CHAIR

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<sup>450</sup> Disability Services Commission, *Disability Reform in Western Australia – Fact Sheet*, Government of Western Australia, 19 August 2013, p44.

# Appendix One

## Committee's functions and powers

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The functions of the Committee are to review and report to the Assembly on: -

- a) the outcomes and administration of the departments within the Committee's portfolio responsibilities;
- b) annual reports of government departments laid on the Table of the House;
- c) the adequacy of legislation and regulations within its jurisdiction; and
- d) any matters referred to it by the Assembly including a bill, motion, petition, vote or expenditure, other financial matter, report or paper.

At the commencement of each Parliament and as often thereafter as the Speaker considers necessary, the Speaker will determine and table a schedule showing the portfolio responsibilities for each committee. Annual reports of government departments and authorities tabled in the Assembly will stand referred to the relevant committee for any inquiry the committee may make.

Whenever a committee receives or determines for itself fresh or amended terms of reference, the committee will forward them to each standing and select committee of the Assembly and Joint Committee of the Assembly and Council. The Speaker will announce them to the Assembly at the next opportunity and arrange for them to be placed on the notice boards of the Assembly.



## **Appendix Two**

### **Inquiry Terms of Reference**

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On 13 November 2013 the Community Development and Justice Standing Committee resolved to conduct an inquiry into the provision of funding for accommodation and intensive family support services by the Disability Services Commission. The inquiry will examine:

1. The adequacy of current processes for determining funding support for people with disabilities who live with their families;
2. The level of unmet need; and
3. The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future.



## Appendix Three

### Submissions received

Submission number	Name	Position	Organisation
1	Ms Melissa Kelly	Parent of person with disability	
2	Mr Paul Smale	Parent of person with disability	
3	Ms Lesley Pascoe	Parent of person with disability	
4	Closed	Disability sector worker	
5	Mr William Booth	Parent of person with disability	
6	Mr Charlie Studsor	Community Campaigns Organiser	Community and Public Sector Union / Civil Service Association
7	Ms Gaye Hargreaves	Group member	Young Onset Parkinson's Disease
8	Ms Libby Lyons	Executive Chair	Kalparrin (Parents of Children with Special Needs Inc)
9	Mr Matt Burrows	Chief Executive Officer	Therapy Focus
10	Ms Neeva Stephen	Parent of person with disability	
11	Mrs Carol Franklin	Co-founder (and parent of person with disability)	Committed About Securing Accommodation for People with Disabilities (CASA)
12	Closed	Spouse of person with disability	
13	Dr Ron Chalmers	Director General	Disability Services Commission
14	Mr Gary Taylor	Manager for Individual Options	The Centre for Cerebral Palsy
15	Ms Sue Harris	Former disability advocacy group manager	

16	Mr Terry Simpson	State Manager	National Disability Services WA
17	Ms Lisa Dockery	Manager, Operations and Politician Adoption Scheme	Developmental Disability WA
18	Mrs Lee-Anne Brensell	Chief Executive Officer	Headwest (Brain Injury Association of WA)
19	Dr Donna Turner	Manager, Systemic Advocacy and Policy	Carers WA
20	Mr Andrew Jefferson	Executive Director	People With Disabilities
21	Closed	Support group coordinator and parent of person with disability	

## Appendix Four

### Hearings

Date	Name	Position	Organisation
4 December 2013	Mr Andrew Jefferson	Executive Director	People with Disabilities Western Australia (Inc)
19 February 2014	Dr Ron Chalmers	Director General	Disability Services Commission
	Ms Marion Hailes-MacDonald	Executive Director Funding	
	Ms Fleur Hill	Director Strategic Services	
26 February 2014	Mrs Carol Franklin	Co-founder	Committed About Securing Accommodation for People with Disabilities (CASA)
	Ms Taryn Harvey	Chief Executive Officer	Developmental Disability WA
12 March 2014	Mr Terry Simpson	State Manager	National Disability Services WA
	Ms Frances Buchanan	Operations Manager	
	Ms Sue Shapland	General Manager of Member Services	Multiple Sclerosis Society of WA
	Ms Norelle Morris	Chief Executive Officer	Valued Independent People
	Mr David Granville	Service Development and Strategic Relations	The Centre for Cerebral Palsy
	Mrs Janet Wagland	Manager, Services for Younger People	Brightwater Care Group
	Ms Sandy Komen	Manager, At Home Services	
19 March 2014	Mrs Lee-Anne Brensell	Chief Executive Officer	Headwest
	Ms Sue Harris	Former disability advocacy group manager	Disability Services Commission
	Prof. Sherry Saggars	Chair, Independent Priority Assessment Panel	
	Ms Mary McHugh	Senior Manager	

### Briefings

Date	Name
10 March 2014	Parents/carers of people with disability



## Appendix Five

### Glossary

Accommodation Services	Direct services provided by the Disability Services Commission (DSC). Many people with Combined Application Process (CAP) funding are supported through the DSC and non-government accommodation services but services are also provided to people without CAP funding in an emergency and transitional capacity. <sup>451</sup>
Block funding	Where an organisation is funded to provide a particular service to a target group under certain terms of agreement. <sup>452</sup>
Combined Application Process (CAP)	Process for determining the allocation of DSC funding towards Accommodation Support, Intensive Family Support (IFS), and Alternatives to Employment (ATE) funding streams. The CAP is a single application point and provides the opportunity for a blended solution involving these different funding initiatives. <sup>453</sup>
Community Living Initiative (CLI) (also referred to as <i>Community Living Support Strategy</i> and <i>Community Living Program</i> )	An alternative pathway for individuals seeking funding from DSC which leverages off existing community supports. Community Living (and Family Living Initiative) Plans are considered by a DSC panel but unlike CAP the focus is on whether the application covers a sustainable plan that will yield positive results for the person. Community Living Plans are limited to a maximum funding level of \$24,000 per annum. <sup>454</sup>
Estimate of Requirement for Staff Support Instrument (ERSSI)	DSC tool used to estimate the total amount of staff support and the amount of funding required for an accommodation support option. The ERSSI was endorsed by the DSC Board in 1998 for application to accommodation support funding in order to keep funds at a predicted level. <sup>455</sup>

451 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

452 Council of Regional Disability Services, *CEO Resource Manual*, CORDS WA, Western Australia, 2012, p75.

453 Disability Services Commission, *Combined Application Process Implementation Policy*, Policy No. 136, June 2006, p1. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

454 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

455 Disability Services Commission, *Policy on a Fair Level of Funding for Individual Accommodation Support Funding*, March 2002, Policy No. B34, p1. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

Family Living Initiative (FLI)	DSC funding/support available for families with a focus on planning. Families can apply for funding on the basis of a plan that complements informal supports provided by families, carers, friends and the community. FLI plans are limited to a maximum funding level of \$19,000 per annum. <sup>456</sup>
Group homes	<i>See shared supported accommodation.</i>
Independent Priority Assessment Panel (IPAP)	Independent panel tasked with assessing all Combined Application Process (CAP) applications. Decisions are put through to the DSC Director General and Board for approval. <sup>457</sup>
Individualised community living	Refers to a variety of arrangements where a person is supported to live independently or with other people in their own home. <sup>458</sup>
Individualised funding	A funding model through which a package of funds is allocated to a person with disability and is portable. <sup>459</sup>
Intensive Family Support (IFS)	DSC funding/support available for families and accessible via the CAP for families under stress or at risk of family breakdown. Funding is allocated based on eligibility, support needs and priority of need. <sup>460</sup>
Local Area Coordinator (LAC)	DSC staff responsible for providing support, community referrals and advice to people with disabilities, their families and carers. LACs cover metropolitan and regional areas and use local knowledge to work with between 50 and 65 people with disability within a community. <sup>461</sup>
My Way	A WA-based individual funding initiative for people with disabilities which is being managed by DSC. My Way is currently being implemented in the Lower South West, Cockburn-Kwinana, Perth Hills and Goldfields. <sup>462</sup>

456 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

457 Submission No. 13 from Disability Services Commission, 2 January 2014, pp2-3.

458 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p8. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

459 Disability Services Commission, *Individualised Funding Policy*, 12 August 2013, p1.

460 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p13. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

461 Disability Services Commission, *Local Area Coordination* brochure, Government of Western Australia, February 2013, p2.

462 Disability Services Commission, *What is My Way*, nd. Available at: [www.disability.wa.gov.au/ndis-in-wa/ndis-in-wa/what-is-my-way/](http://www.disability.wa.gov.au/ndis-in-wa/ndis-in-wa/what-is-my-way/) Accessed on 3 January 2014.

National Disability Insurance Scheme (NDIS)	A national entitlement-based funding mechanism agreed to by the Council of Australian Governments in 2012. It is intended to provide individually tailored supports based on a uniform assessment process. In March 2013, the <i>NDIS Act 2013</i> (Cth) was passed and an independent statutory agency (National Disability Insurance Agency (NDIA)) was established to implement the NDIS. <sup>463</sup>
National Injury Insurance Scheme (NIIS)	A companion scheme to the NDIS which would fund the lifetime care and support needs of people who have acquired a catastrophic injury. Individual states would be responsible for operating the no-fault insurance scheme under a national framework. <sup>464</sup>
Shared supported accommodation (or group homes)	Support that is provided to a person to live away from their family in a shared arrangement with other people with disability. <sup>465</sup>
Statewide Specialist Services	Direct services (therapies, specialist support and advisory services) provided by the DSC. <sup>466</sup>
Supported living	Support provided to people with disability so they can live in their home and community. It relies on an individual funding allocation which people can apply for through the DSC Combined Application Process or Community Living Program. <sup>467</sup>

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463 DisabilityCare Australia, *Our history*, 2013. Available at:

[www.disabilitycareaustralia.gov.au/about-us/our-history](http://www.disabilitycareaustralia.gov.au/about-us/our-history) Accessed on 24 October 2013.

464 Productivity Commission, *Disability Care and Support* (Report No. 54), Commonwealth of Australia, Canberra, 31 July 2011, pp852, 913.

465 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p8. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.

466 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

467 Disability Services Commission, *Sector Development Plan State-wide Overview document*, 2013, p8. Available at: [www.disability.wa.gov.au](http://www.disability.wa.gov.au) Accessed on 2 January 2014.



## Appendix Six

### Acronyms

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ABI	Acquired Brain Injury
ACAT	Aged Care Assessment Teams
AS	Accommodation Support
ASD	Autism Spectrum Disorders
CALD	Culturally and Linguistically Diverse
CAP	Combined Application Process
CACPs	Community Aged Care Packages
CASA	Committed About Securing Accommodation
CLI	Community Living Initiative Also known as – Community Living Support Strategy Community Living Program
COAG	Council of Australian Governments
CPSU/CSA	Community and Public Sector Union / Civil Service Association
DDWA	Developmental Disability WA
DSC	Disability Services Commission
EACH	Extended Aged Care at Home Packages
ERSSI	Estimate of Requirement for Staff Support Instrument
FLI	Family Living Initiative
HACC	Home and Community Care
HADSCO	Health and Disability Services Complaints Office
IFS	Intensive Family Support
IPAP	Independent Priority Assessment Panel
LAC	Local Area Co-ordinator
MS	Multiple sclerosis
NDS WA	National Disability Services WA
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NIIS	National Injury Insurance Scheme
NFP	Not for Profit
PWdWA	People with Disabilities WA
PWC	PricewaterhouseCoopers
TCCP	The Centre for Cerebral Palsy
WA	Western Australia
WAADF	WA Autism Diagnosticians' Forum
YOPD	Young Onset Parkinson's Disease
YPIRAC	Young People in Residential Aged-Care



## Appendix Seven

### Other types of disability funding

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As outlined previously, CAP funding is just one type of funding that is available to people with disability. Some other types of funding (which may play a more prominent role in coming years) are summarised below.

#### ***LAC discretionary funding***

Local Area Coordinators (LACs) are allocated limited discretionary funds by DSC (up to a maximum of \$12,000 per LAC per year). LACs can allocate these funds to people with disability to help meet short term financial support needs.<sup>468</sup>

#### ***Direct services***

DSC Statewide Specialist Services (for example therapies and advisory services) and accommodation services provide support to individuals with CAP funding. However, accommodation services may also provide emergency and transitional accommodation, if required, to people without CAP funding.<sup>469</sup>

#### ***Community and Family Living Initiatives***

The Community Living Initiative (CLI) and Family Living Initiative (FLI) are alternative sources of DSC individualised funding designed to assist with community living options and family wellbeing respectively.<sup>470, 471</sup> Both initiatives build on an individual's existing supports and rely on the completion of a personalised plan which is then evaluated by a DSC panel. Unlike CAP however, the CLI/FLI are geared towards planning rather than addressing critical needs and as such, comparatively lower amounts of funding are available. CLI funding is limited to a maximum level of \$24,000 a year and FLI to \$19,000 a year.<sup>472</sup> A total of \$4.2 million was allocated through CLI/FLI in 2012-13, compared to \$23.6m in CAP funding.<sup>473</sup>

The CLI and FLI are considered to be particularly valuable as early intervention programs which could mitigate the need for higher level funding later on.<sup>474</sup>

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468 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

469 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

470 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, November 2012, p91.

471 Refer also to Glossary at Appendix Five.

472 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

473 Disability Services Commission, *Disability Support Funding Bulletin* Issue 2, Government of Western Australia, September 2013, p1.

474 Submission No. 17 from Developmental Disability WA, 21 January 2014, p5.

### ***Block funding***

Block funding refers to the practice of purchasing a “block” of services from a provider – in other words funding an organisation to provide a particular service to a target group under certain terms of agreement.<sup>475</sup> DSC uses block funding to purchase services to assist individuals who are generally not in receipt of individual funding for that support.<sup>476</sup> Programs block-funded by DSC include Disability Professional Services (e.g. physiotherapy, occupational therapy, psychology, social work and speech pathology), the Community Aids and Equipment Program, respite, and advocacy services. The amount of services that DSC can purchase is limited by budget even though it is acknowledged that demand can outstrip supply.<sup>477</sup>

In its 2011 report on Disability Care and Support, the Productivity Commission noted that a move towards NDIS represented a shift from the more traditional method of block funding disability services towards greater individual choice. That said, block funding can never be completely replaced as there are some situations where it performs better than individual funding, including, but not limited to: crisis situations where individual funding may be inadequate in meeting immediate needs; in rural/remote areas where the small market for disability services may otherwise result in under-servicing and unmet need; and in relation to advocacy which does not align well with a user pays system.<sup>478</sup>

DSC noted that while block funding would be reviewed as part of its overall contract review process, there are no plans to phase it out or change existing arrangements if these are working.<sup>479</sup>

### ***Home and Community Care (HACC)***

The Home and Community Care (HACC) program provides basic support services to older people, people with a disability and carers to enable them to continue living independently at home. Supports may include help with: daily household tasks; improving diet, independence and safety; participating in social activities; and undertaking essential activities such as shopping and banking. The HACC target population includes younger people with a moderate to profound disability who might otherwise be at risk of entering long-term residential care, and their carers.<sup>480</sup>

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475 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, November 2012, p75.

476 Submission No. 13 from Disability Services Commission, 2 January 2014, p4.

477 Council of Regional Disability Services, *CEO Resource Manual*, CORDS, November 2012, pp85-88.

478 Productivity Commission, *Disability Care and Support* (Report No. 54), Commonwealth of Australia, Canberra, 31 July 2011, pp515, 517-524.

479 Disability Services Commission, *Individual Funding* (DSC Bulletin), Government of Western Australia, 28 November 2012, p2.

480 Department of Health, *Home and Community Care (HACC) in Western Australia*, nd. Available at: [www.health.wa.gov.au/HACC/home/whatis.cfm](http://www.health.wa.gov.au/HACC/home/whatis.cfm) Accessed on 18 February 2014.

The program is jointly funded by the State and Commonwealth governments. The State Government recently announced an almost 8 per cent increase in its contribution to the HACC program, which equates to a total funding pool for Western Australia of \$266.4m in 2013-14.<sup>481</sup>

Priority access to HACC is reserved for individuals who live alone without any informal supports, do not receive formal services and/or do not have access to other government assistance. That said HACC may be used to complement funding from other sources including CAP funding, but only where this does not duplicate existing supports and funding does not exceed \$45,000 per year. Individuals with other DSC funding (for example Community Living Initiative or Family Living Initiative) may also be eligible for complementary HACC support.<sup>482</sup>

### ***Post School Options***

The Post School Options program commenced in 1992. It is currently being transitioned to school leaver support through individual planning. It has provided school leavers, who may have difficulty obtaining employment, with meaningful activities and developmental opportunities to support continued engagement in their communities. The level of funding provided to school leavers with disability has been based on an assessment of the individual, undertaken by the DSC, in consultation with the individual's family and/or other close supports. Unlike CAP, the Post School Options program has allocated funding (albeit smaller packages than are typically provided through CAP) to all eligible individuals leaving school. Beyond enabling continued skill development and community participation to school leavers, the Post School Options program has had an incidental impact of also providing a respite effect for many families.<sup>483</sup>

### ***Alternatives to Employment***

Alternatives to Employment (ATE) provides support for adults who have not received support through Post School Options at the time of leaving school, and who require an alternative to paid employment. This may include participation in clubs, skills development programs, voluntary work and recreation.<sup>484</sup>

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481 Hon Kim Hames, MLA (Minister for Health), *Funding boost for Home and Community Care*, Media Statement, Western Australia, 18 February 2014.

482 Department of Health, *Home and Community Care (HACC) service provision guidelines for younger people with disability*, Government of Western Australia, October 2012, pp1-8.

483 Submission No. 13 from Disability Services Commission, 2 January 2014, p3.

484 Submission No. 6 from CPSU/CSA, 19 December 2013, p2.