

PARLIAMENTARY INQUIRY INTO ACCOMMODATION AND INTENSIVE FAMILY SUPPORT (IFS)

The Intensive Family Support funding provides a range of flexible assistance to families/carers who support a family member with a disability. The primary aim of the Intensive Family Support is to build and enhance family well-being and strengthen family, carer and community relationships.

IFS funding aims to achieve the following outcomes:

- Support for existing and new relationships, community connections and support networks so they are developed and enhanced.
- Increased capacity to promote and maintain a positive home environment for all concerned.
- Facilitate the independence of the person with a disability.
- Individuals, families and/or carers engage in community activities that are appropriate and reflect the individuals and families cultural identity.
- Community inclusion is increased.

The Intensive Family Support recognises that families living with a family member with a disability have expenses beyond their usual living expenses. IFS aims to supplement the supports families already have. The supports are individually tailored to meet the needs of the individual with disability and their families.

The Western Australian Parliament's Community Development and Justice Standing Committee is holding an Inquiry into Accommodation and Intensive Family Support with a particular focus on the following aspects:

- The adequacy of current processes for determining funding support for people with disabilities who live with their families;
- The level of unmet demand; and
- The nature and extent of planning required to meet increasing demand for these support services in Western Australia

The Centre for Cerebral Palsy Provides IFS to 15 service users (10 adults and 5 children) and accommodation to 140 adults in a variety of accommodation options including community homes, individual units, individual community houses and a nursing home. In addition, The Centre provides respite services to 201 service users, either in facilities managed by The Centre or in the homes of service users.

The Centre provides the following comments to the Inquiry for its consideration.

The adequacy of current processes for determining funding support for people with disabilities who live with their families

The current process has improved considerably over the years. The current process encompasses a higher level of equity than previously existed. However service users and their families continue to face some challenges regarding the funding process that need to be addressed. The current process involves a lengthy application form which asks for details about the person with the disability and their family/carers, the disability support needed, the supports currently in place and Information about the options already tried.

Although the current application form has been reduced in length, it 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.

The application form is then assessed on the basis of an assessment tool. The Centre notes that the underpinning philosophies of the application form and the assessment tool are considerably different. While the application form attempts to create a positive framework, the assessment tool appears to focus more on the negative, rather than appreciate positive achievements. This attitude seems to go against the current philosophical underpinning of the disability sector and which has been strongly adopted by the National Disability Insurance Scheme. People with disabilities/their families able to present the 'best story' in their application form seems to attract CAP funding. A service provider urges potential service users to be aware of the following in their application:

'It is important to keep in mind the number of applications requesting funding for disability support services is more than the amount of money that is available each round.

'Only applications describing the most critical need are likely to succeed, so make sure the application describes the reality of your situation.

‘On your worst day at home, what is life like for you, your family or your loved one with a disability?’

‘We appreciate your experiences can be very hard to live through, let alone repeat to a stranger, but sharing your experiences will demonstrate the very need you face and will help your application stand out against all the others.’

The funding appears to be crisis-driven rather than based on a preventative model. In addition, funding is spread too thin with most service users not receiving adequate funding.

The tool used to determine actual funding is directed more readily towards service users with challenging behaviours and service users with intellectual disabilities rather than service users with high medical needs. When their application for funding has been rejected a few times they tend to give up applying. Since this situation has broader implication for the future it is important they this situation be addressed urgently. It is also the case that the Disability Services Commission (DSC) does not encourage potential service users to apply for CAP funding. When they do encourage potential service users to apply, it is to urge them to apply for less than they require explaining that an application for more funding is likely to be unsuccessful.

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. The whole notion appears to be based on ‘urgent and critical’. However, these are subjective criteria, the definitions of which can change from person to person. The Centre recommends that more people with different types of expertise be invited to undertake CAP assessments.

It is also the case that under the current system family circumstances rather than an individual case is the primary catalyst for receiving funding. While the support for families is critical, it is equally important to ensure that the level of disability of an individual is a critical criterion for funding allocation. It is also important that the economic circumstances of families not be given too much focus when funding assessments are being made. Currently, there are many families making financial sacrifices to keep the family member at home. It appears that these sacrifices are accepted as part of the system denying family members to be truly productive members of their community. Research also shows that families of people with disabilities are not financially well off. Also, that carers themselves carry disabilities and are ageing.

The current funding system also requires a specific plan for each service user. The Plan requires achievable goals to be documented and reported. The Centre supports the increased accountability that the documented goals bring and the regular monitoring that is required, however, it should be noted that many service users and their families find the entire planning process challenging.

Level of unmet demand

The Productivity Committee's report on Disability Care and Support which led to the establishment of the National Disability Insurance Scheme (NDIS) made the following observation: 'There is a significant unmet demand for disability services in Australia, and this has been the case for decades. It has led to rationing and the growth of waiting lists, which leads to greater unmet demand. It affects a wide range of everyday activities including self-care, mobility, communication, cognition and transport...Funding is insufficient across all jurisdictions.'

The Centre is aware that there are three levels of unmet demand in just about all facets of disability services. They relate to people with disability who:

- Do not receive any support they require;
- Receive some support but require more than they currently do;
- Receive some support but require types of support that are not accessible.

The Centre is aware of people with disability and their families who have given up on applying for CAP funding because their applications have not been successful over a long period of time. Rather than be disappointed yet again their preference is to stop applying. There is also a cohort who have never applied for funding. Although this cohort of people form a sizeable group, it is difficult to gauge the extent of their proportion because they are no longer registered anywhere in the system. Therefore, any estimates of unmet demand for funding would be underestimated.

Although a range of accommodation options is currently available, the Centre is aware that there is a shortage of housing options for service users whose preference is to live independently in the community with support. Current service models provided by The Centre, particularly in relation to accommodation and support services, reflect the transition between group homes and types of accommodation intended to maximise outcomes for individuals, in line with broader policy initiatives in the disability sector for individuals to be independent and participate in the community.

The range of accommodation currently facilitated through The Centre provides greater scope for people with cerebral palsy to live independently, have some degree of choice and greater potential to be active participants in community life. However, limited resources and economies of scale place restrictions on the types of accommodation available. Service users who wish to live in independent housing have considerable waiting times before they have access to these houses.

In the IFS area another major area of unmet demand is respite. Respite is an essential ingredient for continued good relations within a family with a person with disabilities. The IFS program provides for family respite primarily either in the family home or in a community home managed by a service provider. Although contemporary, non-traditional respite is currently provided by several service providers there is a distinct shortage of this type of respite requiring service providers to juggle available funds for respite to stretch services and provide the type of services preferred by the service users. Shortages in respite services to family in the IFS program can cause considerable disruption to a family which may even lead to a family break up.

The Centre is aware that respite can at times be abused by some families who are not successful in receiving funding and accommodation. These families use respite as medium to long term accommodation. They leave the family member in respite and do not collect them when the respite period is completed. A respite place then becomes an unfunded accommodation place for a service provider.

A major area of unmet demand relates to the changing needs of adults with disabilities. For example, the services for people with disability who age prior to their chronological age (showing signs of disabilities that are usually associated with people who are ageing) are extremely limited, with many of them having no option other than to be absorbed by the aged care system, which in their case is inappropriate. There appears to be a reluctance on the part of government agencies to take responsibility for this cohort of people, often leaving many of them in a state of limbo.

Some of the people with disabilities who have coped with the support of families until they are older find it challenging to enter the disabilities support loop to obtain more formal support with ageing. With carers becoming older and carrying a disability themselves, this situation is likely to recur frequently. Over the next thirty 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.

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 have stated that the process for transferring between one sector and the other is neither transparent nor easily manoeuvrable.

Mental health services including psychiatric services is another major area with a considerable unmet demand. The health system and the health and community services systems are responsible for the provision of these services. In an ideal world these two systems should be responsible for these services. However the reality is that these systems are overstretched and are struggling to cater to the needs of people with mental illness. A review of the WA sector by Professor Bryant Stokes in November 2012 found that mental health services in Western Australia were fragmented and lacked adequate staff and resources – he found that staffing levels were about 50 per cent less than what they should be. Following the review, the Director General of Health in WA admitted that the State’s mental health system cannot keep pace with demand and that the sheer weight of demand on mental health workers has been too much to handle. He said ‘We have had unprecedented demand for our mental health services in this state over a number of years now...we have simply not kept pace.’

There is anecdotal evidence to suggest that service users being referred to mainstream mental health service providers are frustrated by the services they receive from them. Their main concern is that most mainstream service providers lack the training required to provide services to people with disabilities. In particular, there is tendency to show little respect, if any, for people with a high level of disability and to be bewildered by the behaviour of people with disabilities who show no obvious signs of their disabilities. Training of mainstream staff is a key issue to enable them to provide a quality service to people with disabilities.

The nature of planning required to meet increasing demand for these support services in Western Australia in the future

Due to the exposure of current and potential service users and their families to discussions, debates, workshops and other forms of education forums relating to the disability environment, service user rights and the availability and benefits of services, many service users and their families are well educated about possibilities. They certainly are in a position to know what’s best for them and to play the central role in their planning process. As a result, expectation is high amongst service users and their families that they will get what they need. The current planning process includes many conversations with the service user and others of importance to the latter to accurately recognise their wishes and in particular the goals they identify, which staff would need to facilitate and make happen. From the service providers’ perspective the new planning process increases the latter’s level of accountability to both the service user and to the funder. It is also the case that real goals and outcomes are understood by staff, many of whom have had a tendency to confuse goals and outcomes with everyday tasks and processes.

From the perspective of the service provider the new planning process increases accountability and makes service provision more transparent. Service monitoring would also play a critical role in ensuring that the goals and outcomes are being achieved or show reasons why they are not progressing as well as expected. It is likely that this planning process will take considerable time for service providers to achieve an optimum level.

Most planning thus far has followed a 'tick box' approach rather than being an open, all-inclusive process where the service user has been central and together with those close to him/her has directed the development of the plan. Moreover, it is also likely that most service provider organisations would not have the skills required for developing plans. Even if an organisation has one or two persons with the necessary skills they may require more staff with the necessary skills. These skills include planning skills, excellent communication and interpersonal skills, considerable experience in working with people with disabilities, strong listening skills, an understanding of human rights, and demonstrated empathy for people with disabilities. It is also important for financial and IT systems to be reviewed and upgraded so that the funds attached to the plans and the information related to each plan can be stored, easily accessed and be a dynamic document as directed by the service user.

Despite likely teething problems in implementing the planning process there is much to be gained from the new planning process. However, a major drawback may be encountered from the service users themselves. The Centre is aware through its users that they do not appreciate long drawn out planning sections. In this context, the up-skilling of the planners becomes even more critical, due to the skills of support workers, however experienced they are, will be different to a planner.

The Centre has identified a major gap in the planning process which needs to be addressed for the benefit of service users. In addition to the lead role of the service users in the planning process, it is unclear how much of a role the service provider will have in the planning process. On the basis of the information available through the NDIS the main bureaucratic role would be played by personnel outside the service provider organisation. This decision was to promote equity, impartiality and to ensure that the service user was not restricted to the services of any particular agency. The Centre acknowledges these benefits but is concerned that the benefits of relationships built over many years between service users and long term staff who have supported them may be lost. For some service users paid support workers are the only family they have known and it may not be in the best interest of the service user to have these relationships compromised for the sake of impartiality and equity.

At the broader level, sector planning is critical. It is also important for the sector to undertake research through an analysis of available data so that long term planning and forecasting for different types of disabilities can be made. The lack of funds pervades through the system. Sector wide planning and forecasting will provide some idea of what is required to enable the practical realities of service provision to complement the philosophical underpinnings of the sector.