

# Supporting Australians with Disabilities

Formal submission to the Productivity  
Commission Public Inquiry into a  
Long-Term Disability Care and  
Support Scheme August, 2010



## **Introduction**

This submission is a subsequent and complementary submission to that provided to the Productivity Commission on the 3<sup>rd</sup> of June 2010. It has been written to help further the discussions had during that presentation and on the issues raised, as well as based on further input from our workers, participants<sup>1</sup> and partner organisations.

This submission designed to be read in conjunction with our initial submission, attached as Appendix A.

## **The Importance of Flexibility in a Disability Care and Support Scheme**

One of the major issues that has been raised by participants in discussions around such a scheme has been the importance of ensuring that nobody 'slips through the cracks' of a scheme.

Participants are too often confronted with the difficulty of having their needs unaddressed due to them slipping through the cracks in the system – Be that through the nature of their disability or their needs, their geographical location or socio-economic status, or simple issues of timing and program or funding guidelines. Too often these issues cause someone with real need for support to be left without or being required to take further action to obtain what is their right for support and assistance.

A related issue which emphasises the importance of broad inclusive criteria and the separation of eligibility and entitlement is in regards to the changing nature of some disabilities and the changing needs of individuals over time. A support scheme which provides meaningful assistance over the lifetime of an individual must be prepared for and have mechanisms in place to handle significant changes in support needs. This is due both to the nature of some disabilities

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<sup>1</sup> UCCO uses the term 'participant' when referring to those people we work with, rather than 'consumer' or 'client'.

(MS for example), but also to take into account the changing needs of various life stages – For example, the transition from school to work, marriage and children, and retirement. Each of these will have their own unique needs which are perfectly reasonable as they are reasonably traditional expectations of life.

A comprehensive long-term disability care and support scheme will need to ensure that, as much as possible, as large a cohort of people with a disability as possible are able to be included in the scheme, with the aim of ensuring that nobody ‘slips through the cracks’.

To this end, UCCO strongly recommends that the scheme have as broad a set of criteria in relation to eligibility as possible. We suggest that the issue of eligibility and entitlement be separated in a scheme, so that as many people as possible are able to be included in the scheme’s parameters, with levels of entitlement to be decided by subsequent processes and criteria.

### **Transition to a new Support Scheme and Prioritisation Issues**

A support scheme of the magnitude to support most if not all Australians with a disability will require a complex, multi-faceted and potentially lengthy transitional period. This raises the inevitable potential of increasing inequity for a period of time, and risking marginalizing some individuals or groups through that process.

While not seeking to suggest that any one individual or group of people is more deserving of an earlier or speedier transition to the new scheme, there are some principles worth considering in the design of the transition process:

- Identification of those who have experienced systemic disadvantage due to the current system. This could include people with a certain range of disabilities not encompassed by current systems, in rural and regional areas, indigenous and CALD groups, or those with complex needs.

- Those with disabilities who would benefit from increased early intervention. This would include children and young families, as well as those in the early stages of later-onset disabilities.

However, UCCO wishes to emphasise that in any transition the support scheme should seek to overcome inequities in the current system before transitioning the majority of individuals to this scheme, to avoid the risk of further entrenching inequity and systemic disadvantages.

### **The Process of the Scheme**

Concerns have been raised by UCCO's participant committee in regards to the potential for processes in such a scheme to create inequity and alienation.

One of the major concerns is in regards to how long it would take for such a scheme to engage with an individual who has experienced a disability. In most experiences with current disability support schemes and programs, there is a time-lag between an application for support and the provision of that support. This period of time can be extremely difficult for participants, especially in the case of having received a disability through an accident or illness, and is also a time where there are a significant number of critical expenses and activities which would benefit from timely support provision.

Another process-related issue is in regards to the initial implementation of a support scheme. Almost universally, participants have already experienced numerous requirements for documentation and continue to face this whenever a change in circumstances occurs. If and when a scheme is to be implemented, it would benefit participants and ease their transition into such a scheme significantly if the process did not require the provision of additional documentation, but took the existing material as sufficient (or at least endeavoured to keep any additional requirements to a minimum).

### **Additional Employment Issues**

In our initial submission and in our presentation to the Commission, UCCO has discussed a number of issues in relation to workforce.

A related issue which has been raised by our participant committee has been in regards to the employment of people with disabilities in the establishment and operation of this scheme. Clearly, a scheme of this magnitude will require a substantial workforce to implement and manage. This is a prime opportunity to model desirable workforce patterns by ensuring a significant number of people with disabilities are employed within this scheme's workforce. This will not only provide an opportunity for employment, but will also assist to inform the scheme to the needs of people with disabilities more readily and accurately, and build faith in the scheme in the community as truly seeking to meet the needs of people with disabilities.

UCCO also wishes to re-emphasise the concept of enabling currently unpaid (mostly family) carers to be employed by the person that they are caring for. Many of those we have spoken to with disabilities about this scheme have expressed as much concern for their carer as for themselves, questioning how much support their carer could receive. By creating mechanisms through which unpaid carers can receive a salary for their caring duties, many of these concerns are addressed without more complicated, separate arrangements around carer support.

## **APPENDIX A**

### **Preliminary Submission to the Productivity Commission Enquiry into a Long-Term Disability Care and Support Scheme**

#### **Introduction**

This submission is intended as an interim contribution to complement our presentation before the Productivity Commission in June 2010.

#### **About UnitingCare Community Options**

UnitingCare Community Options is a not-for-profit provider of services for older people, people with disabilities, and the unpaid carers that support them. Our goal is to provide the support people need to remain living at home. Each year we work with over 3000 people across the eastern metropolitan region of Melbourne.

Established in 1987, UnitingCare Community Options first provided in-home support to older people with dementia. We now support a broad cross section of the community with a range of services including information, planning assistance, case management, community development activities and respite services. We are supported by Commonwealth and Victorian Government funding and provide support to over 3000 people per year across the Eastern Metropolitan Region of Melbourne through over 150 staff.

UnitingCare Community Options is auspiced by the Uniting Church in Australia. We are part of the wider UnitingCare Australia Network, which consists of more than 400 organizations and provides over 25,000 residential and community care places.

UnitingCare Community Options is dedicated to helping people realise their personal goals and dreams living as valued members of their local community. We believe that informal and community networks are essential to helping people achieve their goals and reducing their dependency on formal services.

While the services that our staff provide and broker are vital to the work that we do as an organization, it is our approach rather than the services we provide that distinguishes us from other providers of case management and support services.

We employ a strengths-based approach that focuses on the humanity, strengths, capacities and interests of each individual rather than on any limitations imposed by a person's condition. We provide information and expertise where needed and tailor the level of support we provide to each individual according to their particular needs. Where possible we work with people to help them take control of their own lives with the assistance of planning, positive right relationships, facilitation, guidance coordination and support.

Our Vision is to achieve a Good Life for All. To do this we work to ensure that people have what they need to sustain their lives in the community and to create positive futures.

Our Mission is to work with vulnerable and disadvantaged individuals and their families so that they can live a valued and meaningful life and remain connected to their community..

We Value the uniqueness and value of every individual; right relationships that allow people to be influential in their own support arrangements; the strengths and abilities of all; creativity and innovation in pursuit of our goals.

### **A Rights-Based Approach to Disability Support**

As referred to by the Productivity Commission in its issues paper, the Shut Out Report (National People with Disabilities and Carer Council) clearly demonstrates how at a fundamental level the disability support system

currently operating in Australia is flawed and in need of overhaul to meet the large amount of unmet need in the community.

This outstanding need in the community results in significant infringements of rights, through but not limited to the significant disadvantage and marginalization that people with a disability and their families and carers face in the community, public life, employment and education. A primary factor in the reason for these infringements is the severe lack of resources that the current, crisis-driven and reactive system entails. Until a support system is put in place which enshrines adequate and appropriate disability support as a human right this will continue to be the outcome – Inadequate resourcing is a primary issue, but it is equally important to ensure that adequate resourcing is provided in a rights framework and overcomes the shortcomings around eligibility and appropriate supports that the current system currently faces.

On this right basis we advocate strongly for any support scheme to be regarded and framed as a basic entitlement for all those who require such assistance, either by birth, accident, ageing or medical condition. The model that UCCO would recommend would subsequently be funded by all taxpayers through general revenue or a Medicare-type levy and would provide funds for essential care, support, therapy, aids, equipment and training. It would also have the capacity to provide for other services or assistance (such as home modifications, and other services or products not traditionally associated with disability support but which would have evidence of being important to the wellbeing of that individual).

In regards to means testing, we are concerned that this does not reflect a rights based approach and that it could create ongoing inequality and marginalization, but would consider the possibility that a capacity to pay or co-pay may be factored in to such a system for some elements of service.

## **The Person, Carer and Family at the Centre**

UnitingCare Community Options (UCCO) employs a person-centred, strengths-based framework to service development and service delivery. Our framework focuses on peoples' strengths, capacities and interests.

Where possible we work with people in a way that enables them to maintain control over their own support systems. UCCO understands that planning is a major component of the State Disability Plan and in fact, we have been using planning as a central part of our service cycle since 2005.

The rationale for our person-directed framework is:

- A belief that people with disabilities and carers know what they need to achieve a good life and should be at the centre of the planning process as we believe that they are the experts in regards to their own lives and aspirations. We work on equal terms with people in assisting them to plan for their future.
- A belief that people with disabilities and carers want to take responsibility for their own situation in order to develop independence.
- A belief that people with disabilities and carers can help UCCO provide even better support through their participation and involvement with the organisation.
- Our capacity to develop flexible packages of support based not on program descriptions but on responding to peoples' needs.
- Our commitment to assisting people with disabilities and carers to develop both formal and informal networks of support.
- Our personal drive to help people with disabilities and carers to not just live in the community, but to be a part of their community.
- A commitment to people with disabilities and carers that ensures that the support provided is regularly reviewed and is able to be reassessed where necessary.
- A belief in the importance of positive partnerships

On that understanding, it is our belief that the decision making authority of any disability support scheme needs to be placed with individuals and families, not service providers, bureaucrats, or other 'gate keepers'. Within this scheme, UCCO believe that increased flexibility in provision of supports is required, whereby the individual and their family, have the ability to direct the creation of the services to suit their needs, rather than meeting the bureaucratic needs of service providers or funding bodies. This includes the potential to include services which may not be traditionally conceived as 'disability support' but which will make a demonstrable improvement in the quality of life for that individual.

It is our experience that when provided with adequate assistance in planning, supports (including appropriate levels of case management) and capacity building, the vast majority of clients are able to manage their own supports and care quite adequately. This increases the confidence of the person receiving the support, and ensures that they and/or their carer remains in control and is able to use their direct experience and understanding to purchase the necessary and appropriate care components leading to positive and beneficial outcomes

The provision of a one stop shop model at a local community level can enhance a person-centred approach by providing information and access into the system at a local, readily accessible level, whilst being strongly integrated and connect with other community services. This model has the potential to assist in a seamless, person-centred and effective approach at both urban and rural/remote levels by enhancing people's capacity to direct their own care and provide the necessary assistance when required.

The one stop shop allows for an individuals journey to be seamless when engaging with the broader system, and takes away the constant affirmation of their disability or situation.

## **Service Provision**

As a Victorian provider of disability services, UCCO has extensive experience with the Victorian State Disability Plan. We believe that it has the policies, principles and directions which would work well as a basis for any future disability care and support scheme, however it has failed in its implementation due to a lack of proper resourcing and outdated systems that are not consistent with the espoused philosophies and values.

The current system that is in place to support people with disabilities is reactionary in nature, using a deficit model whereby the higher the level of crisis in an individual's life, the higher the likelihood of a system response. In contrast, to achieve optimum outcomes for individuals, and allow them to reach their maximum potential, enjoy a good quality of life and be productive, contributing and valued members of the community, a system which places a strong emphasis on early intervention and long term, whole of life planning is required.

To achieve this UCCO believes that the service system needs to be multi faceted so as to include whole of life planning, a support service cycle which can be intensive or episodic at times, and have available as necessary a strong case management service model. This is a model which UCCO practices and embodies, where specialist supports and services are provided where required but access to a wide a range of generic services and opportunities is also practiced and encouraged. Within this model services are integrated and accessible, and consistently person centered and directed.

Essential within this system is the role of community development as a relatively untapped resource regarding social and community inclusion and to this end, community education around capacity of individuals regardless of perceived abilities.

UCCO supports the separation of functions and roles. In terms of government, it is ideally placed to set policy, with the federal government maintaining ultimate authority and responsibility and the states performing on the ground monitoring and management, liaising closely with NFPs. Separate bodies would manage the funds and the assessment and planning processes, with service provision provided by NFPs. This would then all be overseen by an independent regulator.

### **Workforce**

An issue with increasing importance is that of having an appropriately trained and adequate workforce.

Whilst funding and adequate resourcing of client support needs through an appropriate scheme is a foundational issue, it is of little use if there are insufficient workers to actually provide the support.

The workforce in this sector is increasingly stretched, with the attractiveness of work in the disability care and support field suffering, both due to the nature of the work and the remuneration provided. The workforce is ageing, increasingly transient, and focused on narrow demographics within society.

Consequently, in parallel with the development of increased resourcing through a more effective support scheme, investment must be made into making work in the disability sector more appealing and building up a sustainable workforce. This can be through marketing campaigns, skilled migration-focused efforts, and systems focused on the tertiary education sector, as well as through increasing remuneration across the sector to make it more equitable with other similar sectors.

Additionally, a new service model would require a re-shaped the workforce. Efforts therefore need to be made to ensure that this workforce is appropriately trained, skilled and professional with a focus on community

development, person-centred support, and with highly developed facilitation, case management and people skills.

Given the long lead time required to build a workforce, and the possibility that there may not be adequate persons to fill the necessary roles, a disability framework will need to embrace flexible and innovative responses to support needs. This can include such elements as using the provided support funding to purchase services from previously un-used sources, including the employment of family members as carers (with the necessary safeguards and checks in place). It could also entail clients using funding to purchase more 'upstream' services within an early intervention model which will reduce demands on the more acute (and labour intensive) parts of the service sector.

*The development of this scheme is a once-in-a-lifetime opportunity improve outcomes for individuals with disabilities, their families and the broader community. And while the provision of additional funds goes a long way to improving outcomes, it is critical that we ensure that these funds are provided in such a way as to overcome inequality, guarantee those things which are necessary for positive outcomes, and ensure self directed , comprehensive. planned, whole-of-life outcomes, regardless of how, when or where a disability occurred.*

*UCCO looks forward to engaging with the Productivity Commission during this inquiry and appreciates the opportunity to provide this and future input.*



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