

Carers Tasmania



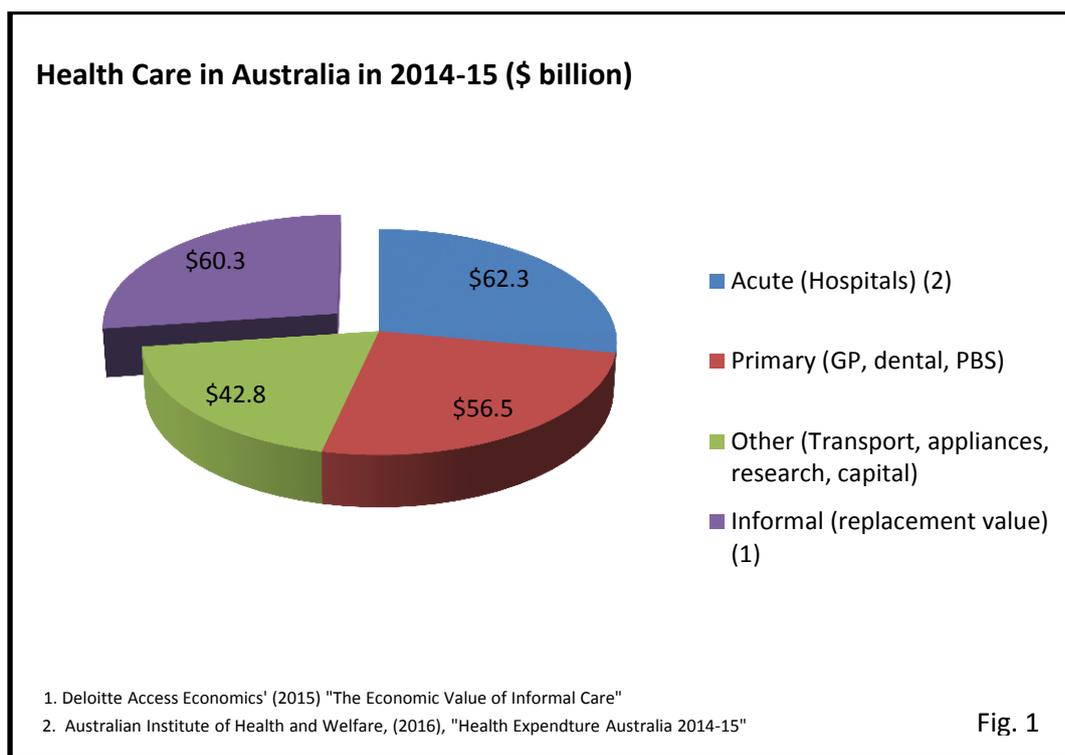
RESPONSE TO THE
TASMANIAN HOME AND
COMMUNITY CARE
DISCUSSION PAPER 2017

Purpose:

Carers Tasmania welcomes the opportunity to provide a response to this discussion paper, and commentary into the potential reform of the Home and Community Care (HACC) Program. Carers Tasmania receives funding through the HACC program to provide Tasmanians under the age of 65 in caring roles with emotional support via individual and group counselling. Providing input into the proposed policy directions to the Home and Community Care Program is therefore extremely relevant to Carers Tasmania as any changes could directly affect the people (carers) that receive support from us by virtue of the HACC program funding.

Introduction:

In the matrix of the health system in Tasmania (see figure 1.0) the value of ‘informal care’ is only surpassed in expenditure by the hospital system. The Australian Institute of Health and Welfare reported that expenditure on health care in 2014-15 was \$161.6 billion and made up 10.03% of Australia’s GDP (gross domestic product)¹. In comparison, Deloitte Access Economics, reported in 2015, the value of replacing informal care with paid care at \$60.3 billion, 3.8% of Australia’s GDP (gross domestic product).² This is a significant component of unpaid care provided by family members and friends in terms of the overall health sector. The **value of unpaid** care provided by family members, to the community and to the government cannot be underestimated.



Given the significance of this contribution by family carers to our community and health system, it is important that this perspective is heard clearly in this fast-paced time of complex reforms in the social services and health sectors.

¹ Australian Institute of Health and Welfare, (2016), Health Expenditure Australia 2014-15

² Deloitte Access Economics' (2015) The economic value of informal care in Australia

Carers Tasmania is dedicated to improving the quality of life of the 84,000 family carers living in Tasmania³, and is the only organisation completely dedicated to supporting the needs and representing the views of carers throughout the state.

As such, Carers Tasmania is extremely invested in being a part of this conversation. Not only is Carers Tasmania a key service provider in the 'community care' space, it supports one of the most significant care-provider 'services' in the whole health sector – that is the family or friend / 'informal' care giver.

Seventy four percent (74%) of care in our community is provided by unpaid carers.⁴ When a Tasmanian is vulnerable due to illness, disability, or ageing, the first place they are likely to turn, and the first people who naturally support them, are their family or friends. Carers are the people who remind their loved one to take their medication, support them through doctor's appointments, ensure other supports and service delivery occurs when needed and as expected, help with cooking, cleaning, shopping and gardening, wash them, dress and feed them (if required), support them emotionally, and encourage them to maintain relationships in the community. Family carers are likely to support them through their interactions with acute and primary services.

Carers take on this role out of love, because that person is their husband, wife, brother or sister, mum or dad. To some extent, they do it out of a sense of obligation, and in doing so provide a backbone of care to those in our community who may be among the most vulnerable.

In fact, if the Federal Government needed to replace the care provided informally on a national scale, it would cost 60.3 billion⁵ dollars per year (replacement cost) – a burden that Government budgets and the health system simply could not bear.

Government also relies to some extent, on these family members and friends, as the first port of call in caring for someone who is unwell, particularly in the case of a care recipient not having the capacity (due to a myriad of potential factors) to articulate care needs. The importance of the family carer, and their inclusion and support, should therefore be a core consideration of any future policy direction where there is a wellness and reablement approach.

Identifying family carers, including them, and supporting them so that they can continue in their role is an ultimate wellbeing and reablement strategy for Government to consider in its review of the Tasmanian Home and Community Care (HACC) program. To provide the required supports to the person requiring care is obvious, but supporting and maintaining the carer in their role is less visible, and yet imperative to the person's quality of life in the community. Carers Tasmania therefore seeks to address the questions asked by the Department in this discussion paper through the caring lens.

³ Australian Bureau of Statistics Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2015

⁴ Australian Bureau of Statistics (2014) Caring in the Community, Australia 2012: Summary of Findings 2012

⁵ Deloitte Access Economics (2015) The economic value of informal care in Australia

What supports would community sector organisations find useful in implementing or developing a wellness and reablement approach to care? What should be considered when implementing a wellness and reablement approach?

A wellness approach involves working with individuals (and their carers) to maximise their independence and autonomy. The approach involves assessment, planning and delivery of supports that build on the strengths, capacity and goals of individuals, creatively addressing complexities, problems and barriers and encouraging actions that promote a level of independence in daily living tasks, as well as reducing risks to safely living at home.⁶ It focuses on independence and resilience, and promotes social and emotional wellbeing at home and in the community.⁷

Reablement refers to time limited interventions that are targeted towards a person's specific goal or desired outcome to adapt to some functional loss or regain confident and capacity to resume activities. It is highly likely that in any care situation the primary source of support, in between the 'time-limited' nature of the formalised or service interventions being provided to an individual, is via a family member or friend carer. The care they are providing is likely to be the most responsive, intensive, regular, and flexible the recipient is receiving. **The family carer is therefore a key player in maintaining care recipient wellness.** They also have a role in supporting services to implement a reablement perspective with the client in terms of often understanding a clients broader health situation, (particularly in a scenario when the client may not have the capacity to articulate these needs.

A carer needs to know and understand the wellness approach, and work with service providers to enable the person they care for to be as independent as possible. Services provided directly to the carer then also need to be provided from a wellness perspective and ensure that adequate skills, knowledge, expertise and support is provided to the carer to enable the wellness and reablement approach to be implemented in a sustainable way (particularly in the home setting).

A wellness and reablement approach to a client should involve a holistic assessment that uncovers the strengths of the person requiring care, their goals, and the context of their need for support. A best practice assessment should involve identifying family members or friends who are providing care, given the significant role they play in providing support that maintains the person in the community and the importance of sustaining their capacity to care.

For this reason it is imperative that any organisation providing services take into account at least the view of the carer. This includes involving the family carer in any decision making that occurs (with consent from the care recipient) while also providing carers with referrals to specialist carer supports to sustain them in their role. The service provider should realistically ask the carer for their perspective on what is needed for them as well as the care recipient, if they are able to continue to provide informal care, and any assistance they may need to do so. The importance and value in doing this has been recognised by the National Disability Insurance Scheme which now incorporates a "Carer Statement" in the planning process. The Carer Statement may include the impact of the caring role on the carer (including its impact on work, study, travel, social, cultural or religious engagement activities), whether the carer is able and willing to continue to care, any other informal

⁶ Department of Social Services (2015) Living well at home: Commonwealth Home Support Program Good Practice Guide

supports the person with a disability has, and any other information NDIA should know in assessing the supports required.

The concept of wellness and reablement is not new to Carers Tasmania and is already inherent in much of what the organisation provides to carers in relation to services and support.

Carers Tasmania undertakes its own assessment process of Carer needs through a “Carer Support and Wellbeing Check” (CSWC) when a new carer enters the service. This enables initial assessment of both the carer and to some extent the care recipient and their situation, and enables a series of support needs to be put in place as and if required. The care recipient’s broad situation is taken into account at this point as well because it is the relationships between the carer and the care recipient that can significantly impact on the supports that need to be put in place. A joint understanding of the care-relationship is therefore recognised to be an important part of the success of a wellness and reablement approach.

For a wellness and reablement approach to be delivered in the HACC program in Tasmania, from an organisational perspective commitment to adequate workforce development would be needed. This would include the training of staff across the sector so that they have the skills and expertise to implement this approach, with it filtering down through policies and procedures and becoming part of a new workforce culture for the whole service system.

The wellness and reablement approach also relies on an assumption around the existence of services in the market place that HACC assessors can refer to, which match this new model. In rural and remote Tasmania there are already examples of NDIS participants not being able to access a service they are eligible and have had funding allocated for, because the service is simply not available.

A further consideration is the critical nature of services being connected and collaborating effectively, so that the services received by the ‘client’ are coordinated, needs that are identified along the way are addressed, and no issue or person slips through the cracks.

From a procedural perspective, the ideal scenario would be the use of a shared technology portal for customer relationship management (record management) and reporting that would result in a ‘one system’ approach. However, it is acknowledged that this would require significant dollar investment and planning with new software and training for Department staff and all community service providers. Training for consumers/patients and their carers would also be necessary should this portal be available to the sector. Utilising the Federal Government’s existing Data Exchange (DEX) system across the whole sector is an approach Carers Tasmania discusses later in this paper.

The implementation of a wellness and reablement approach would also require an effective and timely communications strategy to ensure community understanding of this new approach, and the changes that are occurring. Consumer and carer consultations to provide this information would be helpful to ensure perceptions and expectations are accurate and managed effectively.

It is worth noting that the Tasmanian Government’s “Tasmanian Carer Policy 2016”⁸ (the Policy) provides a framework for actions to identify carers and deliver support and services they need, and for carer involvement in decisions that might affect them and the role they have in our community. Carer awareness and understanding is a key part of the Policy and underneath is the opportunity for

⁸ Department of Premier and Cabinet (2016) Tasmanian Carer Policy

a series of protocols and processes that enable the carer perspective to be taken into account at all points of service delivery. It is understood that the Action Plan is currently being finalised by the Tasmanian Government but it reiterates the recognition that Government has in terms of the role that carers have in the community.

What wellness and reablement models of care are providers currently utilising?

Carers Tasmania's approach to supporting family members and friends who are caring has wellness and reablement embedded in the supports it provides, and has been in place for some time. The "Carer Support and Wellbeing Check" offered by Carers Tasmania, is one example.

The first part of the Wellbeing Check (Part A) is completed by Carer Support Officers either over the phone or face-to-face, and establishes a strong and trusting relationship. It is this foundation which is critical to the successful delivery of a wellness and enablement approach – it is where trust is built between the carer and the organisation. This is again why organisational capacity to deliver a wellness and reablement approach is critical (as highlighted in the earlier section).

Carer Support Officers gather information about the carer's situation (including their own health and other commitments/stressors), personal details and the care they are providing, garnering insight in to the complexities of the caring situation and the stage of their caring journey. They learn what supports are currently being accessed by the carer (including services or other informal supports). Carer Support Officers then suggest immediate referral to services the carer and the person they care for may benefit from, both internally and external to Carers Tasmania. An initial assessment of the carer's overall emotional and mental wellness is then completed using a Wellbeing Survey. This Survey is based on an eight question 'Leichardt scale'. A score then identifies the wellbeing of a carer, which is passed on to a counsellor for review. Should the wellbeing score be low, a carer will be contacted to offered emotional support via one-to-one counselling and/or therapeutic groups and/or education and training, either internal or external to the organisation.

Part B of the CSWC is routinely offered to the carer and is undertaken by a counsellor in a separate appointment, either face-to-face, over the phone or using Skype. The counsellor and carer discuss the caring role, its impact, what self-care strategies are in place, or the need for new strategies and goals which can be developed and supported via further counselling or other external services.

This counselling (if delivered 'in-house) is for carers under the age of 65 through the HACC program and over the age of 65 through the National Carer Counselling Program.

Carers Tasmania's Education and Training program and therapeutic groups (enabled through funding from the Federal Government) also provide a wellness approach in their aim to equip carers with the skills they need to sustain them, and information and assistance to navigate their life and what can be experienced as an increasingly complex system. Workshops and groups available to carers include: Mindfulness; Managing Stress and Carer Fatigue; Beyond Frustration and Anger; Effective Boundaries and Communication; Caring for Someone with Dementia and Qigong classes.

What should be considered in ensuring a single point of access, through which all referrals are processed, operates well?

It is Carers Tasmania's very strong view that the development of a state single point of access for the HACC *should only occur with detailed consideration of other Federal Government entry points for service through the national reforms currently in progress, and how they may interconnect* e.g. National Disability Insurance Scheme; MyAged Care; mental health service commissioning and Integrated Carer Service System reforms on the horizon. In the case of carers, the relationship between the access point and the National Carer Gateway and the potential for Integrated Carer Support Services (depending on how these are eventually determined by the Federal Government) would need to be considered and with clear processes for both service providers, consumers and carers. Effectively, there is so much happening in the reform environment for the social services sector, that taking account of all of these changes is material to minimising any negative impact in any potential change to the HACC program.

A point to note from the carers perspective throughout any reform or change is that research conducted in 2007 and revised in 2015 showed that carers had the lowest personal wellbeing index of any group previously studied and reported high rates of depression and stress⁹. For this reason Carers Tasmania is of the opinion that there should be 'no wrong door' for carers. Carers, overwhelmed and seeking support, need the most timely, clear, stress-free process for accessing support.

What this means, is whilst in principle a single point of access provides simplicity for Tasmanians, *flexibility should be allowed and enabled for people in need and looking for support*. Learnings from some of the challenges that have occurred with the implementation of the national entry point in the aged care system, MyAgedCare, could be taken into account - staffing levels, expertise and knowledge of the assessors 'on the ground' (see earlier commentary about workforce development), limitations around the understanding of services, and in some cases a lack of local knowledge in terms of the services that are available. Potential reforms of the HACC program should try to avoid these unintended consequences of change and again consider the critical importance of services working collaboratively (and allocate time and therefore funding to ensure that this occurs) to ensure effective and timely support reaches people who need them.

Carers have voiced their frustration that the IT/technology systems they are required to navigate in seeking support through these whole-of-sector reforms that are occurring, and that it is complex and stressful to navigate. Any entry point to support carers effectively needs to be simple and reduce unnecessary stress. This could be achieved via the consistent use of a **common** needs assessment tool right across the sector and HACC providers, which included questions which would identify the carer (either because the consumer has a carer or because the person is under 65, requires assistance, and is also in a caring role).

A common assessment tool could identify a carer, express the importance of carer wellbeing, resulting in the routine referrals to specialist carer services such as those provided by Carers Tasmania and other providers (who may or may not be funded by either the Federal or State system). It would be hoped that this could occur in a coordinated way, so that the carer does not need to repeat information, as this a significant frustration for carers. Any carer-friendly assessment

⁹ Cummins, R Deakin University and Carers Australian Unity, 2007. Report Revised 2015 – What makes us Happy

tool would also need to consider carers' diverse needs and be sensitive to some groups of carers including Aboriginal and Torres Strait Islanders, CALD communities, LGBTIQ+ people, carers with poor literacy, and carers with disabilities.

Any access point would also require an escalation process for those with urgent or immediate needs and a priority triage system for those with complex needs. This would be imperative to provide timely support and avoid inappropriate referrals to the acute system.

Carers, who are often stressed and overwhelmed, require a flexible approach that will meet their individual circumstances and address their individual needs. Any approach to supporting carers requires a comprehensive assessment, identification of those at risk and follow up of individual support needs.¹⁰

If this point of access was to be online, consideration needs to be given to whether a consumer or carer would be able to complete the initial online process autonomously and if so how adequately the demographic of service users would be able to engage with this. This is because information gathered in the Council on the Ageing Tasmania's (COTA) *'Finding out: accessing the right information at the right time project'* suggests that access to and capacity to use technology decreases significantly with age, with only 40% using websites to access information. This decreased with age, with only 12% of 60 -74 year olds using websites. Problems survey participants raised were limited access to the internet, lack of familiarity, and problems with online instructions and forms.¹¹

Any access point would require security and privacy to be of utmost consideration and be regularly assessed for quality control. The first level of responsibility for this rests with the service provider. A new approach, with a new data system, and new assessment and reporting systems, will require development and then most likely a trial, and later, maintenance. The process of implementing this is multi-layered and would require the allocation of adequate resources (i.e. transitional funding) to ensure a smooth transition, let alone appropriate amount of time to implement and embed the changes successfully.

¹⁰ Broady, T. Aggar, C (2017) Carer interventions: an overview of service effectiveness

¹¹ Council on the Ageing Tasmania (2015) Finding Out – Supporting older people to access the right information at the right time

What assessment tools are Tasmanian HACC providers currently using to assess client need? What are the advantages and disadvantages of these tools?

As noted earlier in this paper, carers that are identified, actively referred, or self-referred to Carers Tasmania are guided through a Carer Support and Wellbeing Check (CSWC). The CSWC provides a holistic assessment of carer needs and establishes a clear pathway to the counselling and support services that can be offered in house by Carers Tasmania but also externally by other appropriate service providers.

Advantages of the Carers Support and Wellbeing Check process are:

- It is a valuable tool for engaging carers in conversation.
- It is holistic in its approach.
- It encourages the carer to reflect on their own needs and current wellbeing.
- It can indicate how the carer is coping with their caring role.
- It identifies strengths, informal supports and the need for referrals.
- It helps to build a level of understanding of both the carer and the care recipient situation, the care relationship, and therefore positions the service provider (in this case Carers Tasmania) to be able to provide a service plan that will maximise the outcomes for the carer.

Disadvantages of the Carer Support and Wellbeing Check process are:

- The Wellbeing Check is a structured process and the carer may feel like the staff member is following a script. Whether this comes across as a personal conversation or not depends on the skill and style of the staff member. This indicates the importance of workforce development and capacity building as well as implementing a standardised assessment tool for a wellness and reablement approach, as mentioned earlier in this paper.
- Following a scripted process for the wellbeing survey is not always easy as the wording is not always easily understood by the carer. This indicates the need for plain English standardised across all future processes.
- Occasionally a carer may have concerns about their privacy, or that of the person they care for (despite being told that all personal information is de-identified for reporting purposes).

Carers Tasmania already has a strong focus on early intervention and ensuring that the services offered are outcomes-based for carers. This is specifically reflected in the approach around regular 'touch-points' with carers – to see how they are going and whether any supports are required or their caring role has altered -and the dedicated and ongoing commitment by Carers Tasmania to identify hidden carers in our community.

Carers Tasmania's Carer Support Officers complete 'an annual 'review' of a carer situation of carers who have not recently been in touch with the organisation, as part of the organisation's early intervention approach and focus. The review involves some general questions regarding how the carer is managing their caring role, whether there have been any changes, and assesses the need for supports. A wellbeing survey is also completed to help determine how the carer is going. The carer is also provided with some information about current workshops and therapeutic groups, and peer support groups and other external services, if appropriate. The review also includes an update of the minimum data set that is required by funders. Some quotes from carers about how they view this approach include include:

“It is really kind that Carers Tasmania keeps in touch. Even though I haven't called upon them for help recently, I will do if/when times get tough again. I do appreciate so much that they are there for me and for others experiencing the challenges as well as the joys of caring”.

‘As soon as I spoke to Carers Tasmania I could tell they were caring, loving and understanding. Some organisations give you so much information you feel confused and overwhelmed. I felt that they felt honestly do care”.

“It is a pleasure to get an update [from Carers Tasmania] on what affects carers legally and what is available for us to gain more knowledge both about diseases and disorders and also how we can best tackle our caring roles.[And] I’ll tell you another thing I like. In Tasmania, I am not sure if everywhere, we get rung up here and there [by Carers Tasmania] to have a chat about how we are going and what do we need? We are not forgotten.”

How could the Tasmanian HACC Program standardise client assessment?

There is great value in having one assessment process using a standardised tool that could be delivered by any organisation, and any assessor. This process would need to be delivered using plain English, ideally using a single IT system (i.e. 'one system'), where potential clients are asked a routine set of questions, and the outcomes reported in a similar way across the sector.

Carers Tasmania sees the inclusion of carer related questions in any assessment process as **imperative**. The easiest way to guarantee this occurs is to add carers to the eligibility criteria in their own right. It should also be recognised that a person may be accessing community care for themselves and simultaneously providing care to a family member or friend. Identifying this could be crucial to understanding the circumstances of the person and the supports required 'care at home' to continue with support of the broader health system.

A thorough assessment would involve prompts for the assessor to follow that guarantee an understanding of the context of the situation, the health information of both the person requiring care and the carer and provide a process that enables an understanding of the full complexity, strengths and resources available to the person. This will inevitably enable an appropriate and adequate support and service response.

Any standardisation of assessment would be a major change management piece for the Tasmanian Government to consider through the HACC program. It could not be rushed, and would take time. There is so much happening in the social services sector reforms, that there needs to be a 'fairness' test applied to the vulnerable members in our community experiencing the change, but also the service providers and organisations also experiencing it. Transition in terms of 'time' and transition in terms of 'funding' must be incorporated and to alleviate any consequences of yet more change to the social services and health sector.

***Do you think assessments and reviews should be conducted independently of service providers?
Why or why not?***

Carers Tasmania is concerned that separating assessment and reviews from service providers poses a number of issues.

While a standardised assessment process guarantees consistency, the value of this assessment being delivered by a service provider offering a specialised service to a particular cohort cannot be underestimated. For Carers Tasmania this allows a nuanced and flexible approach to carers that enables the full complexity of a situation from a carer perspective to be understood, and the supports offered to be tailored based on that assessment. For example, the conversation with the assessor and information garnered during that initial process and communication can be shared internally to other team members without the challenge of other organisational policy, privacy considerations and then the carer's own concerns about multi-organisational conversation to navigate. Carers very much appreciate connecting with an organisation that focuses on wholly supporting them and who are completely dedicated to their needs. The loss of this approach could place further stress on carers.

An independent (centralised) assessor would need to maintain high levels of knowledge of what is being provided by the service provider they are referring to. Regardless of a centralised assessment service, it is likely that any subsequent service provider would still be required to do their own assessment, and as such creates "double handling". We are hearing this is already a frustration, for carers, through the federal government reform process. As mentioned previously, only having 'one door' can complicate the provision of support to those already stressed and overwhelmed, if there is no flexibility allowed.

Separating assessment from service provision can also pose the risk of information that is very important to the service provider, and often nuances, being lost. There is also risk that the service provider may not be able to confirm, from the assessor, points that have occurred in that original assessment, depending on the privacy and policy requirements of the organisation in question.

Once carers are connected and involved in the organisation, Carers Tasmania also believes it is the service provider's role to take an early intervention approach and make regular contact to further tailor supports. This internal review process ensures a trusting relationship between the organisation and the carer that reduces risk of detachment or communication breakdown and optimises benefits for the carer. This is certainly the experience of Carers Tasmania. Carers don't necessarily have the time to check-in themselves, and as previously noted in this paper, many carers appreciate the fact that we take the initiative of contacting them which is absolutely inline with the Federal and State Government's move towards 'early intervention' in social services reform.

In what other ways can the Tasmanian HACC Program better support the health system?

The Tasmanian HACC Program supports the health system to some degree, but there is always room for improved efficiency. The nature of the segmented health system (State and Federal) inevitably results in confusion for some and fragmented patient flow. Mechanisms to improve oversight of the whole system, such as utilising the DEX reporting system, could enable improved support systems for Tasmanians. It could even shift the balance away from acute to more preventative measures, with the approach of early intervention to benefit Tasmanians along their life path. Having started to use the DEX system through the Federal Government reporting mechanisms, it is obvious to Carers Tasmania that its reporting potential is significant.

By utilising the DEX system, rather than the Tasmanian Government delivering on a new platform, would offer a more holistic data processing / reporting / extracting mechanism that could provide an overview of all services being utilised as well as significant demographic data.

Community service/ community health organisations are pivotal to better health outcomes for Tasmanians in need, and Carers Tasmania is funded by both the State and Federal Government to enable carers to remain healthy and well to be able to continue to support care recipients at home, therefore reducing the impost on acute care. The more dollars invested in early intervention community care, the greater the benefits for Tasmanians as we alleviate pressure on the health system, reducing overall costs. Ongoing HACC funding support to carers is critical to helping enable this outcome, given –as discussed earlier – the role that the informal health care system plays in providing care.

Communications between the acute, primary and community care sectors has long been a challenge, particularly given the workload of each sector. Acknowledging and allocating time to maintain relationships and share information between each of these sectors could be very helpful, and in the long term, improve efficiencies. Increased investment in collaborative projects, building referral pathways (or mechanisms by Government being put in place to *ensure* referral pathways are enabled) could help as well.

Clear, simple and timely pathways for escalation of support when an individual's health declines would also be beneficial to the health system.

How could Tasmanian HACC services be extended to people of all ages to provide time limited care following hospitalisation?

Carers Tasmania interprets this as Tasmanian HACC services currently being provided to people under 65 years.

Anecdotal evidence tells us that the current HACC support of 3 weeks post-op of 2 hours per week to support the patient in their own home is not providing enough support to those in need. More reliance is therefore put on the informal carer leading to greater risk exposure to reduced health outcomes for the patient and the carer.

Carers Tasmania recommends a co-ordinated approach to discharge that involves all stakeholders including HACC services to ensure that referrals are made to supports that could commence in a timely manner upon return to the community. Ideally, hospital staff would assess the capacity of the family carer as part of discharge, checking on their understanding of the tasks they will be required to do, whether they feel confident and able to perform these roles and whether they require support.

The time directly after discharge is perfect for Carers Tasmania to engage with carers. Part of the work done at this time would be to ensure they are connected with practical, emotional and social supports that will maintain them in their role. Knowing that there is an organisation that is there to support them and feeling confident to seek further help is likely to reduce stress.

The provision of multi-expert allied health packages for the service user, delivered with a wellness focus would be beneficial, and consistent with a wellness and reablement approach. Clear achievable goals would ensure that this service provision was focused and time limited.

It is interesting to note here that the over 65 years MyAgedCare approach transitional care packages currently provide more comprehensive supports to post-op patients at home of up to 12 weeks after hospital discharge.

It is noted that Carers Tasmania has recently developed a resource for carers of people being admitted to hospital in Tasmania.

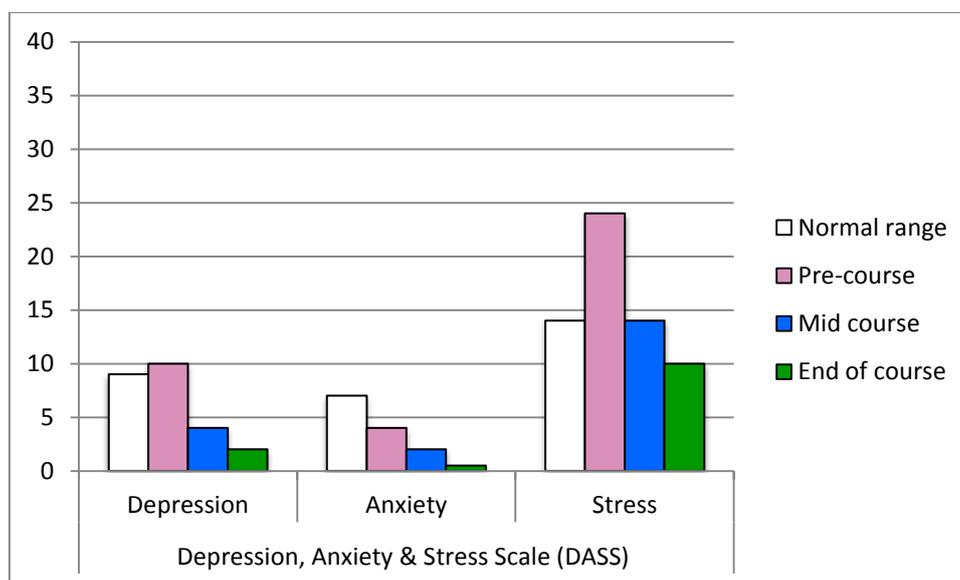
“ I Care” is a resource for family and friend carers negotiating a hospital admission, to help them feel less overwhelmed and clearer about what supports are available to them and the person they care for, particularly around hospital admissions and discharge. Nothing else like this exists in Tasmania to support carers at this often very stressful time and can be found on our website at www.carerstas.org (under How Can We Help).

Does your service currently measure the quality of services or the impact of services on clients in any way? If so, how? Do you currently undertake continuous quality improvement in service delivery? What do you use to inform these improvements?

When carers access Carers Tasmania’s counselling or therapeutic groups, they are asked to complete a pre and post Wellbeing Survey, developed using the Australian Unity Personal Wellbeing Index tool. This provides quantitative data regarding the impact of services upon wellbeing. It is a clear way to determine where the carer is placed at service ‘entry’ and then the degree of positive impact on the carer overall wellbeing at service ‘exit’.

Carers also complete an evaluation of their experience which is reviewed and collated for quality assurance purposes. Carers Tasmania document case studies to further illustrate and review the work that they have completed and these are discussed at team meetings as appropriate to provide an opportunity for professional development and reflective practice.

Carers Tasmania also utilises the DASS (Depression Anxiety Stress Scales) to measure the three related negative emotional states of depression, anxiety and tension/stress for carers who participate in the 9 week Mindfulness course (this course forms part of early intervention services and activities delivered under the Carer Support Information an Advocacy contract through DSS). DASS is completed pre, mid and post course completion and data is able to inform the benefits of participation in the course for individual participants, many of which have experienced profound improvements in their wellbeing as a result of participation, and also ongoing practice. The following graph is an example:



Carers Tasmania regularly conducts Carer Consultation as part of their carer engagement and systemic advocacy role. There are often opportunities to provide feedback within these settings.

In addition Carers Tasmania has undertaken several member surveys via Survey Monkey; these have offered a readily accessible opportunity for members to participate remotely (as face to face participation is not always possible due to caring circumstances and for many members as a result of geographical isolation).

Team members have their performance reviewed on a quarterly basis, with the use of an Individual Work Plan (IWP) to guide the review and open up discussion. This ensures that all team members

are able to contribute equally and at the same time ensure that Carers Tasmania meets contractual obligations.

Continuous Quality Improvement is a cornerstone of Carer's Tasmania's quality service delivery, with a number of processes in place, including: -

- Complaints and Compliments procedures are utilised to ensure clear and consistent processes and pathways relating to feedback and complaints.
- Risk Framework (both strategic and service-level risks) which includes mechanisms for identifying and managing / mitigating risks. Risk management is an integral component of continual improvement and as such is a regular agenda item for all team meetings.
- Standard Operating Procedures have been developed that clearly define processes for administrative, operational and financial functions across the organisation. Procedures are reviewed regularly.
- Guide to Good Practice protocols have been developed and implemented throughout the network of Carers Associations, it defines the principles and features of good practice that underpin quality and effectiveness in delivering support services for Carers.
- Policies and Procedures are reviewed regularly in consultation with team members.
- A collaborative approach to continuous quality improvement with all team members ensures that quality remains at the forefront.

Continual review, assessment, escalation and reparation are addressed on a monthly basis during team meetings at Carers Tasmania, with Risk, WHS, Policy reviews and Standard Operating Reviews forming a part of rolling Agendas

Are you aware of the Department of Health and Human Services' Outcomes Purchasing Framework? If so, what assistance do you think Tasmanian HACC service providers will need to develop and implement outcomes and measures in their Funding Agreements?

Carers Tasmania is aware of the Outcomes Purchasing Framework and supports the aims of the Framework to 'achieve better outcomes for the community.'¹² and to negotiate with organisations on their performance indicators and targets.

Service providers are currently operating during a time of significant social services reforms across disability, aged care and mental health sectors, which creates extra and sometimes complex additional work. To develop and implement outcomes in their Funding Agreements, Tasmanian HACC service providers need:

- Support to understand the desired outcomes of the Funding Agreement and what transitional measures may be acceptable particularly if significant investment is required in the area of "IT" or systems and reporting for example.
- Direct engagement with the Department of Health and Human Services (DHHS) to develop the Program Outcomes and at the same time ensuring that these outcomes also align with the Federal Government's reform agenda.
- Clarity from the DHHS to translate Program Outcomes into Performance Indicators and agreement between the DHHS and the service provider on how these would be measured and recorded.
- Understanding from the DHHS of the additional costs for community organisations in infrastructure (IT), development of procedures and policies and staff training; and if necessary support in the transition phase (time and funding).
- Consistency and transparency across the sector in the processes that are implemented whilst understanding the unique position of organisations such as Carers Tasmania, who remain completely focussed and dedicated to advocating for and improving the quality of life for its particular cohort – carers and ensuring their needs are not lost in the reform process that is largely focused on care recipients.
- Communication, feedback, consultation and sharing of knowledge between the Department and Service Providers.

¹² Department of Health and Human Services (2014), 'DHHS Funded Community Sector Outcomes Purchasing Framework'

Would you like to see the Tasmanian HACC Program use the Australian Government's DEX system for its reporting requirements in future? Why or why not?

Carers Tasmania currently uses the Data Exchange (DEX) system for federal (DSS) funded reporting. DEX records quantitative measures. Carers Tasmania can extrapolate data such as gender, age, client disability status, CALD and ATSI status as well as sessions of service by case and session focus. Carers Tasmania does not currently record *qualitative* data into DEX (the SCORE – Standard Client/Community Outcomes Reporting - component of the system reporting) as this is currently an optional element and requires significant financial commitment to develop. However the “SCORE” function is presently being investigated for implementation. A cost to upgrade our current information technology platform has been obtained, to enable not only data collection but automatically upload of the SCORE information. This cost is not insignificant.

Implementation of the concept of reporting against Clients, Cases and Sessions was not without implementation challenges. There were fairly broad guidelines and assistance to implement not specific enough to prevent inconsistencies with processes (for individual organisation across Australia particularly those without in-house IT resources) and as a result data integrity was challenging in the inaugural reporting phase. Should the DHHS proceed with utilising DEX for reporting as an alternative to NEF, there would need to be significant guidance for new users.

When interpreting data for a specific region or demographic caution would need to be taken in order to ensure that only similar organisations / service types were being compared and that a holistic picture of services being delivered against a contract was considered. For example, there are many complimentary services delivered by organisations that do not translate well in to a client / case / session scenario, together with the fact that sessions do not clearly demonstrate the hours of services delivered. For example 1 hour interaction will appear in the same way as a 4 or 5 hour interaction in the DEX which impacts on the perception of organisational outputs and also individual client usage data and return-on-investment in terms of service delivery efficiency.

After initial teething problems associated with processes and data integrity, the DEX portal has proven to be an effective and efficient means of capturing data associated with a wide variety of services. It's reporting functionality has significant potential and could align State program implementation reporting to Federal programs.

Using one single platform for reporting may enable more streamlined processes internally, and more comprehensive data nationally (there would need to be safeguards and processes pertaining to levels of access, data visibility and privacy) This can in turn inform decisions pertaining to the allocation of funding and resources to high need cohorts and regions. Consideration would need to be given to costs associated with shift from NEF to DEX. Even for organisations already utilising DEX there would be significant costs associated with the development of an additional layer of reporting for bulk upload mechanisms. It is acknowledged that utilising the DEX system for both State and Federal data could reduce costs for service providers and improve efficiency, providers and potentially Government. This may also improve communications and processes, particularly for those on the cusp of 65 years (or those transitioning from the State into the Federal support system) and may help to reduce the risk of some people ‘falling through the cracks’.

Transitioning investment support would need to be provided to service providers as they include DEX in their reporting processes, with appropriate training and development of community sector staff to optimise the use of this system and the data that is inputted.

Are the proposed eligibility criteria appropriate? Should anything else be considered with respect to the proposed eligibility criteria?

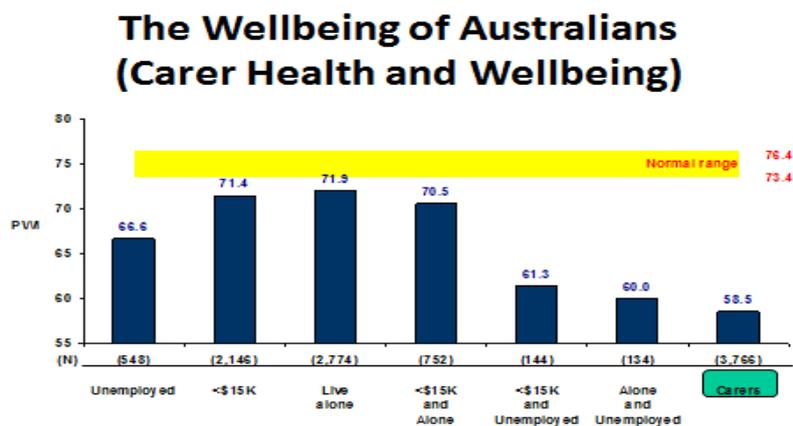
Carers Tasmania considers the current HACC eligibility criteria to be appropriate. However, Carers Tasmania sees it as an imperative for carers to be added as a seventh eligibility criterion. Currently HACC recognises carers merely as an addendum “Carers of people eligible for Program services may also receive support. For a carer to receive support the person cared for must be assessed as being eligible for Tasmanian HACC Program services.”¹³

Carers Tasmania firmly believes that carers need to be identified, included and supported, and not be left to the discretion of the assessor dependent upon the care recipient’s needs. It must also be remembered that a carer may also receive supports as the service user in their own right, providing they meet the preceding criteria, and may also be in a caring role. Caring roles are often complex and require more discussion and exploration than what can be provided by a simple tick box process. Assessment processes need to be such they will uncover the complexities of caring and the possibility of existing co caring situations.

Those newly arrived to the country may need special consideration too, given the presence of trauma and possibly the need for longer term supports.

In order to ensure that Carers are adequately supported by the Tasmanian HACC program it is essential that carers are a seventh cohort in order to meet the needs specific to that of a caring role. Carers must be identified at the commencement of intake and assessment processes, i.e. whether the person being assessed has a carer, or whether the person being assessed is a carer in their own right.

Carers have the lowest personal wellbeing index. Cummins et al developed The Australian Unity Personal Wellbeing Index in the early 2000’s as a barometer of Australians’ satisfaction with their lives, and life in Australia. It is based on, and develops, the theoretical model of subjective wellbeing homeostasis. Personal Wellbeing Index measures levels of stress and anxiety and, as you see on the graph, carers score the lowest PWI, that is, essentially carers have the highest levels of stress and anxiety and depression.¹⁴



¹³ Discussion Paper: Tasmanian Home and Community Care Program Version 2.0-21 April 2017. DHHS.

¹⁴ Cummins, R Deakin University and Carers Australian Unity, 2007. Report Revised 2015 – What makes us Happy

Carers Tasmania are the only organisation in Tasmania solely dedicated to improving the quality of lives of carers and therefore are the expert when it comes to assessing the needs of family carers, and in turn supporting them during their caring journey. The needs of a carer fluctuates during their caring journey, their needs are more often than not, not met or directly addressed by the provision of services associated with the needs of the person they support.

It is essential that the heightened needs of carers, who are themselves living with chronic health conditions, whilst supporting a loved one are acknowledged and supported. This is because, as already identified in this paper, carers are pivotal to the stability of the health system.

How does your service prioritise client need? Do you experience problems with prioritising client need?

Good practice principles guide Carers Tasmania in prioritising clients' needs. Processes following Standard Operating Procedures result in (summarising): -

1. Intake and assessment by phone or face-to-face (9am-5pm Monday to Friday) using the Carer Support and Wellbeing Check and a minimum data set.
2. Referral acknowledgements are sent to referring providers.
3. Build rapport, and support the carer, providing suggestions for internal and external supports (both practical and emotional).
4. Complete referrals (with carer consent, both external and in-house).
5. Data entry to record relevant carer information.
6. Follow up referrals to ensure outcomes are completed.
7. Minimum annual review process.
8. Carers who are referred into the Counselling program are monitored for changes to their situation at the completion of their contact of support.
9. Recommendations from the Counselling Team to Carer Support Officers in terms of other external and practical support needs are escalated and actioned in a timely manner to ensure Carers' needs are met.

The initial contact via the intake system, completing Part A of the Carer Support and Wellbeing Check (CSWC), results in suggestions being made to the carer for relevant referrals and supports. An important part of the CSCW, the Wellbeing Survey score, enables the identification of signs of carer stress and escalate the carer to a counselling appointment, fitting the early intervention approach to prevent crises. Referrals for practical supports occur within two days of contact with the carer.

Carers Tasmania is not funded to provide a crisis service, but will do whatever it can to support a carer in immediate distress. Access to immediate counselling 'in-house' can be difficult as counselling appointments may be fully booked. Carers who need support immediately are emotionally supported by Carer Support Officers who listen and gain a summary of the circumstances, and provide information and referrals to crisis services that may help to support the carer and alleviate the situation. There are times where this process in itself reassures the carer and they are able to wait for an appointment with a counsellor. However, if this is not appropriate or possible, Carers Tasmania has access to a counsellor who works on a sessional basis for the organisation.

Those carers with particularly complex circumstances at times benefit from case co-ordination. The amount of work required to assist such carers is sometimes above and beyond a Carer Support Officer role, and requires an advocate who can work face-to-face with the carer and the services they are finding challenging. The dilemma for the carer is that, sometimes, they may have a different perspective to the person they care for, and in such cases advocacy services align themselves with the client. This can mean that the carer, who is often shouldering huge responsibility for a person who will not accept services or speak up on their own behalf, feels very alone.

Staff capacity is managed well at Carers Tasmania; however funding constraints can create strain. Carers Tasmania prides itself on making contact with carers in a timely and thorough manner and doing all we can to support carers in need.

How could the Tasmanian HACC Program's prioritisation criteria be improved?

The flexibility of the Tasmanian HACC program is seen as strength of the program, but prioritising carers according to need is best approached through a triage process for identification of those carers with high, complex and immediate needs – including the identification of carers as a matter of course.

The Tasmanian HACC Program currently recommends that service providers should prioritise access to services based on the following criteria:

- Client eligibility;
- Level of client functional need for the service type;
- Client and staff safety;
- Clients with special needs, as described in Equity of Access;
- Clients without carers or support networks;
- Clients vulnerable to further deterioration.

As can be clearly seen / demonstrated through this paper:

- Carers are often eligible for services in their own right;
- Carers may be at risk / experience escalated risk as a result of factors associated with their caring role;
- Carers may themselves have specific needs associated with access and equity;
- Carers are often socially isolated themselves, with limited or no social networks as a result of their caring role;
- Carers commonly experience deterioration in their own health and wellbeing due to caring for another.

Through the assessment process, a process should be implemented to identify clients who have a carer, so they can be included in the assessment, giving a more thorough understanding of the needs of the client from both a formal and informal service provision / needs perspective. Many who are service users in their own right may also be in a caring role, these individuals could be flagged additionally; so it is understood that as well as having their own needs, they are managing the needs of another / others. It is not uncommon for circumstances such as this, and result in challenging situations should a carers needs increase dramatically as a result of delayed access to services and or services that do not adequately support the carer and the recipient.

It is essential that prioritisation criteria is consistent and thorough, and that those with high needs receive intervention and support as soon as practicable. In addition, identifying other service providers' involvement in supporting clients/carers would give a more holistic picture of the situation.

How could the charging of fees for Tasmanian HACC Program services be improved?

Carers Tasmania does not currently charge fees for the services it provides under the HACC program and approaches this concept with caution. This is due to several factors which are explained below

A family may already be paying fees for HACC services for the person requiring care and these are no longer capped at ten dollars a week to maintain affordability. These services are likely to be the highest priority for the family.

Recent research by the Australian Government validates Carers Tasmania's anecdotal knowledge that carers experience financial strain as a result of both the 'direct and indirect' costs associated with caring. These include loss of income, loss of long term financial security, and on a day to day level, direct costs associated with additional heating and cleaning expenses, transport, medical costs, and costs of services, along with often helping the person they care for to pay for their expenses.¹⁵ Furthermore 24.3% of those caring and on a Carer Payment were found to be living below the poverty line in a 2016 Australian Council of Social Service report.¹⁶ Consequently, a carer may not see paying for services for themselves as possible or a priority and as such a fee attached may pose a further barrier to seeking support.

Alongside this, Carers Tasmania sees the possible implementation of imperative fees as being cost negative for an organisation if they are to be maintained at a level that a) enables the user to afford the fee and b) doesn't discourage the user from utilising the services thus creating a reverse-intent affect for the Tasmanian health system. It is a fine balance, because a low fee can, as mentioned, be 'cost-negative' - the administrative costs of creating and administering this process (i.e. creating accounts, invoicing, collecting debts) outweighs any positive gain (financial and non-financial), thereby reducing the capacity of the organisation increase service provision (the rationale behind charging fees)

And further more, Carers Tasmania would be concerned that a low value debt with the organisation could still deter a carer from seeking further supports that are seriously needed. As a result there is a risk that a fee process could impact on KPI's.

However, if charging fees becomes a mandatory process, Carers Tasmania sees the need for clear guidelines, with set dollar figures. And importantly, that all people using a service have a good understanding of eligibility and circumstances where waivers would apply. In addition, it is also important that any waiver fee is not overly arduous, as this could potentially deter a carer / consumer for applying for a waiver.. Any fee process would also require accountability and transparency.

It is essential that any fees structure that is implemented is simple and affordable in order for clients to access services that enable them to maintain their indolence and wellbeing; and potentially utilising a flexible model that offers a range of payment methodology options.

¹⁵ Department of Families, Housing, Community Services and Indigenous Affairs (2011) The costs of caring and the living standards of carers

¹⁶ Australian Council of Social Services (2016) Poverty in Australia 2016

What transition issues need to be considered in implementing the changes proposed by this paper?

This question needs to be approached in the broader context as transitioning issues are already very much part of the changing national service delivery environment significantly affecting consumers and service providers.

Recent social reforms include: Consumer Directed Care, My Aged Care, National Disability Insurance Scheme, and the Integrated Carer Support System, of which the National Carer Gateway is the first initiative. Carers Tasmania is cautious about the added complications and potential risks that could eventuate if a state government implementation process of the proposed changes in the Tasmanian HACC Discussion Paper are carried out without consideration of the broader reform environment. Carers – who are supporting ‘pillars’ of all of these reforms – are at risk of ‘falling through the cracks’.

Carers Tasmania puts forward the key priority for DHHS to recognise carers as eligible in their own right for Tasmanian HACC support. Training for service providers in carer awareness, their rights and responsibilities would be integral for this new carer-inclusive approach.

The overarching shift in approach to one of wellness and reablement will not only require a cultural shift in organisational approach and practices for both service users and providers, but will require planning and clear communications, suitable time for transition, with reviewing and measuring processes recording efficacy, and escalation strategies with an eye on continuous improvements.

Despite current reforms designed to increase integration and efficiencies, choice and control, the role of the carer remains just as integral to Tasmania’s vulnerable people as regardless of the ‘new way’ of service delivery in the social services sector, carers will still continue to provide the majority of support to loved ones. This was evidenced in Carers Tasmania’s recent report into ‘The impact of the NDIS on Carers in Tasmania – The Picture So Far’¹⁷, which has illustrated mixed responses to the value of the NDIS for the carer.

The survey showed that we cannot presume the NDIS is going to magically improve the lives of all carers and their care recipients. We must not forget the role carers are providing in supporting those most vulnerable in our community, let alone in assisting our health system. We need to provide them with the necessary skills and supports to do this. This is beyond the capacity and the role of the NDIS. Key findings of the report include:

- 57% of carer respondents find it challenging or very challenging to source relevant and appropriate services for the person they care for.
- 40% of those carers self-managing the NDIS plan for the person they care for find it fairly difficult, and 9% of carers are not coping at all.
- Almost 70% of carers that responded indicated that nothing has changed for them in terms of having more time out for themselves as a result of the NDIS plan for their carer recipient – in fact some have less time.

This indicates that the NDIS does not replace the carer, and it can in fact create a new type of care burden for those managing a plan. There are also issues of eligibility; not all medical conditions that

¹⁷ Carter, D. Favelle, S, Arnold J (2017) A report on: ‘The impact of the NDIS on Carers in Tasmania – The Picture So Far’.

require a carer are covered under the scheme. As a result, Carers Tasmania believes it is very important that there is communication between NDIS and HACC.

It must also be remembered in creating reform that people are far more complex than they might appear on a form, or with a tick box. In the case of the carers, their circumstances are influenced by their physical health, their social and financial circumstances, and their mental health. Caring scenarios are also not simple, and neither is the support they require. Key findings from the 2015 Survey of Disability, Ageing and Carers (SDAC) illustrated that over one-third of primary carers (37.8%) were living with disability themselves¹⁸. This means that they too require care, and that they exist in a co-caring arrangement. New approaches therefore need to cater for such complexities.

As well as more human service related considerations, changes to data systems will require significant work, and should include training for all who are likely to use it. The development of electronic forms would be required and the need for new invoicing/fee-for-service processes.

If there is a transition to a new Tasmanian HACC system, then Carers Tasmania recommends it dovetails into current federal programs in both systems and processes, to better meet the needs of carers now and in the future. The ideal philosophy is to increase people's choice and control while providing a fair and inclusive safety net for the more vulnerable in our community.

¹⁸ ABS 2015 4430.0 – Disability, Ageing and Carers, Australia: Summary of Findings, 2015