



## **INTO ACCOMMODATION AND INTENSIVE FAMILY SUPPORT FUNDING FOR PEOPLE WITH DISABILITIES**

### **From CASA (Committed about Securing Accommodation)**

To the Chair of the Community Development and Justice Standing Committee

CASA welcomes the opportunity to make a submission to this inquiry recognising that inadequate funding for accommodation and intensive family support services continues to cause great hardship and heartache in the lives of Western Australians with disability and their family carers.

CASA was established on the initiative of parent carers in 1999 to advocate for the long term care, support and accommodation needs of Western Australians with intellectual and developmental disabilities.

At the time, most of Western Australia's larger non-government disability service providers had joined together to campaign for an increase in funding to address the unacceptably high levels of unmet need for accommodation support and other services. The variously titled Welcome Home and Time to Care Campaigns were mobilised under the banner of the Developmental Disability Council of WA. CASA was part of this campaigning effort which extended well into the 2000s.

Today, the level of unmet need remains unacceptably high but it is harder to identify exactly how many people are waiting to have their needs met and what their family circumstances are because the Disability Services Commission no longer publishes bulletins after each funding round as it did until a couple of years ago.

At the same time, the advocacy voice from non-government agencies on behalf of the unmet needs of Western Australians with disability appears to have fallen silent.

While we recognise that unmet need for accommodation support and intensive family support services impacts on many Western Australians with disability, our concern is specifically with the needs and issues facing people with intellectual disability and their family carers which, we maintain, are qualitatively different than those experienced by people living with other disabling conditions.

More generic reporting on disability issues and outcomes under a whole of disability framework not only masks these differences, but limits the capacity to respond appropriately to systemic issues that impact on people with specific disabilities – such as intellectual disability.

As many people with intellectual disability are unable to speak or advocate independently for themselves, (much less formulate and execute high profile public campaign strategies) we believe it is especially important that the intellectual disability voice is not lost when the needs, and unmet needs, for disability support services are being considered.

CASA would be happy to provide further evidence to the committee at the public hearings.

Carol Franklin  
Co-Founder of CASA



## **ABOUT CASA**

(Committed About Securing Accommodation for people with Disabilities)

CASA is an unfunded parent group that has over two hundred members. We came together over the lack of funding for desperately needed services. Accommodation is the core main concern of our families.

We were formed in 1999. We are a united and committed body of parents, with a vision of securing permanent supported accommodation for people with disabilities, and supporting their rights to plan to live independently in the community, when the time is right for them and not reliant on a family crisis.

Our goal is to make the governments aware of the critical unmet need in accommodation, respite and therapy services for people with disabilities and their families.

Carol Franklin Co-Founder

## THE NEED FOR INDEPENDENT ADVOCACY

Many agencies that previously performed an advocacy role on behalf of people with intellectual disability are now heavily indebted to funding through the Disability Services Commission – too timid to “rock the boat” in case their funding viability is threatened.

No-one appears to be speaking up, or out, on behalf of people who are unable to advocate for themselves ie:

- people with intellectual disability (especially those who lack the capacity to speak for themselves and/or understand the issues and/or frame a persuasive public policy or individual case)
- family carers who are socially and/or personally disadvantaged who may have limited resources and don't know how to mount a convincing case for support, or to “work the system” or at least to challenge it.

This document provides some background information and key questions relating to six issues which, it is argued, need to be addressed on behalf of people with intellectual (and other) disabilities and their family carers.

The six issues are:

1. Unmet need for disability support services in Western Australia
2. The Combined Application Process (to allocate disability support funding)
3. Outsourcing of DSC services for people with intellectual disability
4. People with intellectual disability under NDIS and My Way
5. Public accountability
6. Ongoing monitoring.

As an appendix we include a couple of personal stories that highlight the impact of unmet need and the current CAP assessment process on people's lives.

## **ADVOCACY ISSUES:**

### **1. UNMET NEED FOR DISABILITY SUPPORT SERVICES IN WESTERN AUSTRALIA**

First and foremost, the level of unmet need is a measure of the extent of personal hardship and unrealised potential in people's lives.

We need to have an accurate understanding of the level of unmet need to:

- inform advocacy aimed at ensuring people's needs are met
- measure progress (or not) towards meeting people's needs
- support service planning and funding to address people's needs.

The NDIS promises that the needs of all people will be met.

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 of behalf of those people who are still waiting.

The results of outcomes of each funding round to address unmet need are no longer publicly available. However, it is understood that in the funding round finalised at the end of August 2013, only about 10% of applicants were offered the support they sought.

The DSC has, however, published two funding bulletins on its website providing details of funding allocated and people supported in 2011-12. The first bulletin was dated January 2013 with a promise that the bulletins would be posted every six months. A second and more substantial bulletin was posted in September 2013.

*For copies of the bulletins on the DSC website, follow the link below. You'll need to scroll down the page.*

<http://www.disability.wa.gov.au/about-the-commission/about-the-commission1/corporate-publications/>

If the bulletins are to have any value as a way of monitoring trends a standard format should be adopted.

### **2. THE DSC COMBINED APPLICATION PROCESS (CAP)**

The CAP process in Western Australia determines whether people who apply for disability services support are funded or not funded to ensure their needs are met.

The current (and historic) CAP process is secretive, and lacking in transparency and accountability.

Indeed, it seems to be even less transparent and accountable today than in 2007 when the WA Auditor General found that the process was deficient in these qualities (Auditor General, 2007, pages 23-25).

*"... the DSC's assessment process has several negative consequences. Firstly it is not an open process..."*

The report cites two examples indicating the closed nature of the process:

- “The points to observe ... to rate applicants against each other in terms of their ‘relative’ need are not disclosed to applicants ...
- “Applicants who are unsuccessful are not told the specific reasons why they have missed out...”

The report comments that applicants are however “provided with a summary that outlines the funding outcomes of that round and their relative ranking in broad terms”. *It should be noted that this information is no longer provided to applicants.*

The Auditor General goes on to challenge the level of accountability in the CAP process:

- “Due to the limited documentation recording how the Panel has rated applicants, the DSC cannot demonstrate that it assesses applications accurately and consistently. This leads applicants to question the process, and prevents independent validation of the assessments.
- “As the Independent Priority Assessment Panel has no statutory authority, accountability for assessment decisions rests with the Director General” – but the Director General approves the recommendations without attesting to their validity.

**“Cumulatively, these factors give the assessment process an air of secrecy that is out of step with modern public administration”** (emphasis added).

The Auditor General’s Report noted that the Commission was trialling a new assessment process as of the June 2007 assessment round for implementation by the December 2007 funding round.

Under the new assessment process applicants would be scored under a risk assessment framework on the basis of 44 risk factors. The score could be transferred across funding rounds and “could improve the objectivity and consistency of the assessment process”.

**QUESTION/S:**

- To what extent were the recommendations of the Auditor General acted upon?

**CAP Application Form**

The written application form assumes the applicant has verbal capacity, literacy skills and high level conceptual skills.

Written in the first person, the form does not cater to, nor accommodate, the needs of many people with intellectual disability who are likely to be limited in these skill areas. For most, if not all, people with intellectual disability the application form will have to be completed by a third party who does not have an intellectual disability.

The AIHW report on disability support services and recipients in 2011-2012 indicates that 27% of service users with an intellectual disability had no effective means of communication.

<http://www.aihw.gov.au/publication-detail/?id=60129543841>

If written application forms are to be maintained as the sole form of assessment of need, separate application forms should at least be available for people who can complete the form on their own behalf and for those who cannot.

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.

### **Advice to Applicants**

The advice provided to unsuccessful applicants is lacking in detail, as well as being abrupt and perfunctory (especially in comparison to the level of detail provided to unsuccessful applicants in earlier years which, even then, was strongly criticised in the 2007 report by the Auditor General on the process of applying for accommodation support services).

As the 2007 Auditor General's report recommended:

"The DSC should develop mechanisms with stakeholders that provide more suitable feedback to applicants who have unsuccessfully applied for Supported Community Living services".

#### **QUESTION/S:**

- What feedback is provided to unsuccessful applicants and how does it reflect the process recommended above by the Auditor General?

### **Advice on outcomes**

Over a number of years, the outcomes of each CAP funding round were made available to applicants, as well as being posted on the DSC website.

During the early – mid 2000's, the funding bulletin included information on:

- the number of applicants for each funding category (including the number who were applying for the first time and those who were re-applying from previous rounds)
- the number of successful and unsuccessful applicants in each funding category
- the number of applications lodged on behalf of people living with family and those living away from family
- the age of parent carers for those applicants who were living with family.

Over time, the amount of detail included in the funding bulletins became more and more spartan.

A one page analysis of annual outcomes for each of the years 2008-09 to 2011-12 is currently available on the website of the WA Disability Services Commission.

<http://www.disability.wa.gov.au/services-support-and-eligibility/services-supports-and-eligibility-new/applying-for-funding-/funding-bulletins/>

In the first funding round for 2013-14 announced in August 2013 (and maybe previously), non-government agencies who may have been sponsoring applicants in the CAP funding round were provided with a "**confidential briefing document**" listing the number of people applying for support and the number of people recommended for funding under each service category. It is not clear as to why agencies were bound to secrecy especially when this information was previously freely supplied to applicants.

Data in the table below have come from unofficial sources. Confirmation is required through the Disability Services Commission.

Again the low number and percentage of applicants recommended for funding in each service category is indicative of unacceptably high levels of unmet need.

#### **OUTCOMES OF 1<sup>st</sup> CAP FUNDING ROUND FOR 2013/14**

<b>PROGRAM</b>	<b>APPLICANTS</b>	<b>RECOMMENDED</b>	<b>%</b>
<b><i>Accommodation Support</i></b>			
1. Out of Home	546	36	6.6%
2. In Home Family Support	193	15	7.8%
<b><i>Intensive Family Support</i></b>			
Bands 2-3	60	23	38%
<b><i>Alternatives to Employment</i></b>			
	305	28	9.2%
<b>TOTAL</b>	<b>1104</b>	<b>99</b>	<b>9%</b>

**AMOUNT ALLOCATED = \$8.27 million**

### **3. OUTSOURCING OF DSC SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITY**

On 11 October 2013, the West Australian newspaper carried a story (page 9) headlined "Accommodation Reforms – Disability services shake-up".

The story reported that "The State Government is over-hauling disability services, with plans to outsource most accommodation places to non-government groups as it prepares to join the National Disability Insurance Scheme next year".

A media release on the same day posted on the website of the WA Minister for Disability Services, Helen Morton is headlined "Restructure is a step towards NDIS".

According to the media statement ...

The State Government has announced a restructure of disability accommodation services with an expanded role for non-government and not-for-profit organisations.

Disability Services Minister Helen Morton said the restructure would see a reduction in accommodation places offered by the Disability Services Commission (DSC), with a gradual transition to non-government organisations.

Mrs Morton said the changes went hand-in-hand with core principles of the NDIS, which aims to provide more choice and control for people with disability, their family or carers....

"I believe this change is an important step towards the NDIS, allowing non-government specialist service providers to expand, and provide people with disability more accommodation options and more say in which organisation provides their care.

According to the fact file at the bottom of the media statement 60% of DSC accommodation places will be outsourced, the remaining 40% will remain with DSC

<http://www.mediastatements.wa.gov.au/pages/StatementDetails.aspx?listName=StatementsBarnett&StatId=7823>

Given that DSC accommodation services are provided only to people with intellectual disability, the notion of “providing more choice” to people with impaired capacity to make reasoned decisions is questionable.

#### **QUESTION/S:**

More information is required on:

- What research was undertaken to confirm that this course of action would benefit people with intellectual disability and their family carers?
- If any such research was undertaken, what did it say about
  - the potential benefits for people intellectual disability (especially for those with limited communication and/or those whose capacity for reasoned decision making and choice is also limited) and for their family carers?
  - the potential risks to people with intellectual disability and their family carers of relocating people to non-government service providers?
  - The heightened risks for people with intellectual disability whose family carers are ageing and/or have passed away?
  - the potential costs and benefits to government?
  - the capacity of the not-for-profit/non-government sector to provide the additional services required and over what time-frame
  - the implications for new applicants for accommodation support if capacity in the non-government sector is over-extended providing accommodation for former DSC residents.
- Whether the increasing number of “for-profit” agencies receiving funding from the Disability Services Commission would also be eligible to apply to take over service provision for current accommodation support clients of the Disability Services Commission and what the implications of private for profit agencies taking on service provision for this vulnerable group of people
- What contingency plans would be put in place to ensure continuity of service provision in the event that services failed or were not able to provide support to the standards required at the level of funding provided?

#### **4. PEOPLE WITH INTELLECTUAL DISABILITY UNDER NDIS AND MY WAY**

WA was one of the last jurisdictions to sign up to the National Disability Insurance Scheme (NDIS) approach to disability funding and service provision arguing that its own approach to disability service provision was superior to that of other jurisdictions and especially superior to a nationally controlled and governed scheme.

These initial assertions and any subsequent monitoring of relative performance need to be backed up with rigorously and independently tested data and analysis.



In a recent article posted on the ABC website, CEO of Anglicare Australia Kasy Chambers expresses concerns about the impact of the move towards “consumer directed care” on those who are already especially disadvantaged due to their own personal limitations and/or their family or social circumstances.

“The goals of consumer directed care, which we endorse, are to treat people with more respect and ensure they have more agency in how that support is delivered. However, in the new, highly contested and growing marketplace of disability and aged care, the most obvious business models are likely to privilege the privileged.

“While those with income, resources or capable family carers may do really well from this new more flexible approach, the poorest and least capable might not.

“Well that's the business of business. Without a bigger vision or purpose factored into our community service operations (run for profit or not) people who are more complicated, demanding and distracting will seem to be just that. They won't look like a business opportunity”.

<http://www.abc.net.au/news/2013-10-15/chambers-anti-poverty-week/5022920>

In its submission to the NDIS Senate Inquiry, the Child Disability Group of the Telethon Institute for Child Health Research raised similar concerns.

“While we welcome the NDIS initiative and the principles and commitments that underpin it, we would be concerned if a priority focus on personal independence, autonomy and individual decision-making (as articulated in the objects and principles of the NDIS legislation) meant that the unique issues facing the broader population of people with intellectual disability and their family carers were not afforded sufficient attention and priority in the implementation of the new approach to disability services provision.

“Similarly, it is to be hoped that the new, more individualised, approach to disability services provision will be supplemented by measures that also allow for informed consideration, and action, on many of the policy and systemic issues that impact on the health, wellbeing and quality of life of people with intellectual disability and their families (including the possibility of specialist service development, as well as improved service coordination between agencies working in different portfolio areas to address needs more holistically). “

“This submission cites the findings of some of our more recent research (as well as other relevant research) to support our case that, as well as focusing on the needs of individuals, the implementation of the National Disability Insurance Scheme needs to take account of the special needs and challenges faced by people with intellectual disability and their family carers at a population level.”

See submission #525

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Completed\\_inquiries/2010-13/ndis/submissions](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2010-13/ndis/submissions)

Note also, a recent report by NSW Anglicare “Caring for a child with an intellectual disability and challenging behaviours” (2013) reinforces that people with intellectual disability often have

behavioural challenges over and above the limitations imposed by their disability which greatly adds to the demands of their carers.

“The prevalence of aggression among persons with an intellectual disability range from 39.5% to 87.5%” (p 12)

<http://www.anglicare.org.au/files/pdf/KingsdeneReportInteractivePDF.pdf>

Careful monitoring will be required to assess whether NDIS outcomes differ between people with different disabling conditions (especially those with intellectual disability compared to other disabilities) and/or severity of the disabling condition and complexity of needs that result.

## **5. PUBLIC ACCOUNTABILITY**

It is concerning that the DSC appears to be “hiding” the outcomes of each of the CAP funding rounds – binding agencies to secrecy under the guise of a “confidential briefing”. This is not consistent with the Auditor General’s criticism of the lack of transparency and accountability in the CAP process and the recommendations for enabling it to be more so.

### **QUESTION/S:**

- On what grounds are the outcomes deemed to be “confidential”?
- Why are the outcomes no longer provided to applicants?

## **6. ONGOING MONITORING**

Our advocacy focus is specifically on people with intellectual disability and their family carers.

We assert that people with intellectual disability and their family carers face unique challenges that are not experienced by people with other disabling conditions

- intellectual disability exerts a more pervasive influence on multiple domains of people’s lives than is the case for many other disabling conditions
- the experience of people with intellectual disability and of their family carers is qualitatively different than that of people with disabling conditions that do not affect cognitive capacity
- people with intellectual disability require a higher level of personal guidance and support over the course of their lives than applies for people with many other disabling conditions.

It is important to recognise these differences both in data collection and analysis to inform evidence based policy and program development and in public reporting to maintain transparency and accountability.

Analyses of policy, program and practice outcomes based on grouping all people with disability together may mask differences in outcomes for people with different disabling conditions and the requirement for more targeted responses that may better meet these differing needs.

A failure to report any differential outcomes diminishes the capacity for informed advocacy and/or systemic action that may redress identified or emerging problems impacting on the lives of different groups.

## **APPENDIX**

### **PERSONAL STORIES**

#### **Lisa's Story**

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.

#### **Sarah's Story**

Sarah is a delightful young lady in her early thirties. She was born with a rare genetic disability called Tuberous Sclerosis Complex. She has daily seizures, intellectual disability, and is non-verbal. Her mother is a single parent of three daughters. The other two daughters have left home and are starting their own families. Her mother works part-time but is finding harder to keep her employment due to Sarah's needs. They have given up applying for out of home accommodation after trying for five years. They have access to Intensive Family Support funding and have just been given an increase from DSC not through the CAP process. Although this was a significant amount of money it is only for respite which is not what they want. Sarah would love the company of other young people and have her independence. Her mother would like to be able to go out with friends and not have to worry about arranging support staff. She also lives with the constant fear of if she gets sick who will look after Sarah. Sarah's mother has lost all hope of Sarah leaving home.