



**Submission to the  
Department of Health Discussion  
Paper: Future Reform – an  
integrated care at home program  
to support older Australians**

**25 August 2017**

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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## Preliminary remarks

This submission has been prepared by Carers Australia with input from our Australia-wide Network of state and territory Carer Associations.

In this submission our primary focus is on family and friend carers of the aged, although we have also responded to more general issues relating to propositions for a more integrated home care program to support older Australians. In this context we note that older carers may also be consumers of aged care services in their own right.

We also note that the future for carer supports, including support services for carers of older people, is currently in a state of hiatus, pending Government endorsement of a new Integrated Carer Support Services model which is still under development. The objective of the new model is to provide support services which can be directly accessed by carers (regardless of the age of the person they care for) to support their own wellbeing. However we have not factored this model in as a backdrop to this submission. It is not yet fully developed, approved and funded.

## 2.3 Reforms to date

### **Question: Are there any other key policy objectives that should be considered in a future home care program?**

Prior to the reforms, carers of older people had access to support services such as respite in their own right. Since the reforms identification of their needs and access to many support services is available to carers only as a by-product of the assessed needs of the person they care for.

The failure of the My Aged Care (MAC) and Regional Assessment Service (RAS) systems to deal effectively with carers' has been compounded by the merger of the former National

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<sup>1</sup> As identified in the Australian Market Research (AMR) My Aged Care Stage Two Wave 1 research, carers' assessment and referral needs are not being met through the new access arrangements. Carers' satisfaction with the MAC/RAS system is markedly lower than that of clients. Qualitative interviews confirmed carers are often navigating the system on behalf of family members with care needs and feel they are not always recognised clearly enough as the primary carer. The AMR research indicated that 43% of carers had been included in the RAS assessment process compared to 60% who were included in ACAT assessment. They were also concerned with the competence of RAS assessors in recommending the most appropriate care. Anecdotal reports continue of carers not being able to deal effectively with MAC on behalf of the person they care for due to poor processes for gaining client consent and establishing carers' representative or nominated person status. This has resulted in clients receiving 'cold' calls from MAC even when specifically requested to call the carer rather than call the client directly. As these processes have been prioritised for improvement, it is expected that this issue will occur much less frequently in the future.

Respite for Carers Program (NRCP) into the Care Relationships and Carer Support sub-program of the Commonwealth Home Support Program (CHSP). Previously the carer was considered the 'client' of flexible respite, centre-based respite and cottage respite, and providers reported on the carers receiving these services. Now only people with care needs can be registered as clients with MAC. Referrals from the MAC Contact Centre to RAS and referrals from RAS to CHSP respite only provide information on the person with care needs as the client. Providers of respite are only required to upload client information on the Data Exchange (DEX) system. No carer information is required or captured. This has resulted in a significant loss of data about carer needs and service usage by carers.

Respite service providers also report very low numbers of referrals for flexible respite, centre-based respite and cottage respite from RAS, affecting their occupancy, meeting of performance targets and ultimately their viability. This low rate of referral also acts to perpetuate crisis-driven access to respite care by carers rather than planned access to regular respite care to maintain the care relationship.

In relation to access to residential respite, Carers Australia and the state and territory Carer Associations have recently conducted a survey highlighting growing difficulties in accessing either planned or emergency respite. (See 6.1.1 Informal Carers below.)

### 3.1 Policy Objectives

#### **Question: Are there any other key policy objectives that should be considered in a future home care program?**

While we note that the Discussion Paper identifies 'consumers' as "existing and prospective recipients of home support and/or home care services, and their informal carers/nominated representatives", we are of the view that an explicit reference to carers should be incorporated into the objectives; noting that we prefer the term "family and friend carers" which most carers are more likely to identify with than "informal carers".

We recommend a new dot point under the heading "Policy Objectives"

- Recognise and respect the contribution of family and friend carers.

Under the heading "building on the strengths of existing programs" a separate dot point should be inserted:

- support family and friend carers to access support services in their own right to meet their own needs.

These additions would aid consistency with the Carers Recognition Act (2010).

## 4.2 An integrated assessment model

**Question: What do you think could be done to improve the current assessment arrangements including addressing variations of different practices between programs or care types (e.g . residential care, home care flexible care)?**

Carers Australia supports the NACA position in relation to a government operated assessment process that is agnostic of place, free for consumers and, where practicable, operates independently of service providers.

Carers Australia supports the integration of RAS and ACAT assessments, with the proviso that the integration of the two assessment teams does not diminish the level of expertise represented by ACAT teams. We understand lower-skilled RAS assessors can provide cost effective low level assessments but cannot replace clinical assessments by an ACAT. Great care should be taken to ensure that the skill and expertise of ACAT assessors is not diminished or lost by the integration, and that assessment and referral is still delegated to an assessor with the appropriate skills to assess and identify issues.

In addition to the benefits of an integrated assessment approach identified by NACA, we note additional benefits identified by Carers Queensland in its submission. In particular:

- provision of enhanced career options for existing regional assessment staff
- increasing availability of assessors in rural and remote regions
- increasing the availability of assessors with knowledge in specialist areas such as indigenous health and remote health and CALD friendly assessment.

We support the design elements of the integrated approach to aged care assessments identified in NACA's submission, including in particular that it should be inclusive of carers whatever their age. Feedback from RAS providers has indicated that there is much need for improvement in:

- alerting applicants for aged care assessment that they should involve family or friends who provide unpaid assistance
- alerting carers to the need to identify their own physical and emotional health needs (possibly through the inclusion of a carer stress survey in the assessment process) and their options for accessing support in their own right as well as through the aged care suite of supports
- referring carers to carer support services they can access, including respite, peer support and counselling
- alerting carers to wellness and reablement services which can assist them to preserve or improve their own health and independence.

In this context we note that currently RAS assessors are heavily reliant on the National Screening and Assessment Form (NSAF) and referral pathways through My Aged Care to provide information and referral if they do not have local service provision experience. Anecdotally we find that RAS assessors largely do not refer to supports outside of what is available on the My Aged Care website, meaning that carer support services are invisible to RAS assessors as well as some forms of respite and community supports available through councils and charity organisations. We think there should be a requirement for assessors to attend community forums and training and that referral pathways to the Carer Gateway should be integrated into NSAF referrals.

### **4.3.1 New higher level home care package/4.3.2 Changing the Current Mix of Home Care Packages**

**Question: Would you support the introduction of a new higher package level or other changes to the current package levels? If so, how might these reforms be funded within the existing aged care funding envelope?**

Carers Australia strongly supports the introduction of a new higher level Home Care Package. We have received feedback from many carers of people with very complex needs, especially carers of people with challenging behaviours, that they cannot continue to provide care at home within the funding constraints of the current Level 4 package, even with dementia and other supplements. More assistance to support the care relationship is needed. While we endorse the NACA position that any changes should be supported by a review of the packages in terms of numbers, levels and gaps between levels, we would not support long delays around the introduction of a new, more generous package at the highest level. Carers of people with complex needs are struggling now. While some carers have access to respite care through CHSP in addition to package funds, access remains problematic as CHSP providers are required to accommodate clients without packages

Our comments against item 6.1.1 about the decline in replacement respite care in residential facilities should also be taken into account in this context.

In terms of trade-offs within current aged care funding, we note that increasing the numbers and value of packages for people with high care needs is likely to reduce the demand for permanent admissions to residential aged care at least in the short term.

Whatever changes may or may not be made to the number and levels of home care packages, there is a pressing need to identify to consumers how long they are likely to have to wait for a package. Ideally consumers requiring a services in their home should be able to receive support as soon as they have been identified as needing it, however we are aware of older people who have been approved for home care packages up to 10 months prior to

home care packages being transferred to the national queue, and they continue to wait. In the absence of timely allocations of home care packages consumers and their carers are sorely in need of some guidance as to how long they are expected to wait for a package. Many carers will take time off work, time away from their families or pay for private services out of their own pocket while they wait for an adequate level of home care to be allocated. Carers need to know how long they will need to wait for a package so they can adequately plan for the future and ensure that their interim care arrangements are sustainable for the time required.

Case study:

*Sally (73) provides regular care and support to her friend Stephen who is 83 and lives on her street. Sally cooks meals, does his shopping and provides occasional assistance around the house. Stephen was approved for a level 4 package in September 2016 and has been receiving CHSP and privately funded community nursing, personal and domestic assistance in the interim. Sally is unsure that she will be able to continue the level of support she has been providing for much longer. Stephen could continue to live independently in the community but after waiting over 6 months with no indication of when he will be allocated his level 4 package, Stephen is now considering moving to a nursing home as his situation is becoming unsustainable.difficult to manage.*

#### **4.4.1 Changing the current mix of individualised and block funding**

**Question: Which types of services might be best suited to block funding?**

With respect to thin markets across all geographical areas, we would expect that block funding of services and other supports which are unlikely to attract much, if any, provider competition (owing to limited consumer demand) would be appropriate for block funding regardless of geography and demographics.

In essence, we believe that the Productivity Commission in its 2011 report, *Caring for Older Australians*, provided a sound approach to determining which services are best suited to block funding.<sup>2</sup> It proposed that low intensity services such as community transport, social support, meals delivery, advocacy and supports provided to carers in their own right would be block funded and accessible with minimal assessment or direct referral to the service. This model would allow consumers with minimal support needs who only wish to access one or two low intensity services to avoid an extensive initial assessment. Introducing a low level

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<sup>2</sup> Productivity Commission, *Caring for Older Australians*: Productivity Commission Inquiry Report Vol 2, No. 53, 28 June 2011

assessment support tier is likely to benefit CALD, Aboriginal and other special needs groups who have identified onerous assessment processes as a barrier to service access.

Furthermore, carers of older people who are reluctant to accept formal services, or lack insight into the role the carer plays in their support, will also benefit from the opportunity to gradually introduce the person they care for to community services without having to make the psychological commitment and engagement with often confronting procedures required for them to access support through the formal aged care system.

The following service types should receive block funding and be accessed through minimal assessment:

- Community transport
- Social support
- Meals delivery
- Day therapy centres
- Dementia Advisory Service
- Wellness programs
- Individual advocacy (with flexibility to refer to case management)
- Emergency respite
- Home maintenance
- Low level aids

We note that both the Discussion Paper and the NACA submission identify that block funding will often be required by providers of specialised services.

We also agree with the NACA proposition that block funding is often best suited to services that are primarily delivered in group settings such as centre-based respite and social support group services. It is also suited to services which rely heavily on volunteer workforces.

**Question: Are there other ways of funding particular services or assisting consumers with lower care or support needs, e.g. a combination of individualised funding and block funding, vouchers etc?**

Carers Australia supports the use of vouchers as one means of exercising choice and control, especially in relation to services which do not require a detailed, formalised plan or an ongoing relationship with a provider.

Vouchers are particularly useful in relation to services such as transport. The use of such vouchers should be available to both the older person being cared for and to their carer. In many cases the carer will need to accompany the person being cared for when they are using transport services. In other cases, when they do not have their own transport, carers will need subsidised transport to attend to the care needs of the person being cared for. Examples include: visits to the pharmacy to fill prescriptions or other pharmaceutical products required; picking up referrals from a medical provider; and visiting the person they care for in hospital. In such cases it may not be practical or even possible to take the person they care for with them.

We note that in the UK vouchers (sometimes called respite grants, or carers' grants) can be exchanged for services, such as those offered by care agencies or residential homes. Carers can use these use vouchers to pay for extra costs associated with a holiday, including live-in care workers, short-stay residential care, or the cost of more homecare.

However we agree with the note of caution in relation to voucher systems recommended in the TasCOSS submission:

“It is possible that new flexible systems could provide consumers with more flexibility and choice when accessing entry level support and care. However this will need to be carefully implemented so that additional systems do not further burden providers with unmanageable administrative processes. Providers and consumers need systems that offer timely access to targeted services. Providers carried a large administrative burden with previous voucher systems. This made them problematic, unwieldy for providers and not cost effective.”

#### 4.5.1. Refocusing independence and wellness

**Question: Should consumers receive short-term restorative/reablement interventions before the need for ongoing support is assessed? If so, what considerations need to be taken into account with this approach?**

While we agree that restorative/reablement interventions, if they succeed, are preferable to becoming dependent on assistance in order to function in the home, we do not think there is a single blanket answer to this question. It will depend on the psychosocial and financial circumstances of the consumer as well as their state of health and mobility, all of which need to be assessed. We certainly don't support such interventions being a compulsory precursor to accessing ongoing support for all consumers. If that were the case, it would simply create an additional barrier to consumers and carers receiving much needed support when it is needed in cases where such interventions are unlikely to provide a prospect of lasting functionality ability.

#### 4.8.1 Supporting specific population groups

**Question: How can we make the care at home system work better for specific population groups, particularly those whose needs are not best met through current CDS models and administrative arrangements?**

With respect to Aboriginal and Torres Strait Islanders, Carers Australia is of the view that the National Aboriginal and Torres Strait Islander Residential and Flexible Care Program is a good model which is sensitive to place and the diverse needs and cultural differences between communities and provides for community participation in planning and delivery of aged care.

With respect to improving access to CALD consumers and their carers, since July 2015 the majority of aged care funded services now have access to the Translating and Interpreting Service (TIS National) free of charge. This list includes Aged Care Assessment Teams (ACAT), the My Aged Care call centre, the Commonwealth Home Support Program (CHSP) and Home Care Package (HCP) providers. In contrast, Regional Assessment Service (RAS) providers are still required to budget for interpreters as part of the unit price in their funding agreement.

RAS providers must absorb the cost of using an interpreter which, on top of the additional time required when using an interpreter, increases the unit cost of servicing CALD clients. Unit pricing that does not acknowledge the complexity of individual consumer needs may act as a disincentive to provide adequate time and resources to overcome inequities. This could place pressure on carers to inappropriately cover additional services like interpreting and advocacy. Similarly, very remote and high needs consumers may also be at risk of further access inequity due to real or perceived additional costs.

Mandatory training on the use of interpreters for assessors and call centre staff would support higher quality, more consistent service for CALD communities. Identified bilingual positions would also provide cost effective support and first-hand information in community languages.

#### **4.8.2 Supporting informed choice for consumers who may require additional support**

**Question: What additional supports could be considered to ensure that people with diverse needs can access services and make informed choices and exercise control?**

Assistance to navigate aged care processes, understand their needs and guide and operationalise plans requires expert advice. This can come in the form of case management or advocacy services (neither of which should not be paid for out of packages). Some peer support services can also perform a valuable role, but they need to be funded.

These additional supports will be particularly important to people with complex needs requiring multiple service providers. They will also be vital to people who do not feel confident to exercise choice and control because of language and cultural obstacles to engaging with mainstream service provision or because of disability or educational disadvantage.

Carers NSW notes that since the increasing choice in home care packages reform was implemented in February 2017, it has documented a number of reports from carers taking the initiative to move their care recipients' package to another provider and negotiating new agreements. Many reported that they expected or had already negotiated more services or a better service. We have also heard accounts of carers moving house and successfully arranging a new package provider in another part of the state. Apart from some delays in package transfer times, consumer (or in these cases, carer) directed home care packages appear to have provided increased choice, control and autonomy for a majority carers and consumers who are engaged with Carers NSW. However, it is important to note that all of these carers were articulate self-advocates, had a high level of education, were native English speaking and in every case the change of provider was negotiated by the carer. Carers NSW is well aware that many carers and consumers will not have the time and skills to research and negotiate new arrangements. Carers NSW urges the Department to seek advice from CALD, LGBTI, Aboriginal, rural representatives and consumers without access to an advocate for further advice on how to ensure that these groups can enjoy equal participation in consumer directed, individualised funding.

#### 4.6.2 Accessing services under different programs

**Under the current program arrangements, does allowing some consumers to access both programs promote inequity, particularly if other consumers have to wait for a home care package?**

Our response is focused on access to respite care.

We do agree with the proposition that there is in principle some inequality in allowing people who have packages to access often difficult to obtain respite services at comparatively low cost when others who are not on packages also have a need. However, we well understand why. If respite funding is not factored into packages, either because it is difficult to anticipate the need in advance and was not identified during assessment or because the funds available do not stretch to including respite along with other urgent home or personal care needs, then CHSP respite access may be the only option.

The approach to addressing this issue must come back to other recommendations in this submission. Carers must be encouraged and enabled to participate in assessments which have a focus on their needs and the needs of the care relationship as well as the person they are caring for. An effort needs to be made to engage with carers around any concerns they may have about access to respite care and, indeed, to alert them that their capacity to provide ongoing quality care is likely to be compromised if they don't access respite care. If package funding is so tight that respite care falls off the list of assistance required, then the consequence may be to put the care relationship at risk of breakdown.

Access to sufficient funding to meet respite needs must be revisited in any review of the mix and level of Home Care Packages.

We also note that that Home Care Package consumers and their carers should have access to CHSP services if there is a change in circumstances that result in higher care needs in the short term or while they wait for a package at their assessed level.

### 6.1.1 Informal carers

#### **Question: How might we better recognize and support informal carers of older people through future home care reforms?**

As noted above, there is a pressing need to be proactive in involving carers in home care assessments and helping them to identify their own physical and emotional support needs. Certainly the current level of inclusion of the carer perspective in NSAF is less than effective in identifying their needs and referring them to appropriate carer services. Some RAS assessors have reported that this may be because of pressures to complete assessments within tight time frames. We endorse Carers Queensland's recommendations that carers:

- Have the right to an assessment of their own needs, including discussion of their ability and willingness to continue to provide care and support
- Are included in the assessment processes – ensuring that the support plan can support the carer and the consumer

As noted above under Section 4.2, carers are not currently well supported in the context of NSAF assessments and there is a need to take a more proactive approach in identifying carers and directing them to carer support services. Over-reliance by RAS providers on the MAC website for service referrals means that locally available carer support services are not easily identified. While the Carer Gateway also has its problems as a reliable service directory, it is important that RAS advisors are at the very least aware of it as a resource for carer supports.

We also note that access to both planned and emergency respite in residential aged care facilities has diminished since the implementation of the aged care reforms. Carers Australia and our state and territory Carers Associations recently surveyed organisations across Australia which broker aged care respite services. We received 112 responses. It is very clear from the survey results that demand for residential respite care is not being met.

When asked about specified types of aged respite care, most respondents indicated that they had high or very high demand for emergency (74 per cent) and planned (88 per cent) respite care. None of the survey respondents found emergency respite very easy to access and only 3 per cent were able to access planned respite very easily. In contrast, 68 per cent found emergency respite, and 66 per cent found planned respite, difficult or very difficult to access. Thirty-five per cent of respondents were able to secure respite care most of the time, and a further 46 per cent some of the time.

Unless a solution can be found to this problem, we anticipate that there will be an increasingly high demand for higher levels of formal care in the home – a factor which will need to be taken into account when considering funding levels for home care packages.

We noted in our preliminary remarks that the proposed Integrated Carer Support Services model promises to provide improved access to a range of supports which impact on carer wellbeing and their capacity to carry out their role. These include information and referral, peer support (whether online or face-to-face), education and training, counselling (whether on-line or face-to-face), emergency respite and financial supports. (The extent to which it will deliver better access to planned respite is not clear as, to date, the model simply notes that planned respite is available under aged care.) If the ICSS is not proceeded with or inadequately funded we contend that there is scope for improvement to all the services which are in scope for the model to be made available for carers of the aged through the aged care system.

### **6.1.2 Technology and innovation**

#### **How can we best encourage innovation and technology in supporting older Australians to remain at home?**

Carers Australia has a deep interest in the opportunities offered by new technologies to both assist older people to live more independently and adventurously and to free carers from day-to-day, hour-to-hour assistance and supervision.

While we are aware of a wide range of technologies that can serve these goals, we are less aware at this stage of how they can be made both attractive and affordable to those older people who are less technology inclined and concerned about the cost of access to technology. We believe that when plans for support are developed and as the needs of older people change, they should be alerted to options for assistance to be more mobile, independent and engaged that can be accessed through technological solutions. There may also be a need to provide training and assistance in the use of technology and to emphasise to both carers and consumers the benefits of technological solutions. Feeling stressed and overwhelmed can be a real barrier to embracing assistive technologies.

Carers Australia notes the NACA submission comments in relation to this issue and in particular endorses the NACA position that:

“The best opportunity for improvement in access and affordability of aids and equipment for all Australians is the establishment of a new, federally funded national aids and equipment/assistive technology scheme with harmonised eligibility, access and co-payment requirements across all jurisdictions. This new national aids and equipment scheme could enter into agreements with the NDIS Assistive Technology Scheme, which would allow greater economies of scale for procurement and development of innovation, particularly in technological solutions that may be higher in capital cost, but which may have a longer life,

provide better consumer outcomes and/or reduce future costs in other care settings, such as acute hospital services or residential aged care.”

### 6.1.3 Rural and Remote areas

**Question: How can we address the unique challenges associated with service delivery in rural and remote areas?**

**Question: What other service delivery and funding models could we consider for providing care at home services to consumers living in rural and remote areas, including examples of innovative community models?**

Block funded, integrated aged, health and community services (multipurpose services) which share core funding is one option for compensating for service shortages in thin markets.

We note that NACA in its submission canvasses the option of sub-contracting informal carers. The same suggestion is raised in the Productivity Commission’s 2017 Discussion Paper on *National Disability Insurance Scheme (NDIS) Costs*<sup>3</sup>. In our response to that Position Paper we noted that the issue of paying co-resident informal carers to provide care to family members or friends is the subject of some controversy.<sup>4</sup>

Many family and friend carers would regard being paid to care for a loved one as anathema and possibly an extra source of relationship strain within the family. Among those who are anxious about the consequences of family carer employment and the possibility that carers will become even more entrenched in their caring role is often raised. As noted in a cross-national study of ‘cash for care’ schemes:

“[I]n this type of ‘job’ it is particularly difficult to exit – should these care-givers or care-users decide that they would prefer an alternative form of care (e.g. residential care or a different care-giver), then these relationships are now even more difficult to leave, since to do so would incur direct economic costs as well as emotional costs.”<sup>5</sup>

However, we know from consultations around the NDIS, that other carers and those they care for regard the option to choose to pay family or friend carers, in preference to a worker

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<sup>3</sup>Productivity Commission, Position Paper: *National Disability Insurance Scheme (NDIS) Costs*, June 2017, p.2

<sup>4</sup> Carers Australia submission to the Productivity Commission’s Position Paper: *National Disability Insurance Scheme (NDIS) Costs*, June 2017

<sup>5</sup> Clare Ungerson, *Whose empowerment and independence? A cross-national perspective on ‘cash for care’ schemes*, *Ageing & Society* 24, 2004, 189-212

who they believe would not provide the same standard and quality of highly personal holistic care, is a key element of choice and control.

If this model were to be supported a number of issues would need to be resolved.

- Who would be the employer of the carer? Would it be the participant? If so, would the participant become responsible for superannuation, occupational health and safety, and workers compensation insurance or would these carers be employed through an arm of government? We note that in some other countries which offer cash for care, the carer would register with a provider who provides administrative support and oversight or a local government takes on these administrative requirements.
- Given that many carers are available to provide care and need to be in attendance on a 24/7 basis, how would the hours of care for which they should be paid be calculated? Would it be on the basis of the care needs identified in the participant's plans which cannot be operationalised because of the absence of services?
- Access to family and friend carer support services provided by the Department of Social Services such as respite, peer support, counselling and education, are only available to unpaid carers. Being paid for a proportion of care provided doesn't remove the need for these supports. Provision would need to be made for these "sub-contracted" informal carers to continue to have access to these support services.

#### 6.1.4 Regulation

**Question: How can we further reduce regulation to allow for innovation while ensuring that essential safeguards remain in place?**

With respect to regulation, for innovative services or otherwise, it is important that the role of carers as representatives of aged care consumers be recognised. This entails the right of carers to make complaints on behalf of the consumer and also to complain about their own treatment by aged care providers. Indeed, carers often perform what can be described as a "natural safeguarding" role to the extent that they are very well placed to identify when things are not right and to act to protect the rights and needs of the consumer. In this respect carers often perform an early intervention and more agile advocacy role than formal advocacy and complaints mechanisms.