

## **SUBMISSION**

**The Community Development and Justice Standing Committee –  
Legislative Assembly WA**

### **INQUIRY INTO THE PROVISION OF FUNDING FOR ACCOMMODATION AND INTENSIVE FAMILY SUPPORT BY THE DISABILITY SERVICES COMMISSION**

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I worked in the disability sector, firstly in NSW for four years and then in WA for thirty two years. As a social worker, I worked at the grass roots and in a supervisory capacity for government. I held the position of CEO for the Developmental Disability Council (DDC) from 1994 to 2010. Over that time DDC conducted the Welcome Home Campaign and the Time to Care Campaign, including the development and implementation of the Politician Adoption Scheme among a host of other initiatives designed to inform our community and decision makers of the reality of life for people with disabilities and their families. Our work, and that of the disability sector in WA and nationally, and the countless families and people with disabilities who gave so much in support of the campaigns across the nation, has come to fruition with the new National Disability Insurance Scheme (NDIS).

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I welcome this Inquiry and the opportunity to provide input. The mechanism used by the Disability Services Commission (DSC) to provide funding for accommodation and intensive family support services, the Combined Application Process (CAP), has long been a source of huge concern to me. I regard it as a violation of the values the Disability Services Commission espouses, an affront to people with disabilities and their families and an unnecessary waste of precious disability resources.

In summary, the process does immeasurable damage to too many of the people who are required to participate in it. Further, ranking 'crises' and 'criticality of need' is highly questionable, so its appropriateness and 'fairness' as a means of deciding who gets funding and who misses out is debateable. It also fails to provide publicly available, transparent data on the real level of unmet need. This seriously disadvantages advocacy and does not enable the proper planning and decision making required to meet the reasonable needs of eligible people with disabilities and their families either now or into the future.

It is to be hoped that the anticipated National Disability Insurance Scheme, based as expected on eligibility criteria for support services and an inherent assumption of 'entitlement' to needed support services, will enable governments to respond appropriately to people with disabilities and their families into the future. WA's seeming reluctance to embrace the Scheme is of extreme concern. The notion that "all is well in WA" is wildly inaccurate, at best.

**Term of Reference 1: The adequacy of current processes for determining funding support for people with disabilities who live with their families.**

The Combined Application Process is used to determine who gets funding and who misses out. It is based on a group of 'experts' periodically ranking the crises and degree of need of hundreds of people they do not know on the basis of written material. At the completion of the process some applicants are successful and

some are not, people are advised (usually by mail) and the process gears up for the next assessment. This process is very deeply flawed from a multitude of perspectives. In brief, some of these include the following:

### 1.1 Damaging to people with disabilities and to their families

- **1.1.1 Emphasis on problems, shortcomings and failures.** 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, as it is the most desperate story that wins the help so often, so critically, needed. The process is deeply demeaning and undignified for participants. It stifles hope and fosters despair. People with disabilities and their families refer to it as the cruellest of lotteries. Using the medical mantra – "first do no harm" – this process fails unequivocally. People with disabilities, their families and their advocates have been saying this since the process began, through several reviews. It is difficult to understand how a department that genuinely professes such noble sentiments concerning the rights of people with disabilities and their families, and employs professional helping people, can continue to use such a damaging process.
- **1.1.2 Outcome by mail.** People are advised in a routine, official letter about the outcome of their application. There is no personal explanation as to why their application was not successful nor is there any appeals process. People in critical need of help are further stressed and demeaned by this seemingly callous and unprofessional disregard for their difficulties.
- **1.1.3 No waiting list.** The process does not compile a 'waiting list'. At the end of each 'funding round' a new queue is started and people must go through it all again. Many people, in critical need of assistance, cannot face the pain of this process and do not apply, or reapply, for assistance. The process leaves people feeling hopeless, shattered, demoralised and helpless. Many people say that if there were a waiting list, at least they would have some hope that, at some time, their turn would come and they would get the help they needed.

### 1.2 'Ranking' and assessment

- **1.2.1 Ranking 'crises' and 'criticality' of need.** It is morally and ethically inappropriate to 'rank' the 'crises' of people in order to determine who gets funding and who misses out. All people in 'crisis' (see 1.4.3 below) should be funded, without delay. Further, it is simply not possible to rank the 'degree of criticality' of people's need or the likelihood that people will fall into crisis, in anything other than broad terms. (People are extremely complex, as are their crises!) Attempting to do so can only ever, at the very best, be somewhere near the mark, some of the time, therefore failing many people, a lot of the time. To base the delivery of help, or not, on such a ranking, on the basis that it is 'fair', is inappropriate, or wrong.
- **1.2.2 Assessment by strangers using written material.** To add further to the difficulty of attempting to 'rank' people's 'crises' and 'criticality of need', the notion that this can be done by strangers relying exclusively on paperwork is nonsensical. Paperwork is very limited and unreliable in its ability to convey the reality of someone's life, regardless of how many questions are included in a questionnaire. It is blind to the multitude of nuances and indications of a person's emotional state and capacity to continue without help, that they themselves, or a family member or close friend, or a suitably qualified helping professional, are privy to. Further, it is very dependent on what people choose to say and not say, on what they are advised to say and not say, and on the skill of the person compiling the material. There is an abundance of anecdotal evidence that people are reluctant to divulge all the details of their difficulties, that they are often advised by 'helping people' that there is no point applying for help as they have no chance, and that they should apply for what they are most likely to get, rather than for what they need.

### 1.3 Limitations on support options imposed by the process

- **1.3.1 Living with friends/companions.** The process largely excludes some options that some people prefer. 'Group' living options are a prime example. If someone wants to live with other people, for company or whatever reason, as many of us chose to do at different times in our lives, they are reliant largely on those few people who have received CAP funding from which to select compatible living companions. Given the multitude of factors that are involved in us choosing people we want to live with, the likelihood of finding suitable living companions via the current process is virtually negligible. As an aside, in some cases, living with one or a few other people, apart from

being the option of choice, may also be the more cost effective option. It is silly to rule those options out, or operate to make them fail, through lack of suitable living companions.

#### 1.4 Suggestions for an alternative to the current process

In the trial NDIS sites, and in the lead up to the full implementation of the NDIS, it is assumed that systems for entry into the NDIS and the provision of support services will be developed. It is also assumed that a process such as CAP for ranking people's need for support will be replaced by a simple and clear set of eligibility criteria and that all eligible people will be entitled to the support services they reasonably need.

Between now and then, given the very serious and unacceptable shortfalls of the CAP process, I suggest it would be constructive to introduce changes that move towards the new system that is expected to operate under the NDIS. I think that changes should incorporate the following features:

- **1.4.1 Respect for people with disabilities and their families.** Any system should be grounded in positive regard and respect for people with disabilities and their families. It should be flexible, humane and compassionate. It should reflect the truth that people themselves are in the best position to assess what they can and cannot cope with and how they want to live their lives.
- **1.4.2 Transparent and accountable.** Criteria and decision-making should be transparent. There is no place for secrecy in a system that treats people with dignity and respect. History clearly shows us that people with disabilities and their families are more inclined to minimise their own difficulties and to stand back for others they think are in greater need than to manipulate a fair and open system to their own advantage.
- **1.4.3 Immediate response to crises.** All people in 'critical need' should be funded immediately. There can be no justification for not responding immediately to serious crises. The criteria for establishing when a person is in 'critical need' should be transparent, uncomplicated and applied with compassion and flexibility. There should be appropriate appeal opportunities for people with disability and their families.

As a past DSC Head has been quoted as saying: "one dying child is the same as another dying child" – it is not appropriate to be ranking them in order of urgency of need. Clearly, both must be helped, and now.

As a Social Work Supervisor working in the South West Region of the Perth Metropolitan Area for the then equivalent of DSC, Irabeena, in the 1980's, my team of social workers and I developed a set of relatively simple criteria – no more than five or six characteristic, to define 'critical need'. We used these for people in the South West Region over a number of years and found they worked well. It is possible.

- **1.4.4 Waiting List.** All eligible people who seek assistance should have their request recorded and should be placed on a 'waiting list' – the mechanics of developing and maintaining such a list would require careful deliberation. It should however, be as simple and transparent as possible and be managed with the utmost respect for people with disability and families, with maximum flexibility and with compassion.

Until the NDIS comes into effect, the disability budget should be managed such that once 'crises' are taken into account, remaining funding should be offered to people on the waiting list.

If the chosen option of the person to be funded includes other people with a disability, for example living with other people, suitable companions should be found by working down the waiting list as far as is required until compatible people are found. This will mean that some people will be funded regardless of their position on the waiting list, which, if clearly explained to people with disabilities and families, I have no doubt will be appreciated and accepted.

- **1.4.5 Changing needs.** 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.

### **Term of Reference 2: The level of unmet need**

In the best interests of people with disability, their families and the WA community, there should be full transparency about the level of unmet need for disability support services. This is the truth, and in a democracy, this is a prerequisite if government is to make good decisions and to be accountable and if people are to properly assess the performance of government and to make informed choices at election time.

For reasons known best to the Disability Services Commission, there has been a most worrying lack of transparency about the level of unmet need for disability support services for many years. There appears to be a culture of secrecy and denial in play. This is reflected in the failure to publish or make available comprehensive data concerning unmet need and in the failure to maintain a waiting list. The Disability Services Commission must have a huge amount of in depth data on unmet need, given the length of time they have been operating the CAP process and all the information that has been collected on people with disabilities and families seeking help over many years. Very little of this is publicly available.

**From what is publicly available, and from a mountain of anecdotal evidence, it is abundantly clear that there remains a very disturbingly high level of unmet need. By far the large majority of people seeking help in each CAP ‘funding round’ do not get the assistance they need.**

By not being honest and open about the true level and nature of unmet need the Disability Services Commission is, I suggest, betraying the people with disability and families they exist to serve. The failure to disclose this information disempowers advocacy for the supports and services that are needed. If politicians also do not have this information, they are not in the position they should be in to respond appropriately to the needs of their constituents. It would be an extremely serious breach by the Disability Services Commission if this were the case.

It can only be hoped that this lack of transparency will not have the opportunity to operate once the NDIS is fully introduced. In preparation for this time, serious steps need to be taken to address the lack of transparency regarding unmet need.

### **Term of Reference 3: The nature and extent of planning required to meet increasing demand for these support services in Western Australia in the future.**

The key prerequisite for proper planning is the availability of the best possible data on who needs what now and who is likely to need what, and when. This data could, or should, be publicly available but currently is not. It can only be assumed that the Disability Services Commission has this information.

A further prerequisite is the removal of factors that distort the true picture of what people need and what this will cost. The CAP process is a prime culprit here. It distorts what people ask for and when they ask for it. It is well known how difficult this process is and how inflexible it is. Once you have funding, if your needs change, you have to go back to the beginning of the queue and start again. Therefore people ask for the maximum, and knowing how long it may take to get help, many start asking earlier than they need to. Knowing how inflexible the system is, most people are certainly not going to put their hand up if they are receiving more funding than they need at any time. Further, as mentioned above, the option of living with companions, which may in some cases be a cheaper option, is not facilitated by the CAP process.

**I consider the ‘Combined Application Process’ to be just, plain, wrong, and that it should be abandoned. I am confident I am not alone when I add, “and the sooner, the better!”**