



# **Disability Care and Support in Tasmania**

***A Submission from Carers Tasmania in Response to the  
Productivity Commission's Draft Report  
into Disability Care and Support***

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## ***Submission Summary***

Carers Tasmania welcomes the opportunity to provide comment to the Productivity Commission on the Draft Report into Disability Care and Support. The purpose of this submission is to outline key issues specific to carers in Tasmania. Carers Tasmania also strongly supports all points in current and previous submissions made by Carers Australia to the Productivity Commission Inquiry into Disability Care and Support.

### **Priority Need**

Tasmania has the highest rate of profound or severe core activity limitation in Australia (6.8% compared to 5.8% nationally). Overall, the ABS estimates that 23.2% of the 2009 Tasmanian population have a disability (compared to 18.5% nationally).

While detailed 2009 state-level data is yet to be released by the ABS, the 2003 Survey of Disability, Ageing and Carers data can still provide a sense of scale:

- In 2003, there were an estimated 74,200 people with a disability in Tasmania aged less than 65 years old (18.2% of all people <65 years).
- An estimated 53,800 of this group had a core activity limitation; restricting their mobility, communication and ability to self-care.
- 13,400 people with a disability were aged under 25 years old (8.3% of the comparative age group).

Tasmania's population geography has the highest concentration of people with disability and carers in Australia living in rural or outer regional areas.

### **Carer Information and Support**

Tasmania already has a greater number of carers per capita than any other part of Australia. The 2009 Survey of Disability, Ageing and Carers estimates 66,300 people provide care in Tasmania (13.3% compared to the national rate of 12.2%).

All recommendations regarding carers will need to align with the Commonwealth *Carer Recognition Act 2010*.

Carer needs must be appropriately addressed in their own right. All care roles are preceded by a social relationship. Formal and informal care support should enhance and enable the continuation of social relationships rather than replace them.

Carers, care-recipients and care situations are complex and diverse. Capacity to care is variable and dynamic. A life-span model is appropriate for consideration of care situations. Decision-making processes need to be inclusive of carers, especially where the carer's personal circumstances may be impacted by decisions about care.

Carers have the right to good health and wellbeing, to economic security and to make choices about their caring role. They need services which are integrated and responsive to meet their needs.

Flexibility in a new respite system means working with carers to find solutions which actually provide them with respite from the demands and stresses of their caring role rather than simply the provision of alternate care (either in-home or in-centre).

Integrated and responsive supports for carers need to focus on rehabilitation, emotional support, health promotion, stress management, injury prevention, carer skills development and social connection.

Specialist Carer Support Centres offer the potential for improved service delivery to carers, if appropriately structured and resourced. Carers Tasmania seeks clarification regarding some aspects of the proposal and also offers assistance to develop a model which enables improved outcomes for carers.

### **Priority Groups**

Maintain existing early intervention schemes for young children and enable them to keep accepting new referrals until such time that the NDIS is fully operational and only assess children in these schemes for an NDIS support package when they are due to transition out of the existing funding model.

Allocate a queuing priority for assessment and intervention according to length of time with disability in combination with a 'triage' rating of severity of disability based on the existing core activity limitation model (i.e. severe, profound, moderate or mild impairment).

Create a 'fast-track' system for assessment of people with parent carers over 55 years old or people who are in families where multiple people in the same household have significant levels of disability.

### **Diversity**

There are over 7,600 young carers in Tasmania. Research indicates needs of young carers are different to adult carers and need to be recognized as such because of the developmental issues respective to specific age groups.

Over 16% of Tasmania's population was born overseas in 2006. Carers from culturally and linguistically diverse groups require access to specialist services to better meet their needs.

Other special needs groups in Tasmania include carers who are Indigenous Australian, carers who are Gay Lesbian Bisexual Transgender or Intersex, and aged parent carers of adult children with disability.

### **Housing and Supported Accommodation**

Carers in Tasmania are highly vulnerable to housing stress due to over-representation in lowest income quintiles and higher than average dependence on government income support.

Current supplies of supported accommodation and services to support people with disability in Tasmania are insufficient. Strategies to promote inclusive living and expand infrastructure are urgently needed.

### **Workforce Issues**

Workforce skill shortages are already an issue in Tasmania. The community sector will need significant expansion to meet the anticipated demand for services created by availability of NDIS funding.

Minimum standards of training are essential for appropriately supporting the care needs of people with disability and the needs of informal carers, improving safety and preventing injury.

Legislation and sector practice relating to police checks is currently higher in many jurisdictions than that proposed by the Commission. Portable schemes have been successfully implemented in some states and territories.

Economically viable alternate care arrangements must be developed to assist carers to return or stay in the workforce on a part-time basis. Workforce participation will help protect carer economic status and has been linked to improved wellbeing.

### **Regulation**

Appropriate regulation of the NDIS will need to ensure that informal carers have the right to make representation both on their own behalf and on behalf of the person they provide care for.

Streamlining of reporting systems is anticipated to benefit the community service sector.

### **Policy Research and Evaluation**

Outcome measures will be required to evaluate the success of the new system.

Better reporting of data will improve transparency and help with sector planning.

Carer data will need to be better collected and reported.

### **Implementation**

Clear timetables for implementation will assist planning, especially for small community organisations.

Training and mentoring programs will assist small organisations to better manage the transition period.

Block funding grants are essential in several areas. A transition model may also help smaller organisations avoid exposure to unsustainable risk during the implementation period.

Existing state and territory funding for disability needs to continue until the NDIS is fully operational.

### **List of Recommendations**

1. The Commission identify Tasmania as a priority state for rollout of a NDIS and NDIS schemes based on existing higher rates of disability compared to the national average.
2. The Commission align all recommendations relating to informal care with the principles articulated within the Commonwealth *Carer Recognition Act 2010*.
3. The Commission recommend that information pathways be grounded in strong local knowledge and inter-linked with existing community networks.
4. That the Commission support the need for carers to receive a needs assessment in their own right to prevent injury, to maintain their own optimum health and wellbeing, enable their economic security and retain their right to make choices about their caring role.
5. The Commission support the development of structural imperatives to ensure the inclusion of carers in the care needs assessment process and to provide an avenue of appeal in their own right regarding assessments which impact negatively upon them.
6. The Commission adopt a 'triage model' combined with length of disability to determine priority for assessment.
7. That people with parent carers aged over 55 or in families with multiple people with significant disability who are co-resident receive priority assessment.

8. That existing early intervention schemes for young children remain in place until such time that the NDIS is fully operational.
9. The development of sufficiently-funded and appropriate-to-need services to support carers, with a focus on expanded respite, rehabilitation, emotional support, prevention of injury, education and skills development, and health promotion.
10. The Commission provide further information on the proposed Carer Support Centres.
11. The Commission recognise that caring relationships form from a pre-existing social relationship; and that the disability system must promote continuity and opportunities for enjoyment of the social relationship between the carer and the care-recipient.
12. The development of sufficiently-funded and appropriate-to-need services to support carers, with a focus on expanded respite, rehabilitation, emotional support, prevention of injury, education and skills development, and health promotion.
13. The Commission maintain the separation of the NDIS from all areas of income support for people with disability and for carers in relation to Carer Payment and Carer Allowance.
14. The Commission recommend that more work be done to identify diversity of needs and ensure the inclusion of special needs groups of carers, especially young carers.
15. The Commission consider means to promote development of additional supported accommodation and inclusive living options for people with disability.
16. The Commission consider means to better support the expansion and skills level of the Tasmanian disability care and carer support workforce given pre-existing infrastructure issues, particularly in rural and outer regional areas.
17. The Commission reconsider its position on training to better protect the safety of people with disability, improve outcomes for carers, prevent injury and reduce attrition from stress.
18. The Commission consider existing legislation and sector practice regarding police checks which are at a higher level than proposed under a NDIS.
19. The Commission consider priority access to disability support to enable children with disability to better access childcare, out of school care and post-school supports.
20. The Commission enable carer access to the NDIS, both in their own right and on behalf or in support of the older person with care needs.
21. The Commission recommend that collection and reporting of data regarding carers is improved.
22. The Commission consider a range of transition supports to assist small to medium community services during the implementation period.
23. That investment in state and territory disability levels is maintained during the transition period to a NDIS.

## 1. Caring in Tasmania

Carers Tasmania welcomes the Productivity Commission's recognition that urgent reform and substantial investment of the disability system is required to appropriately meet the needs of people with disability and to better support people who provide informal care and support to people with disability. Carers Tasmania broadly supports the Commission's recommendations regarding the introduction of a National Disability Insurance Scheme (NDIS) and a National Injury Insurance Scheme (NIIS). This submission seeks to provide additional input and response to the Commission's draft report.

Disability is a significant issue in Tasmania. Overall, the 2009 Survey of Disability, Ageing and Carers estimates that 23.2% of the Tasmanian population has a disability<sup>1</sup>. This figure is significantly higher than the national disability rate of 18.5%. Importantly, Tasmania also has the highest rate of people with profound or severe core activity limitation in Australia<sup>2</sup>. This rate is estimated at 6.8% compared to a national rate of 5.8%.

While detailed 2009 state-level data is yet to be released by the ABS, the 2003 Survey of Disability, Ageing and Carers data can still provide a sense of scale for how disability from causes unrelated to ageing affects the population. Figure 1 shows that in 2003, there were an estimated 74,200 people with a disability in Tasmania aged less than 65 years old. This was 18.2% of all people aged less than 65 years old. Further, an estimated 53,800 of this group had a core activity limitation; which restricted their mobility, communication and ability to self-care. There were also substantial numbers of younger people with disability in Tasmania in 2003. The ABS estimated that 13,400 people with a disability were aged less than 25 years old. This was approximately 8.3% of all younger people in Tasmania.

**Figure 1: Disability in Tasmania – People Aged <65<sup>3</sup>**

Category	Tasmania	Percentage of Age Group
People with disability aged <65 years	74,200	18.2%
People aged <65 with core activity limitation	53,800	n/a
People with disability aged <25 years	13,400	8.3%

As Tasmania has a higher median age, it is acknowledged that the population age structure has an impact on overall disability rates. However, there was some evidence of higher rates of non-ageing related disability in the 2003 Survey of Disability Ageing and Carers and these trends may still be evident when 2009 full data for Tasmania is published. Disability in Tasmania is also complicated by other issues, including lower state-wide socio-economic levels, geographic isolation reduced access to health care and a lack of rural/outer regional social services infrastructure.

<sup>1</sup> ABS (2009) *Survey of Disability, Ageing and Carers* Cat No 4430.0

<sup>2</sup> *ibid*

<sup>3</sup> ABS (2003) *Survey of Disability Ageing and Carers* Cat No 4430.0

Care is also a bigger issue in Tasmania than in the rest of Australia. The 2009 Survey of Disability, Ageing and Carers estimated that around 13.3% of the total Tasmanian population are already providing care to someone else, on an ongoing and unpaid basis. This rate is 2.1% more than the national rate of 12.2%. In 2009, there were an estimated 66,300 carers in Tasmania caring for people with disability or aged over 65 years old. Again, insufficient data has been released to date to determine how many people in Tasmania care for a person with disability who is aged less than 65 years old.

However, 2003 survey data also offered critical insight into some of the differences between disability care and support in Tasmania compared to the rest of Australia. In particular, the significant number of people with disability and carers who live in outer regional or remote areas must be considered with any care and support scheme. Tasmania's geographic distribution of population is very different to the rest of Australia. As Figure 2 indicates, over 3 times as many Tasmanians live outside of metropolitan or inner regional areas compared to the mainland.

People living in rural and outer regional areas may already be restricted in their access to basic disability care and support infrastructure. Lack of social support infrastructure is already a critical issue, especially in north-west Tasmania, where people usually live in small coastal, farming or mining communities separated by thickly forested mountainous terrain. Limitation in infrastructure and service capacity creates barriers to meeting long term demand for disability care and support services.

**Figure 2: Caring in Tasmania – National Comparisons**

Category	Tasmania	Australia
<i>2009 Survey of Disability Ageing and Carers</i>		
Per capita disability rate	23.2%	18.5%
Estimated carers	66,300	2.6 million
<i>2003 Survey of Disability Ageing and Carers</i>		
Carers living in outer regional or remote areas	36%	12%
Carers not in the workforce	48.3%	33%

Workforce participation is also significantly lower than the national rate for carers living in Tasmania<sup>4</sup>. The 2003 Survey of Disability, Ageing and Carers found that 44% of Tasmanian carers are dependent upon government income support as the principal source of household income<sup>5</sup>. Research conducted by IMC Link notes Tasmanian carers are much less likely to be employed than the general population with only 36% of primary carers and 37% of other carers being currently employed, compared to an expected rate of 60% for the overall Tasmanian population<sup>6</sup>. Carers were also twice as likely to be in part-time work as in full-time work, and this grew to three times as likely if the respondent was a primary carer<sup>7</sup>.

<sup>4</sup> ABS (2003) *Survey of Disability, Ageing and Carers* Cat No 4430.0

<sup>5</sup> *ibid.*

<sup>6</sup> Felmingham, B., et al. (2008) *Report on the profile of Carers Tasmania*. IMC-Link & Carers Tasmania

<sup>7</sup> Felmingham, B., et al. (2008) *Report on the profile of carers in Tasmania*. Hobart: IMC-Link & Carers Tasmania



Care loads are typically very high. Research into care conducted by IMC-Link and lead by Dr Bruce Felmingham and Ass/Professor Natalie Jackson indicated that primary carers reported an average of 103 hours per week in care provision, while other carers reported an average of 36 hours per week<sup>8</sup>. Overall, 61% of respondents reported providing care for more than 40 hours per week.

There is also limited awareness of existing supports and perhaps even a level of reticence in applying for help. This must be overcome to prevent care issues from snowballing to levels where residential care is the only viable option. The Department of Health and Human Services in Tasmania<sup>9</sup> identified that less than 18% of families who were potentially caring for someone with a severe or profound disability were accessing support. Unmet demand for formal support places a greater demand on informal supports such as unpaid carers. This report recommended that people with disabilities and their families be better engaged and supported by a continuum of service delivery models based on flexible and in-home support.

**Recommendation 1:** The Commission identify Tasmania as a priority state for rollout of a NDIS and NIS schemes based on existing higher rates of disability compared to the national average.

## 2. Care and Support

Carers Tasmania supports the need for a flexible, responsive and coherent disability care and support system which promotes wellness and independence, and which assists informal carers to perform their caring roles. The gaps and inequities in the current system mean that the greatest providers of care support to people with disability – the informal carers – are marginalised, leaving them at risk of negative impacts to their own health and wellbeing.

Research conducted by Cummins<sup>10</sup> indicates that stress, injury, ill-health and depression are higher than average in carers. Cummins found that the two biggest barriers faced by carers in accessing health care for themselves was time and cost. Carers are also at greater than average risk of financial hardship due to lower incomes, over-reliance on government support and the high costs of providing care.

As detailed in the previous section, Tasmania already has a greater number of carers per capita than any other part of Australia. The rate was 2.1% higher than the national rate in the 2009 Survey of Ageing, Disability and Carers. Carers Tasmania currently provides services to carers across the state and has done extensive work to identify the needs of carers and offer innovative programs which are responsive to their needs.

All recommendations regarding carers made by the Productivity Commission in its final report on Disability Care and Support will need to align with the Statement for Australia's Carers as it is articulated within the Commonwealth *Carer Recognition Act 2010*.

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<sup>8</sup> *ibid*

<sup>9</sup> KPMG (2008) *Department of Health and Human Services: Review of Tasmanian disability services – final report*. Australia: KPMG International

<sup>10</sup> Cummins, R. et. al. (2007). *The wellbeing of Australians – carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

The Act was introduced as part of the National Strategy for Carers developed in response to the *Who Cares...? Report on the inquiry into better support for carers*.

The ten principles are:

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

Carers Tasmania actively supports the adoption of the ten principles in all programs or services which aim to improve outcomes for carers and for the benefit of the people they provide care to.

**Recommendation 2:** The Commission align all recommendations relating to informal care with the principles articulated within the Commonwealth *Carer Recognition Act 2010*.

### **3. Information and Assessment**

Carers Tasmania supports the development of information pathways which result in improved outcomes for carers. It is essential that any new services are able to actively identify carers rather than simply requiring the carer to self-identify. Information should be supplied which is appropriate to the carer's circumstances and needs, as well as to the needs of the person with disability.

In Tasmania, local knowledge is critical for success, especially in outer regional and remote areas. For example, a person in a national call centre who looks at a database and directs someone to a service 30km away may not realise that it is on the other side of a mountain and cannot be accessed via public transport from the caller's location. More critical is having a good understanding of what is available in remote locations – knowing the community networks and key people is essential for providing a workable and efficient solution.

Carers Tasmania strongly supports the development of an appropriate assessment model which recognises carers as people in their own right and not simply as part of the support system for a person with disability. Assessment needs to be comprehensive, holistic and nationally consistent, as recommend in *Who Cares...? Report on the inquiry into better support for carers*. Such a system should also enable the carer access to a form of assessment of needs in their own right, even if the person with disability refuses to participate in a full assessment process. The Commission needs to understand that care capacity is highly variable and dynamic – it changes over the life-span of the caring role – so opportunities for carer re-assessment should also be available even if the needs of the person with disability have not.

Family structures or cultural practices may mean that several people are care providers rather than just one. Carers and care-recipients also have diverse situations. It must be emphasized that carers – whether in Tasmania or elsewhere in Australia – are not a homogenous group. The level and nature of disability, the socio-economic status of the household (or households for non co-resident carers), the availability of external supports and the geographic location will all impact on the need for support and the type of support which is suitable to meet that need. It is important that assessment can adequately respond to diversity of need.

Shifts to a consumer-directed care model must contain structural imperatives to ensure that carers are not excluded from decision-making processes. Carers Tasmania strongly supports service models which enable inclusion in decision-making processes of both the care-recipient and the person providing informal care. Carers of people with disability should also have a right of appeal in their own right regarding assessments which negatively impact upon them, as well as the right to initiate and/or support appeals on behalf of the person with disability.

**Recommendation 3:** The Commission recommend that information pathways be grounded in strong local knowledge and inter-linked with existing community networks.

**Recommendation 4:** That the Commission support the need for carers to receive a needs assessment in their own right to prevent injury, to maintain their own optimum health and wellbeing, enable their economic security and retain their right to make choices about their caring role.

**Recommendation 5:** The Commission support the development of structural imperatives to ensure the inclusion of carers in the care needs assessment process and to provide an avenue of appeal in their own right regarding assessments which impact negatively upon them.

## 4. Priority Groups

Carers Tasmania supports the Commission's recognition that an effective and efficient system invests in preventative strategies, supports early intervention, and delivers indirect benefit to all Australians and direct benefits to those most in need (through the proposed 3 tier system). Carers Tasmania also supports the Commission's recognition that Ageing Parent Carers are a priority group for support under a proposed NDIS due to the considerable challenges and complexity of need already faced by this group.

However, the priorities for proposed rollout of the system need to be better aligned to avoid creating an underclass of people with disability who are not in a priority group, but who are deemed less 'economically viable' than new cases. It may be administratively simpler to prioritise new cases, but due to the wide heterogeneity of disability a new diagnosis often has no greater or lesser need than a person who has been living with disability for 20 or 30 years with little or no support under the current system.

It is inevitable that the introduction of any new scheme will have a log-jam due to the need to assess 400,000 people. However, there are some transitional strategies which could also help to alleviate the stress and inequity created in the interim:

- Maintain existing early intervention schemes for young children and enable them to keep accepting new referrals until such time that the NDIS is fully operational and only assess children in these schemes for an NDIS support package when they are due to transition out of the existing funding model.
- Allocate a queuing priority for assessment and intervention according to length of time with disability in combination with a 'triage' rating of severity of disability based on the existing core activity limitation model (i.e. severe, profound, moderate or mild impairment).
- Create a 'fast-track' system for assessment of people with parent carers over 55 years old or people who are in families where multiple people in the same household have significant levels of disability.

Any kind of a 'crisis' based system will only perpetuate the well-meaning but inefficient responses of the current system. Regretfully, it is already becoming evident across the sector that growth and development in services has halted because of anticipated rollout of an NDIS. The rollout dates of 2015 to 2018, if the scheme timetable aligns to the Commission's proposal, mean that many people already living with disability face a minimum of four to seven years before they can even get on a waiting list for assessment. This will create significant disadvantage for many people with disability and informal carers if positive obligations are not placed on all governments to maintain existing funding in line with CPI until such time as a NDIS is fully operational.

It is also essential that an effective system of ongoing support under a NDIS model anticipate preparation for times of critical or heightened need to avoid devolving into a 'crisis-driven' model. Times of heightened need include (but are not limited to):

- Diagnosis or onset of disability
- Entry into school
- Transition between schools
- Adolescence and puberty
- Transition to post-school support

- Change of residence
- Temporary or permanent changes in care arrangements
- Impact of other family events (e.g. divorce, death of family members, aged parents entering residential aged care)
- Personal illness or injury
- Sudden declines in functional ability from degenerative conditions or early onset of ageing-related impairment

There are a number of existing future planning tools already in use in Australia which are appropriate for use under a NDIS and secure greater integration of disability and aged care systems to better meet the needs of people with disability as they age.

**Recommendation 6:** The Commission adopt a ‘triage model’ combined with length of disability to determine priority for assessment.

**Recommendation 7:** That people with parent carers aged over 55 or in families with multiple people with significant disability who are co-resident receive priority assessment.

**Recommendation 8:** That existing early intervention schemes for young children remain in place until such time that the NDIS is fully operational.

## ***5. Access to Supports Appropriate for Carer Needs***

The assessment of carers generates a positive obligation to address the needs identified. This requires that suitable funding is provided within the NDIS system to adequately support carers at a level that is sufficient to meet those needs. Carers Tasmania strongly supports the development of specialist Carer Support Centres, but seeks clarification of the anticipated model or structure of the centres. Specialist centres offer the potential for improved services to carers especially if focused on rehabilitation, emotional support, health promotion, stress management, injury prevention, carer skills development and social connection. Are the centres anticipated to be offered through an existing or new government agency system or to be locally based services contracted via community organisations with national branding?

Carers Tasmania is also seeking further clarification of the Commission’s perspective regarding the dissolution of the Commonwealth Respite and Carelink Centre and the incorporation of elements into a new Carer Support Centre in Tasmania. The CRCC is a separate organisation run by a different community service organisation and offering different services to those available from Carers Tasmania. The CRCC and Carers Tasmania have worked in a successful, complementary, informal partnership for many years to provide services relating to both aged care and disability issues.

Clarification is also requested regarding anticipated structural requirements to separate aged care services from disability services. At present many community services in Tasmania fund services through a variety of different funding contracts obtained from many different local, state and federal funding. There is often also significant overlap between disability and aged care services. It would be very helpful for the Commission to provide an overview of the anticipated boundaries and/or overlaps of the new

scheme, especially in light of the recommendations of the parallel Inquiry into Caring for Older Australians.

Importantly, the definition of respite needs to be broadened beyond the current system's provision of alternate care (either in-home or in-centre). For example, respite may involve domestic support to enable the carer and care-recipient to have joint recreation time. Flexibility in a new respite system means working with carers to find solutions which actually provide them with respite from the demands or stresses of their caring role rather than simply relying on the dislocation of one party from the home environment.

All care relationships are preceded by an existing social relationship, and both carers and care-recipients must be supported to benefit from the continuation of that relationship. The person providing care to a person with disability may be their parent, their partner, their sister or brother, their daughter or son, their grand-daughter or grand-son, neighbour or friend. Appropriate support enables time to preserve and enjoy the social dimension of the relationship. That is, time to be a mother, father, partner, sibling or friend rather than solely the person's carer.

Integrated and responsive support is also much more than access to occasional or even regular respite. It involves a rehabilitative focus – to address the poor health and wellbeing of carers. It requires emotional support – through access to counselling services. Most importantly, it requires a preventative focus through access to carer specific education and skills development. Effective programs also assist carers in overcoming social isolation; which is consistently identified in research as a negative outcome created by the demands of a caring role, economic marginalisation and lack of support to enable the social inclusion of the person with care needs.

Carers Tasmania delivers an innovative and highly successful program which has greatly improved outcomes for carers. The Hope, Empowerment, Resilience and Outcomes (HERO) program focuses on injury prevention, health promotion, stress reduction, carer skills development (such as self-advocacy, budgeting and relationship skills), and improving social connectedness to reduce isolation. The program has a practical focus as carers are inherently time-poor people; they will invest in a proven program that offers direct benefit to their caring role. The program has been supported by referral to appropriate respite services when needed for the care-recipient to enable carer participation.

Carers in Tasmania have been highly positive in their feedback as to the lasting benefit of the skills they have learnt, especially in managing the multiple stressors inherent in many care situations. Past graduates of the course are also the best advertisers – frequently recommending the course to others in their community. In Tasmania, we have invested many years of work in developing a recognisable brand underpinned by high quality services. Carers Tasmania prides itself on being a community benefit service, known by the carer community for its trustworthy reputation, specialist understanding of carer issues and ability to tailor services to best meet individual needs. We would be happy to work with the Commission and the proposed NDIS/NIIS agencies to develop a model of Carer Support which will best meet the needs of carers in Tasmania.

Additionally, Carers Tasmania is concerned that the potential incorporation of payments such as Carer Payment and Carer Allowance into a NDIS scheme may cause significant disadvantage and hardship to carers. In particular, Carers Allowance recognises the contribution that unpaid informal carers make – it is not an attempt to compensate for the costs of care or limitations on workforce participation. Any abolition

of such payments should not be made until such time that greater than equivalent supports are available to each eligible carer.

Given the anticipated rollout time for the NDIS wholesale removal of the payment would be inequitable as the NDIS as it is unlikely that all carers currently in receipt of support would also receive priority assessment for an NDIS support package. Absorption of the payment into ISPs for people with disability would result in substantial inequity for carers as it is unlikely to compensate for all additional costs borne by carers. The Commission has previously indicated that the NDIS is about access to supports and care for disability and issues to do with income support are outside of its scope.

**Recommendation 9:** The development of sufficiently-funded and appropriate-to-need services to support carers, with a focus on expanded respite, rehabilitation, emotional support, prevention of injury, education and skills development, and health promotion.

**Recommendation 10:** That the Commission provide further information on the proposed Carer Support Centres.

**Recommendation 11:** The Commission recognise that caring relationships form from a pre-existing social relationship; and that the disability system must promote continuity and opportunities for enjoyment of the social relationship between the carer and the care-recipient.

**Recommendation 12:** The development of sufficiently-funded and appropriate-to-need services to support carers, with a focus on expanded respite, rehabilitation, emotional support, prevention of injury, education and skills development, and health promotion.

**Recommendation 13:** The Commission maintain the separation of the NDIS from all areas of income support for people with disability and for carers in relation to Carer Payment and Carer Allowance.

## **6. Diversity**

A key group requiring specialized support under a proposed NDIS is young carers; those people aged under 25 years old providing care to a person with a disability. Care provided by young carers can encompass a wide variety of situations and activities. It may include providing practical supports such as shopping, meal preparation or looking after other children in the household. It may include meeting the personal care, physical or health needs of the person with disability, such as medication management, mobility assistance, dressing or showering the person with disability. It may include provision of emotional support or supervision of the health and wellbeing of the person being cared for. Some young carers may also need to be an advocate for the person with disability, dealing with other family members and with external bodies, such as doctors or community service providers.

Research<sup>11</sup> indicates needs of young carers are different to adult carers and need to be recognized as such because of the developmental issues respective to specific age groups. Concepts of balance and capacity to be pivotal to young carers' wellbeing; some young carers are well adapted and/or well supported have balance between their care role, education and social needs, while others struggle with lives that are out of balance, missing out on schooling and social opportunities. Recognition that needs and issues change as young carers face transitional points is also important. All adolescents face issues regarding relationships, work and achieving independence from the family home, but issues for young carers may be more complex due to the long term nature of care roles and a lack of alternative care options.

Over 7,600 young carers are estimated to be providing care in Tasmania. Carers Tasmania has developed an innovative program to better meet the needs of young carers. The Self Belief Program has been delivered four times in a twelve month period between Sept 2009 and Sept 2010. A total of 24 young carers have participated to date. Additionally, 9 young people without caring responsibilities have been involved in two of the groups. To date, the Self-Belief program has been delivered twice in Hobart, once in Launceston and once in the North-West of Tasmania.

Other groups will also have specialised needs. The ABS 2006 Census indicates that 16.8% of Tasmania's population are born overseas. Carers Tasmania offers specialised services to support carers who are from cultural and linguistic diverse groups. We also work closely with established and emerging cultural groups to identify carers and improve community awareness of services available to support them. It is important that any proposed NDIS system incorporate mechanisms to enable services to be tailored to individual need and determine culturally appropriate care supports, including access to translators as required.

There is also much work which needs to be done to ensure that a new NDIS system meets the needs of carers who are Indigenous Australians or who care for someone who is an Indigenous person. Carers who are Gay Lesbian Bisexual Transgender or Intersex or who care for someone who is GLBTI also need services which are appropriate to need and inclusive. Carers Tasmania supports investment in explorations of diversity of need to ensure the development of an inclusive and responsive system.

**Recommendation 14:** The Commission recommend that more work be done to identify diversity of needs and ensure the inclusion of special needs groups of carers, especially young carers.

## **7. Housing and Supported Accommodation**

The ABS 2003 Survey of Disability, Ageing and Carers indicates that carers in Tasmania are significantly over-represented in the two lowest quintiles of income (49% of primary carers and 48% of other carers). Government pensions or allowances are the most frequent source of principal household income for carers of people with

<sup>11</sup> See Aldridge, J., Becker, S. (1993) Children as carers. *Archives of disease in childhood*, 69, pp459-462; Cree, V.E. (2003) Worries and problems of young carers: Issues for mental health. *Child and Family Social Work*, 8, pp301-309; McDonald, J., Dew, K., Cumming, J. (2010) Change and adaptation in families with young carers. *Australian journal of social issues*, 45, 4, pp459-475; Moore, T., McArthur, M. (2007) We're all in it together: Supporting young carers and their families in Australia. *Health and social care in the community*, 15, 6, pp.561-568; Rose, H.D., Cohen, K. (2010) The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of youth studies*, 13, 4, pp473-487.



disability in Tasmania. Approximately 5,500 carers lived in Tasmanian state housing in 2003<sup>12</sup>. It is evident that economic pressures can leave carers highly vulnerable to housing stress.

Carers Tasmania recognises that the present supply of supported accommodation is insufficient to meet demand. Consideration must be given to strategies to promote inclusive living within communities and to the development of additional services to support people with disability who wish to live independently.

**Recommendation 15:** The Commission consider means to promote development of additional supported accommodation and inclusive living options for people with disability.

## **8. Workforce Issues**

Due to a smaller population and lower salaries compared to the mainland, Tasmania often faces challenges in attracting and maintaining a suitably qualified workforce. Workforce shortages, caused by younger people moving to the mainland and limited inward migration, are an identified issue. Yet, substantial expansion of the workforce will be needed to provide adequate services to meet the anticipated growth in demand under the proposed NDIS at the same time as meeting increased demand from the ageing population. Carer support services will need to be adequately resourced to attract a sufficient number of workers and have greater provision in funding to offer training places to up-skill their workforce to better meet anticipated levels of need.

Rural and outer regional areas face particular difficulty with meeting even current needs of people with disability and their carers. There is little choice available as only one provider usually operates in a given area. Services struggle with rigid and insufficient funding contracts. Such contracts usually only cover 'bare minimum' service delivery; typically based on metropolitan models of unit-cost pricing. Most services are unable to offer 'family-centred' practice beyond a vague statement included in their organisational philosophy because of insufficient staff and lack of capacity to invest in training and staff development. There is also no current mechanism which facilitates active and ongoing consultation with people in regional and rural areas to help service providers develop services which are appropriate to current and future needs of people with disability and their families.

Carers Tasmania notes with dismay the Commission's 'scepticism' of imposing additional requirements for the training of the disability services workforce. Carers are both persistent and consistent in their views that a minimum standard of care is essential for them to be assured that the person they care for will be safe and well-treated by personal support workers or other service personnel. All the empathy in the world will not ensure adequate safety at a level to meet the health and wellbeing needs of many people with disability. Indeed the majority of complaints from carers involve a well-intentioned person who has created significant distress through ignorance and inappropriate care. Carers Tasmania strongly urges the following minimum standards for any person who is receiving payment for care services provision:

- First Aid Certificate

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<sup>12</sup> ABS (2003) *Survey of Disability, Ageing and Carers* Cat No 4430.0

- Manual handling (or occupational safety) briefing for correct lifting and injury prevention
- Basic introduction to enabling human rights and culturally appropriate care
- ‘Accidental counsellor’ course or similar (as run by Lifeline) to learn the boundaries for appropriate intervention in distressing or challenging circumstances

Investment in this training will raise the standard of care and reduce turnover from people who burnout because they have good intentions but insufficient skills to deal appropriately with the circumstances they face. The assumption by the Commission that informal care is unskilled care is misguided and demeaning to carers. Additionally, access to the above training should be offered without cost to all carers providing unpaid care to a person with disability as part of their carer support package.

Carers Tasmania notes that the proposal for nationally consistent police checks for paid workers is at a lower level than that required by existing legislation in many jurisdictions. The Commission may wish to consider the current legislation in several states and territories which requires checks for all persons in direct contact with persons with disability and informal carers. Such legislation recognises the increased level of vulnerability inherent in many care situations. Indeed many community service organisations have a policy of obtaining police checks for all staff, regardless of whether their client contact is direct or indirect. Successful portable police check schemes have been introduced in several jurisdictions, such as the Australian Capital Territory, which enable disability workers to gain clearances which can be used in multiple workplaces.

As discussed previously, the amount of time demanded by informal care roles can restrict workforce participation options for carers. Given the present level of dependence on informal care, it is unreasonable to expect that formal care services can be expanded to meet all future need. Therefore, a greater diversity of options is needed to ensure that those carers who wish to remain in full-time or part-time work have access to affordable alternative care services. Carers often find it difficult to obtain part-time work or flexible working conditions to enable them to balance caring responsibilities with workforce participation. Yet, part-time workforce participation has been associated with improved economic status and better wellbeing for many carers<sup>13</sup>.

A core priority need is for out of school care for parents of school aged children with disability (both after school care and vacation care). In Tasmania, many children with disabilities are on waiting list. Parents often report that they face discrimination when seeking care places in mainstream childcare and out of school care services perceive their children as ‘difficult’. Both children with disability and children without disability benefit from an inclusive environment. It is vital that funds from a proposed NDIS be able to be used to assist children with disability to access additional support to attend childcare and out of school care services. Additionally, children of high school age with disability have few options for out of school care, yet many are unable to be left unsupervised or access generic holiday recreation programs. Funding under the NDIS needs to be flexible enough to support older children to access recreation support.

Additionally, there are a significant number of children with disability in Tasmania who are currently in out of home care. The care and support of these children is the responsibility of Children and Family Services rather than Disability Services. Carers

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<sup>13</sup> Cummins, R. et. al. (2007). The wellbeing of Australians – carer health and wellbeing. Melbourne: Australian Centre on Quality of Life, Deakin University

Tasmania requests clarification on how children in out of home care will be able to fairly access a NDIS without incurring departmental cost-shifting of everyday care costs.

Priority consideration must also be given to the expansion of post-school options for people with a disability. Workforce inclusion of people with disability in Australia is pitiful. Many people with disability are able and willing to participate in the workforce, but face significant barriers due to discrimination, high costs, restricted access to needed supports and inflexible working conditions. Those people with disability who are unable to work need access to daytime activity which is meaningful and which enables them to maintain the social and self-care skills learnt when at school. The gradual loss of skills caused by lack of post-school options for people with disability is a huge waste of educational investment.

**Recommendation 16:** The Commission consider means to better support the expansion and skills level of the Tasmanian disability care and carer support workforce given pre-existing infrastructure issues, particularly in rural and outer regional areas.

**Recommendation 17:** The Commission reconsider its position on training to better protect the safety of people with disability, improve outcomes for carers, prevent injury and reduce attrition from stress.

**Recommendation 18:** The Commission consider existing legislation and sector practice regarding police checks which are at a higher level than proposed under a NDIS.

**Recommendation 19:** The Commission consider priority access to disability support to enable children with disability to better access childcare, out of school care and post-school supports.

## 9. Regulation

Carers Tasmania has considered key issues regarding the regulation of the proposed system. We support the establishment of an independent authority to oversee compliance and enforcement of regulations, to collate information and to provide a complaints handling and review mechanism. Independent review of assessment and allocation of supports is essential to prevent the scheme from becoming involved in costly court cases. However, it is critical that informal carers also have access to the NDIS and to any arbitration mechanisms developed as part of the scheme. This access needs to be enabled at two levels:

- a) To take action on behalf or in support of the older person, if that person is unable to take independent action on their own behalf;
- b) To take action in their own right – to appeal decisions made regarding the care situation which have negative impact upon them and/or relating to their assessment for carer supports.

Carers Tasmania also supports the introduction of streamlined reporting systems. Complex compliance and reporting arrangements which differ from department to department and from contract to contract place a costly burden upon community services. The introduction of streamlined reporting should free up needed resources to better meet increased demand for services. However, we must reiterate that the system must support the active identification and collection of information regarding the

existence of carers and the dimensions of the caring role, at every level of record-keeping.

**Recommendation 20:** The Commission enable carer access to the NDIS, both in their own right and on behalf or in support of the older person with care needs.

## **10. Policy Research and Evaluation**

If the disability care and support system is to be effective in shifting to a focus of promoting wellness and independence, then adequate measures will need to be put in place to ensure that improved outcomes are achieved for the person with disability and any person who provides informal care to them. These outcomes will need to be identifiable and measurable. Carers Tasmania welcomes the Commission's recognition of the need to improve transparency within the sector. Carer data needs to be better collected and reported. Publication of data will inform sector planning and service development.

The system will require 'flags' to be incorporated at every level to ensure that carers are identified. Poor self-identification with the term 'carer' means that data collection cannot rely solely on self-disclosure of carer status. Independent research and evaluation processes must also be incorporated into the NDIS to assist in developing care models that truly meet the needs of both people with disability and informal carers.

**Recommendation 21:** The Commission recommend that collection and reporting of data regarding carers is improved.

## **11. Implementation**

Carers Tasmania requests that a specific state by state strategy for implementation of the NDIS be supplied at the earliest opportunity to enable community organisations to conduct specific planning and impact assessments. We request that consideration be given to several issues regarding implementation:

- That a transition support program is set up by the NDIS to provide training and mentoring services to small community services to help them successfully adapt to the new system. Training in the new business model and in governance requirements will be especially important to ensure a smooth transition.
- For Block Funding Grants to small non-profit organisations be phased out by percentage reduction over the implementation period to help maintain financial viability and avoid exposure to unsustainable levels of risk. This support could work like a guarantee – that the temporary block funding be offset by payments received under the new 'market forces' model. A system of positive incentives related to building business and deterrents against dependency on the transitory block funding could be incorporated into such a scheme.

- Carers Tasmania also strongly supports the need for block funding to continue where there is an identified need that cannot be sustained under a 'market forces' model.
- That state and territory governments be strongly supported to maintain current investment in disability (plus CPI) to prevent further disadvantage while the NDIS is implemented.

**Recommendation 22:** The Commission consider a range of transition supports to assist small to medium community services during the implementation period.

**Recommendation 23:** That investment in state and territory disability levels is maintained during the transition period to a NDIS.

## **12. About Carers Tasmania**

Carers Tasmania has a constitutional mandate to represent the needs of family carers. The organization was founded by carers and continues to be led by carers. Governance includes a Board which has members who contribute professional skills in addition to current or past experience of caring situations or an affinity with carers.

Carers Tasmania is a non-profit, community based, incorporated association and registered charity dedicated to improving the quality of life of all family carers' living in Tasmania. Carers are those people who are providing unpaid care for family members or friends with disabilities, mental illness, chronic conditions or illnesses, who have palliative care needs, or who are aged and frail.

Carers Tasmania is the only organization completely dedicated to supporting the needs and representing the views of carers throughout Tasmania. Accordingly, a strong focus on rural and remote regions is embedded in all program design and development. Carers Tasmania provides a diversity of services across all areas of the state, including counselling, information, education and training, health and wellbeing support, and social support.

Carers with diverse needs, such as Young Carers, Indigenous Carers and carers from culturally and linguistically diverse backgrounds (CALD) can access specialist support services especially designed to better meet their needs.

Programs at Carers Tasmania are funded by both Federal and State sources. These include: the Department of Health and Ageing; the Department of Family, Housing, Community Services and Indigenous Affairs; and the Department of Health & Human Services Home and Community Care (HACC) Program.