Don’t wait: Carers say listen and act now

A report on the Carers Virtual 2020 summit
In April 2008, the Prime Minister of Australia, the Hon Kevin Rudd MP convened an Australia 2020 Summit at Parliament House, Canberra. Over 1000 hand-picked Australians came together to share their ideas to help shape a long term strategy for the nation’s future.

Carers Australia watched this summit with interest and came to the conclusion that carers should hold their own 2020 to ensure their views would form part of this vision.

So in August 2008, we convened a 2020 specifically focussed on carer issues.

We challenged participants to come up with and debate big ideas that would help provide sustainable support for Australia’s growing population of carers and their families. The year 2020 was used as a benchmark for measuring success, but discussion was not limited to future outcomes. Immediate concerns were also raised.

We wanted our 2020 to be as inclusive as possible and decided that the best way to do this was to hold it online to allow carers to make comments in their own time from their own homes. We were aware that it wasn’t a perfect solution, but it was the best option to allow the widest possible involvement.

The Carers Virtual 2020 was open to anyone with an interest in carers to make a comment throughout August 2008. In that time, despite limited promotion, over 2,000 people visited the site and more than 200 contributed to the discussion. Participants came from every state and territory and included people from both rural and urban areas. With the resources that were available to us, there is no way we could have assembled a group like this to discuss these issues in person.
The Carers Virtual 2020 was funded by the Carers Australia Community Engagement Program. This is a new initiative in partnership with Amgen Australia designed to help carers have a greater say in their community. New media will play a big part in this program as a cost-effective means of reaching people who are both physically and socially isolated. We are very grateful to Amgen Australia for their support in getting this program off the ground.

We would also like to thank the people who contributed the opening articles and those who suggested ideas for new discussion streams. Most of all we would like to thank all the carers from all over Australia who responded with their thoughts, ideas, and insights. We are particularly grateful to the people who contributed to the forum on multiple occasions. You have made this project a success.

This report represents a summarised version of the discussion. The University of Canberra was instructed to prepare this material as objectively as possible so as to reflect a sense of what was said without any interference by us or anyone else.

There are comments in this report that Carers Australia does not necessarily agree with – just as there were on the website. However, we strongly believe that carers need to be heard and their views respected.

Carers Australia considers this event to have been a valuable insight that we will learn from. It will not be a wasted effort that will be filed away never to be seen again. Instead, it will be used by us for our own self-improvement as an organisation that exists for all carers. We will also take it to other people who are in a position to affect carers’ lives so that they too might gain a better understanding of how their decisions impact on real people.

I urge you to take heed of what carers are saying in this report – just as we at Carers Australia will.

**Message from Amgen**

Community support has always been a vital part of who we are at Amgen Australia. Our history of charitable sponsorship has reached a wide variety of organisations in fields such as health, education, environment and animal welfare. Amgen staff have helped strengthen the areas where we live and work through generous donations of money, time and talent. We recognise that providing community support is a defining factor of Amgen, a part of our DNA, and goes further than just funding. At Amgen, we want to make a real difference. The decision to consolidate our support into a single community investment with Carers Australia will provide us with an opportunity to help everyday Australians who face extraordinary challenges.
Don’t wait: Carers say listen and act now
A report on the Carers Virtual 2020 summit

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News Research Group University of Canberra

October 2008 For Carers Australia
Don't wait. Carers say listen and act now

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Executive Summary

This report is based on a comprehensive reading of posts to the Carers Virtual 2020 summit hosted by Carers Australia during the month of August 2008.

The summit received contributions from carers and other participants from across the nation. The title of the report is intended to reflect the sense of urgency with which many people said change was needed and also to capture the frustration felt by many carers about not having been listened to in the past. Participants put forward ideas and suggestions about how to improve the lives of carers and those for whom they care. These ideas related to the following areas: Representation and advocacy; Funding; Accommodation; Services; Financial assistance; Employment; and Rights and other entitlements. The following are some of the key findings presented in the report.

Representation and advocacy
- Elevate the voice and expertise of unpaid carers
- A carers’ union

Funding
- Overhaul of funding arrangements
- Individualised funding packages
- Investment in people with disabilities

Accommodation
- Supported accommodation, particularly the clustered residential model

Services
- Self-directed services
- Flexible and accessible respite
- Supported accommodation
- More and better quality paid care workers

Financial assistance
- Increase in income support to carers
- Increase in the income threshold for Carer Payment
- Simplification of paperwork and application processes
- Tax deductions
Employment

- Incentives for employers to employ carers
- Flexibility in Government Payments
- Accessible respite and support services

Rights and other entitlements

- Legislation
- Government contribution to superannuation
- Insurance for carers
- Carer identification and certificate of service
- Discounts, concessions and rebates
- More home visits from doctors
- Quality information resources
- Permanent online carers’ forum and other support networks
- Increased community awareness of carers

In summarising the findings presented in this report we are mindful of the widespread frustration among carers about not having their voices heard and their ideas met in other forums in which they have participated. As a list, this summary is just that, and we urge readers to take a closer look at the report and the summit itself in order to gain a more in-depth understanding of the experiences and needs of those who participated.
1. Introduction

This report is based on a careful reading of posts to the Carers Virtual 2020 summit hosted by Carers Australia during August 2008.

The first section provides background and an outline of the aims and scope of the report. This is followed by a discussion of the method and general approach we took to the forum and the presentation of its contents. A brief overview of the number of posts to each stream and a summary of the content of each of the discussion streams completes this section.

The second section, which forms the majority of the report, is structured according to the key areas to which people’s experiences and ideas related. It includes comments from participants about how and why certain ideas and shifts in thinking should be put into practice. This section concludes with a discussion of some of the areas identified by forum participants as requiring further exploration and action by governments and others.

1.1 Background

The aim of the Carers Virtual 2020 was to go beyond identifying the problems and to develop practical ideas and solutions to better meet the needs of carers. In order to generate discussion around some general and specific topic areas, Carers Australia invited people to draft original articles that would be posted to the summit website as discussion streams. These articles took varying forms and ranged in length. The forum also provided the facility for participants to request a new stream. As the forum progressed, some of these requests were granted and others were posted by the Moderator for discussion as soon as possible, rather than waiting for someone to write an article per se. These streams were identified on the summit website as being ‘By Request’.

The number of discussion streams naturally grew over the course of the month, as people made suggestions for new streams. At the time of the forum closure, there were 15 streams and a total of 747 individual posts. This number includes Moderator posts and those that were duplicated across a number of streams. Even after these are accounted for, more than 700 posts is indicative of the interest the forum attracted in a relatively short period. Website statistics show there were more than 2000 unique visitors to the website. More than 200 people contributed to the website, with some making up to 50 posts, and on the basis of self-reported postcodes it appears that people from across Australia participated. While it is reasonable to believe that at least some of the views expressed in the summit are shared by many carers who did not participate, we do not claim that the ideas discussed in this report are representative of carers as a whole.
1.2 Aim

The aim of this report is to document the areas identified by summit participants as being in need of change, and the ideas and practical solutions they put forward for bringing about such change. In doing so, it makes substantial use of participants’ verbatim posts in order to articulate problem areas, specific types of problems identified by carers in these areas, and suggested solutions.

The report does not intend to make recommendations but, rather, to compile and communicate the content of the summit with the same integrity as that of carers and other participants who contributed. Clearly, a report such as this cannot adequately capture the intensity of conviction and emotion of people’s posts, nor the totality of contributions to the forum. Indeed, if there is one recommendation that this report would make it is that those who read it make it their priority to visit the online forum and read people’s comments directly http://www.carers2020.com.au/. This report brings together the range of ideas that carers discussed in the Carers Virtual 2020. Its overarching purpose is to offer a reading of the summit as a whole and an accurate presentation of its content.
2. Method

It is not the purpose of this report to ‘analyse’ what people have written in the sense of searching for deeper meanings behind their words.

We are not here concerned with a linguistic or discourse analysis of the forum content, although we recognise these methods as providing alternative ways of making sense of the data. One could, in a way, view our mode of interpretation as ‘naive’ because it accepts at face value what people have said. In response to this we would suggest that a failure to do so could equally be criticised for over-analysing what people have said and, in the process, missing the point. There are numerous ways the online data could have been compiled and the continued public availability of the forum provides an important check on our own presentation of its contents.

One of the reasons for the Carers Virtual 2020 was to provide the opportunity for carers to share their views on what could be done to improve the lives of carers. This inevitably informs the tone and content of our report on the summit. As the authors of this report, we acknowledge our active role in selecting the data to include in the report and in constructing a context within which to make sense of the discussion that took place. We recognise that we are not detached observers but, rather, active participants in bringing to light the issues affecting carers and the solutions they propose to address them. We are also mindful of resentment among many carers in regards to being spoken for by people who do not identify with and who do not understand their experience. There is also a resistance among some carers to ‘experts’ and academic research that often seems so completely detached from the lived experience of being a carer. In this context, as authors of this report we intend our own voice to be secondary to that of the carers whose ideas we present and whose expertise we respect and seek to elevate.

2.1 Process and interpretive practice

We downloaded the entire contents of the Carers Virtual 2020 on the day after the forum closed. Each post was then read with particular attention given to suggestions people had about what could improve the lives of carers. Note was made of specific ideas and responses, if any, from other participants to the idea put forward. This can provide an insight into the extent to which people agreed with, resisted, or built on particular ideas.

Many posts to the forum did not put forward ideas about what can be done, with people instead taking the opportunity to share their experiences and often their frustrations, or to empathise with another person’s experiences. For this reason it was important that we also took into account the content of these posts. Ideas about what needs to be done to improve the lives of carers are born of experience. In order to contextualise people’s ideas, we include comments that illustrate the kinds of experiences from which they derive. In this way, people’s anecdotes are used as supporting material for specific ideas and proposals. In accordance with the aims of the Carers Virtual 2020, the report gives particular attention to the practical solutions and reforms that people suggested.
We begin by identifying the broad topic areas that participants identified. Within each of these topic areas, we discuss some of the problems experienced by carers and, finally, we identify the ideas and practical solutions that people made in response to the specific problems they identified. In so doing we present extracts from people’s posts and, therefore, take them out of the original context in which they were presented to the forum and other participants.

2.2 A note on spelling, punctuation and referencing

The way in which we present the content of the forum is to some extent a product of the nature of the online discussion medium itself. It is often the case that correct spelling and punctuation is not a priority for people participating in these forums. For many, it is more important that they take advantage of the opportunity to get their point across quickly and in response to others. In terms of presenting direct quotes from people, we decided to correct obvious spelling mistakes and to insert words in square brackets to aid readability of posts where necessary. Any emphasis in the form of capitalised letters is that of the participant. We did not interfere with people’s forms of expression because it is their voices that we wish to elevate.

In terms of attribution, we identify people by the name they used when making the post, and the abbreviation of the stream on which it was made. Some names do not begin with a capital letter because we have reported them as they appeared on the website. Where a name appeared to be that of a participant’s real full name, we deleted the surname. Where details are given, we have attempted to provide some information about the kind of caring role and duties of forum participants. We have not, however, sought to make connections between different posts from people with the same user name.
3. Summary of discussion streams

This section identifies the number of posts to each stream and provides an overview of issues raised in each of the streams.

The following figures on the number of posts made to each stream give some sense of the relative activity on each stream but must be treated with caution. The streams are listed in descending order from the most active to the least active in terms of number of posts.

<table>
<thead>
<tr>
<th>Stream name</th>
<th>Posts</th>
<th>Abbreviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial Security</td>
<td>97</td>
<td>FS</td>
</tr>
<tr>
<td>Recognition and Respect</td>
<td>87</td>
<td>R&amp;R</td>
</tr>
<tr>
<td>Health and Wellbeing</td>
<td>81</td>
<td>H&amp;W</td>
</tr>
<tr>
<td>Models of Care</td>
<td>75</td>
<td>MC</td>
</tr>
<tr>
<td>Accommodation Choices</td>
<td>75</td>
<td>AC</td>
</tr>
<tr>
<td>Summary stream</td>
<td>61</td>
<td>S</td>
</tr>
<tr>
<td>Carers in the Workforce</td>
<td>45</td>
<td>CW</td>
</tr>
<tr>
<td>Access issues</td>
<td>44</td>
<td>A</td>
</tr>
<tr>
<td>Other issues</td>
<td>34</td>
<td>O</td>
</tr>
<tr>
<td>Investing not Spending</td>
<td>32</td>
<td>IS</td>
</tr>
<tr>
<td>Representation</td>
<td>31</td>
<td>R</td>
</tr>
<tr>
<td>Education and Training</td>
<td>28</td>
<td>ET</td>
</tr>
<tr>
<td>Assessing Impact</td>
<td>25</td>
<td>AI</td>
</tr>
<tr>
<td>Carer Populations</td>
<td>20</td>
<td>CP</td>
</tr>
<tr>
<td>Legal issues</td>
<td>12</td>
<td>L</td>
</tr>
<tr>
<td><strong>Total posts</strong></td>
<td><strong>747</strong></td>
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</tbody>
</table>

Some discussion streams were clearly more active than others, but it would be too simplistic to conclude that quantity of comments equates to level of concern or priority for carers. There are many factors that must be taken into account, including when the stream was started and the length of time it was online. The above figures also do not account for the length and quality of individual posts, and it is important to recognise that several participants made quite lengthy and clearly well considered contributions.

The following section provides a brief summary of the kinds of issues that were raised in each of the streams, bearing in mind that the same issues were often covered in other streams. We identify the author of the original article and briefly refer to some of the issues they raised. The next section provides more detail about the ideas put forward.
3.1 Financial Security (FS)

Perhaps unsurprisingly, Financial Security was the most active stream in terms of the number of posts (97) made to it. The author of its original article was Joan Hughes, CEO of Carers Australia, who posed the question of what carers are really worth. She said:

Carers Australia believes that carers should not be disadvantaged for taking on their caring role. Carers should be entitled to income support that is appropriate to their needs and a scheme should be established that would give them access to future financial certainty.

Joan Hughes, FS

Hughes outlined the range of Government benefits that are available to carers who meet the specific criteria as well as the money that carers save the economy. She asked whether carers should receive a wage similar to that of the minimum wage, if there should be a superannuation scheme for carers, and what would be an adequate Centrelink system for carers. By far the most common idea in this stream was that the Government should increase the income support available to carers.

3.2 Recognition and Respect (R&R)

Recognition and Respect was the second most active stream in terms of number of posts (87). The author of the article that introduced the stream was the President of Carers Australia, Pam Webster. She said the Australian Government should implement national carer legislation and a National Carer Action Plan. She said:

National carer legislation would provide for formal recognition of carers, a framework for interventions and carer rights in key areas such as participation and rights at work, mandated involvement as partners in health and community care services and access to certain key supports and entitlements.

Pam Webster, R&R

There was disagreement among carers as to the value of legislation, and contributions to the stream covered a range of issues affecting carers. Carers put forward a variety of ideas, each in their different ways relating to how to properly recognise and respect carers. The importance of recognising and respecting carers was an overarching theme of the entire Carers Virtual 2020, and this is reflected in many of the ideas and directions for change that are discussed in the Findings section.
3.3 Health and Wellbeing (H&W)

Kathy Eager from the Centre for Health Service Development at the University of Wollongong contributed the original article at the beginning of this stream, and she posed the question of what works for carers. She discussed the various stages of the Centre’s ‘Effective Caring’ project (funded by the Federal Government Department of Health and Ageing), which sought to identify the needs of carers, factors that sustain them in their caring role, and effective interventions. She said:

Interventions whose content can be closely specified are more likely to be shown to be effective. So for example helping carers with problem solving and cognitive restructuring produces measurable effects. Taking into account the limitations of research to date the Effective Caring report gives lots of detail on what works and why.

*Kathy Eager, H&W*

A total of 81 posts were made to this stream. Some carers were unhappy with the tone of the article and the needs assessment tools to which it referred. Some saw it as symptomatic of a broader trend of carers being spoken for by so-called ‘experts’, and one carer offered a translation of the original article under the heading of ‘In layman's terms’ (invisible, H&W). Another carer questioned the appropriateness of the original article being posted on the forum, given that they thought it was supposed to be a forum for someone to listen to carers rather than the so-called ‘experts’ (faye, H&W). The CEO of Carers Australia, Joan Hughes, responded to these criticisms and defended the role of academics and academic research in the field. A number of posts to this stream included pleas from carers to those who are reading, and especially those who are in a position to affect change, to do so in the knowledge that failing to will have serious and negative implications for the health and wellbeing of carers.

3.4 Models of Care (MC)

The author of the original article in this stream was Vern Hughes, from the National Federation of Families, Parents and Carers, who outlined three possible directions that models of care could take in the future: Patronised; Institutionalised; and Take Charge – *In Control*. The author’s preferred option is inspired by the *In Control* campaign in the UK and it would involve giving every person in community care and their family the option of having their own Individual Budget to take charge of their own support. Of this model, Hughes said:

It regards much of the current carer advocacy as missing the point – carers do not want to be patronised with more and more programs, counsellors, and case managers. What we want is to live as normal a life as possible, both for our loved ones and ourselves.

*Vern Hughes, MC*
He identified four different models of managing individual budgets: Self management, Agent, Trust, and Individual Service Fund. A total of 75 posts were made to this stream and posts were by no means limited to the issue of models of care. There were a number of comments about the NSW Government’s Department of Ageing, Disability & Home Care (DADHC) draft policy documents. One of the strongest themes to emerge in this stream was that caring families ought to have the right to be able to choose the kind of accommodation setting and support that best suits the person with a disability for whom they care.

3.5 Accommodation Choices (AC)

The author of the original article in this stream was Lyn Allen from the Ryde Area Supported Accommodation for Intellectually Disabled (RASAID), who referred to the lack of supported accommodation places for people with an intellectual disability. She talked about RASAID, which is a group of 20 families who have adult children with an intellectual disability and who are seeking to develop a clustered residential model of accommodation for them. This style of accommodation would consist of four or five adjoining houses providing residents with their own private space as well as easy access to their friends. Lyn Allen said this model is more cost effective than a traditional group home as well as being ideal for people with an intellectual disability. She said:

It is time to pursue a more cost-effective means of support while not compromising the quality of life of the disabled person. Clustered residential settings are one way of achieving this outcome and we wait impatiently for our governments and those who are paid to represent us to realise this.

Lyn Allen, AC

There were 75 posts to this stream, many of which agreed with Lyn Allen’s assessment of the lack of supported accommodation for people with an intellectual disability, and responded favourably to the idea of clustered residential settings.

3.6 Summary stream (S)

As the title suggests, this stream was posted in the last week of the summit and it provided a list of some of the ideas presented to the forum, inviting carers to elaborate or add any further ideas. A total of 61 posts were made to the stream. A number of carers used it to make something of a final plea to the Prime Minister and the Government to listen to what carers are saying and do something about it. Others provided their own summaries. One carer was disappointed with the summary provided, which they referred to as a “shopping-list”. They suggested that it means very little and that stakeholders will select two or three points they can live with and ignore the rest. They said the list failed to grasp the shift in strategy needed to reform the things that are not working for carers, and they put forward their own alternative summary (Vern, S). Their list highlighted that the service system, the
income system and the system of formal representation of carers are not serving carers well. It also highlighted the need for supports that are tailored to the needs of carers and their loved ones, an overhaul in the system of income support for carers, options for supported accommodation and new methods of funding them, and a paradigm shift from funding providers to funding families (Vern, S).

3.7 Carers in the Workforce (CW)

The author of the original article at the beginning of this stream was Belinda Tkalcevic from the Australian Council of Trade Unions (ACTU), who discussed the importance of creating flexible working arrangements for carers. She said:

It is essential that carers are able to combine paid work with their caring responsibilities. For this to occur carers need to have access to flexible work arrangements and alternative care options. This is even more essential in light of a projected significant increase in demand for care as the population ages, but also a shortage of both paid and unpaid carers to provide care.

Belinda Tkalcevic, CW

The article outlined a number of steps the ACTU believes the government should take to improve workplace flexibility for carers. There were 45 posts to this stream but the issue of carers in the paid workforce emerged across a number of other streams. Numerous participants in this stream described a lack of support services to enable them to work. They also suggested some things that may help them to be able to engage in paid work, which for many is so important for their own financial security and general wellbeing.

3.8 Access issues (A)

This stream was started in response to a number of requests for a stream dedicated to issues related to accessing services, such as difficulty finding information about services, lack of affordable and appropriate transportation, restrictive eligibility requirements and inflexible delivery of services. A total of 44 posts, covering a range of access issues, were made to this stream.

3.9 Other issues (O)

This stream was created for those who wanted to comment on an issue that did not fit any of the other streams. It included 34 comments on issues ranging from the need for services in remote Australia to fears about cuts to respite. A number of carers also said that they would like to see a permanent online carers forum.
3.10 Investing not Spending (IS)

The authors of the original article in this stream were Fiona Anderson and Gina Wilson-Burns who called for a rethink in the mindset to invest in inclusion. They said support services should be inclusive and directed to meet individual needs, and that support equipment and services required to meet a child’s needs should be 100% tax deductible. The importance of recognising families as being in the best position to decide on the types of support best for their child was also discussed:

The key issue is acceptance of the right of the family to identify and choose the types of targeted supports they consider most helpful at different stages of their child’s life cycle.

_Fiona Anderson & Gina Wilson-Burns, IS_

The authors challenged the Government to shift away from the mindset of counting and fearing the monetary cost of disability services and to focus instead on investing in people with a disability and their families to enable full life-cycle inclusion and participation in society. 32 posts were made to this stream.

3.11 Representation (R)

In the article at the beginning of this stream Liz Stewart discussed the importance of carers being able to speak for themselves, rather than being spoken for by others, which she argued continues to be the case in forums such as conferences and government committees and task groups. She expressed frustration about professional staff of funded agencies representing unpaid carers. She said:

My ‘big idea’ to come out of this Carers Summit is that no paid professional should speak on behalf of unpaid carers or decide policy for unpaid carers - in a task group, conference, summit, consultation with politicians, or advocacy group.

This should be accepted as a National Standard in disability, mental health, chronic health and aged care.

_Liz Stewart, R_

31 posts were made to this stream. Many carers agreed with the view that carers are in the best position to help to shape a better future for people with disabilities and their families. These views are reflected in the first section of the Findings, which is dedicated to the issue of representation and advocacy.
3.12 Education and Training (ET)

This stream was started in response to a number of requests for a stream dealing with carer education and training. 28 posts were made to this stream, ranging in content from calls for weekend courses, support for carers to study, training options for family carers, the possibility of people with a disability working in carer organisations, tax deductions, and a website dedicated to issues affecting carers.

3.13 Assessing Impact (AI)

The author of the original article in this stream was Norman Marshall, the Chief Executive Officer of Parkinson’s Australia, who wrote about the need for Carer Impact Statements. He said:

A CIS could be used by the Pharmaceutical Benefits Advisory Committee and other government decision making authorities when assessing whether or not to subsidise a new drug, treatment option, medical device or other form of intervention.

*Normal Marshall, Al*

The aim of Carer Impact Statements would be to provide Federal Government Departments with the ability to measure the costs and savings in relation to caring for people with Parkinson’s and other chronic illnesses. There were 25 posts to this stream and, while some participants endorsed the idea of a Carer Impact Statement, others discussed the impact of caring more generally, and some people raised other issues.

3.14 Carer Populations (CP)

The Carer Populations stream was suggested on the basis of a number of requests for news streams, which related to the specific needs of different groups of carers, some of which related to the condition of the care recipient (eg. mental illness or intellectual disability) and others to the cultural and linguistic background of carers. 20 posts were made to the stream. One carer provided details about the experiences of Polish carers in Melbourne, some of which included a lack of awareness of available services, a reluctance to access respite as a result of no services able to overcome linguistic barriers, a reluctance to claim the Carer Allowance, and a lack of language supports to help people navigate the system and access services (Elizabeth, CP). One carer responded that many of the experiences described are common in every carer population (invisible, CP).
3.15 Legal issues (L)

This stream was another that was started by request from several participants and it included questions of how carers and their families are impacted by legal issues and what a national Carer Legislation might look like. 12 posts were made to this stream on issues related to carer rights legislation, the need for better assistance when first becoming a carer, and access to legal advice. The parents of a daughter who has an intellectual disability also called on the Federal Government to act to ensure that State Governments implement ‘Substitute consent’ for medical procedures for people with an intellectual disability (david and valda, L).

The aforementioned summaries provide a sketch of the content of each of the discussion streams. The streams by name were very broad and they do not represent mutually exclusive topics/categories. Nor are they representative of all of the content posted to that stream. Posts often did not relate to the original article that provided the basis for the name of the stream. In this sense, the original articles tended to be used by participants more as a platform from which they could build and discuss their own ideas, rather than as putting limits or boundaries around what could be discussed. In this context, it made more sense to discuss the forum in a holistic manner and to structure the report around topic areas and ideas as they emerged across the forum as a whole.
4. Findings – Ideas and directions for change

Let the outcomes of this forum reveal it is not a hollow drum we have been playing, but a seriously minded forum designed to alleviate and improve the lot of all those who care for people who are dependent on others for their existence.

*Tristesse, IS*

One of the most common messages to come out of the summit was *listen* to carers and *act* on what they say needs to be done. For this reason, at the beginning of each new topic area we include a quote, like the one above, from a summit participant in order to illustrate how important it is to carers that their comments are taken seriously and acted on.

Based on our reading of posts to the forum, we identified the following topic areas to which people’s posts related and about which they suggested ideas for change: Representation and advocacy; Funding; Accommodation; Services; Financial assistance; Employment; and Rights and other entitlements. The absence of, and a desire for, voice, choice, control, recognition, respect, investment, inclusion, flexibility, access, and availability in each of these areas can be seen as shaping and underpinning the specific ideas carers put forward.

4.1 Representation and advocacy

*My hope is that into the future we will have such a strong voice that governments will hear the cry of our hearts and hear what we have to say and do something about it.*

*webstar, R&R*

*The moral of this tale is this:- the whole issue of Carers’ needs are not beyond Government’s abilities all they have to do is look for the key that’s in the door and LISTEN TO CARERS!*  

*country dave, IS*

This section identifies some of the contributions to the forum that emphasised the importance of elevating the voice of carers and recognising their expertise. Carers expressed frustration at having their voice represented by professional rather than family carers like themselves in a range of forums, especially those which have direct outcomes for them and the people for whom they care. A number of participants, particularly in the ‘Representation’ stream, described the importance of recognising the knowledge and expertise that carers have gained over years of experience, and for these carers to be given a say at the policy making table. Some carers suggested that a carers’ union is one possible way of making their voices heard and gaining a seat at the table to represent their interests.
4.1.1 Elevate the voice and expertise of unpaid family carers

The need to recognise the carer voice and the importance of carers speaking for themselves was a common theme in the discussion forum, especially the ‘Recognition and Respect’ stream. Participants expressed frustration at conferences and summits, government committees and task groups on carers’ issues, not involving carers themselves or only involving professional staff from funded agencies. One carer, who was also the author of the original article on the ‘Representation’ stream, said:

This is a major problem, because the thing about unpaid carers is that we are NOT PAID. To have our interests represented by paid professionals undermines the integrity and purpose of wanting the voices of unpaid carers in the first place.

Doesn’t the ‘carer industry’, which is now growing rapidly because of more funding from governments, tend to get in the way of us carers speaking for ourselves?

Liz, R&R

A number of participants replied to this post, which was to become the original article of the ‘Representation’ stream. It clearly struck a nerve with many carers and provoked responses from carers who are frustrated about having their experiences represented by ‘academics’ and ‘carer advocacy organisations’. One carer said:

The Government needs to heed the message that we - as Carers - will no longer accept paid “advocates” speaking for us - we are quite capable of speaking for ourselves.

faye, R&R

Another said:

I agree, it should be a basic right to have an experienced, authentic voice in Government to ensure that the needs of caring families are understood and met. How many hours have we carers spent, in vain, struggling to have our voices heard every time there is a consultation, inquiry, submission etc. the outcome of which dictates the future of us and our families.

joy, R
Another carer, who referred to the lack of time allowed for carers, compared to peak bodies and advocacy groups, to give evidence at a recent inquiry said:

The years that we have spent caring deserves to be recognised, they are years of learning that cannot be gained at a university. Governments need to give us a real say at the policy making table regarding the policies that govern our lives and the lives of the people that we care for.

jane, R

One person did, however, suggest that in their experience most carers could not attend conferences and the like because of the lack of available alternative care arrangements or adequate respite to enable them to do so (Gaye, R&R). This is suggestive of the way in which a lack of support systems can function to prevent carers from participating in the decision-making processes that affect their lives. It can also be seen as evidence of the need for carer associations and advocacy organisations.

The CEO of Carers Australia, Joan Hughes, responded to the posts about representation of carers. She agreed it is an important issue and said that the online forum was one way that Carers Australia sought to facilitate carers having a direct voice. She said that in order to influence government individual voices needed to be supported by collective ones and that, for some carers, paid advocates are essential because they do not have the means to advocate for themselves. She also said that paid staff of carers associations, including Carers Australia, include current and past carers and that it would be misleading to suggest that carers are not involved in the policy development of these organisations. Support for Hughes’ views were found in calls from some carers for Carers Australia and other carer associations to act on their behalf.

The author of the original post titled ‘Speaking for ourselves’ was not entirely happy with this response. Liz said it was inappropriate and offensive to have a “young trendy professional worker trying to advocate on behalf of an untrendy poor stressed overworked unpaid carer”. According to this carer, such a voice lacks authenticity:

It is not our voice. It is somebody trying to pretend to feel what we feel - until 5pm when it’s knock off time and they stop pretending.

Liz, R&R

They argued there is a “massive conflict of interest” in being both service providers and advocates for carers, and that something should be done about it. They also suggested that policy produced by carers’ associations is more influenced by trends in the community sector and government than by the views of carers:
For example, every carer will complain about the waste of money in services and advocacy groups that they have witnessed over the years. But the professional Policy Workers never take this up and run with it. Nor do they ever take up different ways of funding carers. Nor do they ever promote debate about this.

_Liz, R&R_

A mother who has cared for her disabled son for 25 years said that she was insulted by the idea that a peak body or academic could possibly know what was best for her son, her self or her family. For this carer, being in control of the decision-making is a right granted to the parents of ‘normal’ children and should be no different for parents whose children have a disability. They said:

I have cared for my son willingly despite the huge impact it has had on my emotional, social and financial health and I firmly believe that the massive savings I personally have contributed to the Australian economy give me the right to consultation in regard to the services I consider appropriate for my son.

_Catherine, R_

Other carers agreed that non-carers speaking for carers is an infringement of the rights of carers and people with a disability, and one that would not be tolerated by parents of non-disabled children (David, R). One carer said:

Liz has summed up the opinion of many other Carers including myself. It should be accepted as a National Standard that no paid professional should ever again speak on our behalf or our children’s behalf. This should be written into legislation and maybe now that Australia has just ratified the UN Convention on the rights of people with disabilities it will become a legal right, the right to self-advocacy and self-determination.

_faye, R_

This carer also said that government funded advocacy is tokenistic and presents a conflict of interest. They argued that the Government should cease funding many of the so-called advocacy organisations as well as academics and researchers whose work has little or
no effect on the lives of carers. They said this funding should be redirected to services and support for people with disabilities and their families, which is discussed further in the following section.

On the other hand, some carers did not agree with this position or the views put forward in the original article in the ‘Representation’ stream, arguing instead that the work of carers associations and researchers has benefited carers (Bert, R). This participant said:

What we need now is government funding to support carer representatives to sit on committees to tell the bureaucrats who make the recommendations to government what carers need. The best scenario would be where people who work in paid work to support carers and “real” carers (ie those who have either had caring experience in the past or current carers) are both members of the same committees. That way other members of the committee get to hear all the facts and figures and, most importantly, what it is like to experience the outcomes of the decisions that are made in those meetings.

*Bert, R*

They argued that there is a need for both funded advocates and funded carer representatives and called on the Government to fund Carers Australia to provide carer input at federal, state and local levels.

Another carer said, while they agree in principle that unpaid carers should be representing themselves, it is unrealistic to expect carers to take on advocacy roles on top of their caring responsibilities without being paid to do so (Jen, R). Nonetheless, there is certainly a view among some carers that paid professionals are, at present, failing to represent the interests of at least some carers.

People made a number of suggestions in regards to ways in which the expertise of carers can be harnessed in the pursuit of better representation and, ultimately, a better deal for carers. It is difficult for any one organisation to be able to represent the needs of all carers. In recognition of the diverse needs of carers, one person suggested that carers band together in order to have an input into how services are run. They said:

For example there could be a committee of carers from different backgrounds and people with different disabilities as a reference group to government or even having representation on the local services.

*Care Manager, CP*
One carer said health professionals, the community and the government need to listen to and understand the lives of carers. They suggested this could be achieved by involving some carers in doctor training and professional development days for relevant Government Departments, such as the Department of Education and Training (webstar, R&R). Another carer said:

Doctors, health professionals etc need to understand that we usually do know more about that particular condition than they do and not berate or ignore us just because we seem to have more knowledge on the subject. It really isn’t an attack on their ego!

*Cynical, R&R*

Another carer, at the end of a lengthy post about what their caring work entails and what some of the needs of carers are, said:

I would love to offer a course on Resilience to politicians and perhaps they would be able to pay me for doing this. I promise to bring a smile to their faces.

*Sienna, R&R*

As these comments suggest, there are numerous benefits to drawing from the expertise of carers, and various ways of doing so. It would seem to be the first important step toward ensuring that the needs of carers are met.

The next section deals with another form of recognition, which received support from some carers.

### 4.1.2 Carers’ Union

In regard to the question of what carers are worth, one suggested that carers, like other workers, are entitled to expect and to receive fair pay for a fair days work (vikinglily, FS). This carer said:

What I am proposing is that full time carers are valuable to those they care for and provide a service to the community by freeing up the scarce government provided resources. Therefore, the same doctrine should apply.”a fair days PAY for a fair days work’.

*Vikinglily, FS*
In response to this, another carer agreed with the idea of a carers’ union and said that a National Day of Action may be one way of making governments take notice of and fairly remunerate carers, according to the value of the work they do (faye, FS).

One carer who argued that materialism was being put ahead of decent social policy, with governments lacking the political will and integrity to improve the situation of carers, suggested that a carers’ union is needed to collectively send a message to the government that carers will no longer put up with being ignored and disempowered (Faye, IS). This carer said that a carers’ union is the type of strong representation that is needed:

Through a Carers Union we would be able to demand rights and have a strong voice in policy making, decisions and the future direction of disability services. This is the type of representation we need - strong representation. Polite diplomacy has got us nowhere.

*Faye, R*

They also distinguished the idea of a union from that of an advocacy organisation, saying that the former would not be made up of paid professionals.

But carers are restricted in their ability to take the kind of strike action that has been such an important option for other unions in their efforts to win pay rises and better conditions for their members. As one carer said:

But we place ourselves in positions of powerlessness because the only bargaining tool we have is our labour and governments are exploiting us, knowing that we will not go on strike. The cruel thing is that we will all eventually leave our PWD [person/people with a disability] because, in most cases, they will outlive us. Maybe strike action is the only way to make them take notice of us.

*Sarah, R*

Some of the ideas discussed in this section are perhaps directed more at carers’ associations and advocacy organisations than governments per se. To the extent that carers are a section of the workforce of considerable size, the idea that they establish a union to represent their own interests is one that is worthy of further investigation. However, it will ultimately require the leadership of individual carers and, as some forum participants suggest, not all carers are in a position to be able to participate in this way and to advocate for themselves. As such, many carers are appreciative of the work carers’ associations do to advocate on their behalf. Moreover, a union would also face the problem of not being able to represent the diverse interests of carers. There is, however, a view...
among some carers that they are not being represented, which may point to the need for enhanced dialogue between these carers and existing carers’ associations and advocacy organisations.

In addition to this, the importance of valuing the voice and expertise of carers is of equal relevance to policy makers and the range of service providers that come into contact with carers. It is the actions and attitudes of these stakeholders that can, ultimately, determine the experience of carers as a whole and of individual carers in their day-to-day dealings with them. By recognising and respecting the voice and expertise of family carers these stakeholders will be better equipped to invest in their needs and the needs of the people for whom they care.

The next section deals with the issue of funding, which is central to the kinds of outcomes that are achieved for carers and the people for whom they care.

4.2 Funding

I have participated in so many forums and research, yet the reports appear to remain sitting on the shelves gathering dust. It is time the system is held accountable and is totally revamped to help the ever growing group of carers who are struggling with the responsibility of care. It is no longer enough to rely on the love of unpaid family carers - the system is destroying lives.

Rainbow, H&W

I only hope this ‘virtual summit’ comes to something that is workable and acceptable by the only people it should affect, the carers and those needing that care. Not the idealists and those who want to point score from it.

invisible, AC

Many carers stressed the need for an overhaul in funding arrangements in order to ensure carers, and the people for whom they care, get the optimum value for the money that the government invests in the area. Concerns that money is not getting to the ‘coalface’ where it is needed were common. In recognition of the scarcity of funds, one carer specified the importance of funding services for those most in need, particularly those lifelong carers of a person with a disability (tristesse, R). For some carers, there was no question that ensuring value for money for carers and the Government required directly funding family carers in the form of individualised funding packages that would allow them to decide for themselves how funds would best be spent, in accordance with their needs. Directly funding carers, some carers suggest, is the only way to ensure that carers can develop and access services that meet their needs and the needs of the person for whom they care.
4.2.1 Overhaul of funding arrangements

A number of carers spoke of the need to redirect finding away from service providers and other areas and give it directly to carers. For example, one carer who questioned the amount of money the government gives providers simply said:

If the government let us manage at least some of the money they give to providers our lives would be a lot easier.

_Gaye, R&R_

Another carer, who referred to the lack of financial support for families of children with a disability, said:

Government needs to seriously look at providing more funding not to the bureaucrats, but to those that need it and will use it wisely. Providing carers/families/people with disabilities an allowance to be spent how they see necessary, not on an unsuitable service that they must ‘use or lose’, is a start. 100% (or higher) tax deductions on equipment and therapy services would go a long way to helping too.

_Elizabeth, IS_

This person also said they have been frustrated by not being seen as the expert when it comes to understanding their child’s needs in a holistic way. The issue of tax deductions, which this carer suggests would be helpful, is discussed further in the Financial assistance section.

Another carer whose disabled five-year-old son was on a waiting list for a wheelchair, after having his first application for assistance denied on the grounds that there was not enough money, said:

Researchers undertaking research for research sake without practical benefit should not be beneficiaries of the small pot of funding currently available to cater for those with a disability and/or their carers.

_Gina, H&W_

For many carers the issue of having direct control over how money is allocated and used is an extremely important one. One carer, who said they can manage what providers are willing to do but need help with the heavy lifting, also said:
I am now using the $200.00 dollars per month the ‘Provider’ charged for employing people to do some of the heavy work for me.

Appropriate and adequate support needs to be provided under our own control - not controlled by some agency.

Shouldn’t we all be in control of our lives and supported to do so.

*Tiny, R&R*

Experience with unhelpful and overloaded caseworkers led many carers to question the money that is spent in this area. In particular, one carer who referred to the NSW Government’s Department of Ageing, Disability & Home Care (DADHC) recently spending $466,000 on a five day Case Management Induction, said:

> Just what we need - more Caseworkers - that’s right they’re recruiting more of them - more money wasted on yet more useless Caseworkers who cannot/will not do their jobs. We need more Caseworkers like a hole in the head.

*Debbie, all streams*

This carer posted this post, which also included further details of the money spent by DADHC, on each of the streams under the subject heading of ‘shame on you DADHC’. In response, some carers raised questions about where the money that is supposed to provide services, equipment and support goes, and others suggested that in NSW there needs to be an audit of DADHC to find out (Veronica, FS; Karen, FS).

Another carer, who described having been frustrated with a caseworker who was of no use to their family, suggested that they could have used part of this person’s salary to stop themselves from drowning in debt and put it towards their daughter’s needs. They also said:

> …instead of all the reports and increasing the size of government departments for disabilities and coming up with services which do not meet our needs, you just give the money to carers/families.

*Suzie, H&W*

One carer of a child with special needs offered a funding-related solution to her unmet need for respite:
Currently my need for respite is not being met. It would appear that there are numerous agencies who receive funding from either State or Federal to whom you have to apply to be considered for respite.

Each of these organisations employ social workers who are paid to spend inordinate amounts of time deciding which of their applicants will receive how much of the funding depending on their ‘needs’ What a waste of resources!

All carers should get the same entitlement to leave and support. If an annual allowance was allocated to each person who receives care, to be used to buy ‘respite’ then all the agencies need to do is employ the staff.

Deborah, H&W

Across all of the streams frustration and anger at the NSW State Government, in particular, was voiced by a number of carers. They were especially critical of recently released DADHC draft policy documents and comments made in parliament by the Minister responsible for Disability Services. Some carers suggested that Disability Services be deferred to the Federal Government. One carer said:

I think there needs to be an acknowledgement in the summary of the frustration and unhappiness many Carers have referred to in regards to services and lack of support from their State Governments. Some people have even recommended that disability services should be deferred to the Federal system. Several times people have spoken about 2 recent NSW Government policies that they are very concerned about. I would like to see these issues acknowledged in what Kevin Rudd is to be presented with.

Thanks.

Faye, S

Another carer agreed:

We must insist that disability services are funded from Canberra, as aged care is. After all, our PWD often have the same level of needs as the aged and our state government is clearly unfit to deliver services to meet those needs.

Sarah, S
Another said:

We need individualised, self-directed funding - now. Preferably funded Federally so we don’t need to have any further dealings with Keneally’s Government and its services. We need self-directed funding NOW - before more families are forced by this awful State government to hit rock bottom - then it’s too late.

David, S

While there was widespread agreement that there must be a major overhaul of funding, there was no consensus about the precise form it should take. One carer was less convinced as to the merit of transferring funding responsibility from the states to the Federal Government, saying it would be a waste of time. They said:

What’s more important is to get them BOTH to shift funding from agencies to family-directed budgets. Bit by bit they are moving in this direction.

Vern, S

Some carers suggested that bypassing service providers could be achieved through the provision of individualised funding packages.

4.2.2 Individualised funding packages

There was strong support among carers for individualised funding packages to allow people with disabilities to plan for their own future and cater for their individual needs. People gave a number of reasons and discussed some of the different experiences that have led them to the view that self-directed funding would be a solution to many of their problems. In addition to the need for a mechanism to enable families to access private, public and philanthropic investment for their own solutions, one carer said:

We also need individualised funding so that families can use their support funds, and access public capital for housing development, for their own solutions, instead of these funds being tied up in providers where families cannot access them.

Vern Hughes, MC
There was frustration among carers about the failure of advocacy organisations to lobby hard enough for a change to funding arrangements for carers and, more specifically, for the need for individualised funding like that of In Control [http://www.in-control.org.uk] in the UK (Liz, MC). It was suggested that there had been a lack of leadership in the area from government, service providers and funded advocacy groups and that the innovative developments are coming from families putting their own money into creating options (Vern Hughes, MC). As one carer said:

For years, advocacy groups have said yes, individualised funding is our preferred way of organising money so that it meets the unique needs of each person and their family. But they then go and campaign on all kinds of passing issues, and never get round to putting the hard work into changing the most fundamental part of the system - the funding arrangements.

The result is that courageous individuals with disabilities or illnesses and their families, have to re-invent the wheel every time they try to personalise their support arrangements.

Liz, MC

This carer also discussed the In Control system in the UK, which they said about 45 local governments have now affiliated with and made individualised finding available in their area. They suggest that Australia must learn from this approach in order to take the push for individualised funding to the next level.

The In Control model, described by one carer as cutting out the middle man, received much support among summit participants. It appealed to the need among carers to be empowered to make decisions about their child’s care. One carer of a daughter with a disability said:

It is about having control of ones own life and I believe the only way to achieve this is to have control over ones own support dollars (with this it stands to reason we all have to be accountable and the dollars spent monitored.)

kevin, R&R

Another carer said:
After spending years growing more and more disillusioned with disability services I am now absolutely convinced that we need a whole new model of support. One that offers choice, flexibility and control, one that empowers the parent (the person who knows the child best) to make decisions for their own child without being dictated to by services and arbitrary policy.

*faye, IS*

Another said:

So I think a ‘big idea’ to come from this Summit should be recognition that families, not providers, must decide the type of support required by their loved ones, with a range of support tools (finance, information, brokerage, individual budgets) available to support families to do this.

*Liz, IS*

One carer described being patronised and looked down upon since their son was diagnosed with a chronic genetic disability. They said they had experienced difficulty having their views taken seriously because of assumptions that people make about the degree of their adversity. On the basis of this experience, they said:

To me, this is an argument for [an] individual family model of support, whereby needs can be met equitably but in diverse ways decided upon by the individual and their care giver(s), and their disease specific service providers. To do otherwise would perpetrate assumptions and misunderstanding.

*Rainrtr, R&R*

A number of carers expressed frustration about being treated like second and third class citizens, whether by members of the general community, service providers, governments, bureaucracy such as Centrelink, or the education system. For some carers, like the author of the above post, these are the kinds of attitudes that make it necessary for families to be able to be in control of defining their own needs and deciding how they can best be met.

After describing their damaging experiences with caseworkers, a person who has been a carer for two disabled children for 30 years said:
Bring on individual packages, a list of services we can purchase when we need them, replace caseworkers with advocates and the government will halve their costs, create a happier environment for carers who will have a new sense of empowerment and more than likely be able to continue their caring role longer.

_invisible, A_

Another carer, who described similar experiences of unhelpful caseworkers, supported the idea of a self-directed model of service, such as that of *In Control* in the UK. They said:

Not everyone would choose this model of funding of course but for those of us that would it would mean that funding could be re-directed away from tokenistic roles such as Caseworkers and into PROPER supports for people.

_Faye, A_

Similarly, another carer who referred to having to beg for respite said:

We need self-directed services such as In Control to cut out the middle-man, get rid of the non-gov’s from administering the packages for those of us who choose it, let us do it ourselves, that way more money will be saved that can go into providing more packages.

_Jack, A_

Another carer disagreed with this view, however, and suggested that non-government organisations are important for administering the complexity of service delivery and client support. They said:

As there are genuine NGO’s around then I see them as perfect administrators for the accommodation model I believe is most suitable for my person with ID as we find ourselves at a place, and time where the opportunity for that type of service delivery approaches. Supported living.

_tristesse, AC_
The issue of supported accommodation is discussed in more detail in the Accommodation section. In regards to individualised funding packages, no-one is suggesting that this is the desired option of all carers, but among those who participated in the forum it was one of the more popular ideas and something that many carers agreed should definitely be an option for those who want it.

The next section discusses the importance of investing in people with a disability, which is another area of priority for many carers.

4.2.3 Investment in people with disabilities

Investing in people with a disability can take a variety of forms and for many carers it is something that would assist them in their caring role in a number of ways. Conversely, the failure of the government to invest in people with a disability is a source of considerable pain and frustration. The following comment goes to the heart of the issue of investing in people with a disability. It is from a person with a disability who emphasised the importance of carers and people with a disability working together:

If the Government supported PEOPLE WITH DISABILITIES THEMSELVES properly and fully then no one would have to be a carer in the present sense of the word. Parents of children with disabilities would just be able to be Mum and Dad as their disabled child would have their needs met in the same way as non-disabled children do. Carers of adults with disabilities would be able to return to their primary role of mum, dad, brother, sister, friend to that adult.

Glee, R&R

As a person with a disability who does not have a carer, they describe feeling invisible. They suggest that carers’ associations should join with the Australian Federation of Disability Organisations (AFDO), an organisation that represents all people with disabilities. On the ‘Financial Security’ stream this participant also said:

Give people with disabilities the same bonus as the aged and carers get. I am on the DSP and live alone with no carers and have never received any damn bonus. How is it that pwd who are the most disadvantaged of all three groups get nothing. I fail to work that one out.

Glee, FS
One carer provided a strong case for investing in people with a disability:

It makes sense therefore to INVEST appropriate amounts INITIALLY to help individuals help themselves, as much as possible for as long as possible, rather than needing to SPEND MORE money once the harm is done & the person’s potential for growth & development is restricted & their carer(s) are worn out/injured & in possible need of support too. INVEST MORE initially to SPEND LESS long term!!

_A Voice, IS_

In regard to the importance of better support for people with a disability, one carer said:

I believe that people who require the long term care of their families should be supported by the Government. In my experience many difficulties arise for families and support workers and organisations who deliver the services, from the shortfall of Government funding for people who need the care.

_Tracey, R&R_

A carer whose adult son has a physical disability said:

What I did say was, that you can’t look at the carer as separate from the person they care for. As a parent, what upsets me is the lack of regard for not only my son’s support needs in pursuing his tertiary education (zero support) but that the govt is compared to the rest of the developed world, disinterested in research and treatment of Duchenne muscular dystrophy (which is the most common childhood genetic disorder) in favour of high profile life-style disorders.

_Rainrtr, R&R_

They said that equity for people with a disability would flow on to their carers. Similarly, a carer of a son with schizophrenia emphasised the lack of government support she has received in her attempts to find training and work opportunities for him. She said:
I would like to see provision of assistance by the Government in training of people in this position and then active assistance in helping attain suitable positions in order that they can provide for themselves.

*Eniko, R&R*

Another forum participant, who identified as a mental health consumer, posed the question of whether there are opportunities for people with a disability to be involved in education and training or as volunteers within carer organisations. They said an important part of their self management strategy has involved working as a volunteer community educator and providing input into research studies and online forums. They suggested there is a range of practical activities in which people with a disability could be involved. They also said:

Involvement as Mentors is another key area that people with disabilities can be active in because of the first hand knowledge, experience and understanding gained from the “lived experience” and especially those who are managing their illness or disability.

*Brian@bluevoices, ET*

‘Blue Voices’ is the consumer arm of the Beyondblue depression initiative. As one carer responded, many people with a disability would not be able to engage in the kind of activities to which Brian refers (Tristesse, ET). But for those who are able it would certainly constitute a form of investing in people with a disability, which could be of benefit not only to them but also their carers and society as a whole.

Also on the issue of investing in people with a disability, another person said:

At the end of the day people with disabilities have a good chance of surviving their parents. If appropriate and adequate support is provided under their own control for these people it will help them firstly - shouldn’t we all be in control of our lives or be supported to do so if required? - but importantly will provide the invaluable support carers are so obviously needing.

*Julian, R&R*

Investing in people with a disability is about building a society that values and adapts to difference, in the interests of social inclusiveness and mutual respect for all members of society. One mother whose daughter has special needs, who is not able to speak or be
understood, described the importance of being a voice for her daughter:

I endeavour to give her a voice because I care so deeply about her future and her independence is extremely important to me...the more people that understand her the better and that is why her education is in a mainstream class room, this I feel will enable opportunity for communication and for her peers to have a greater understanding of her.

_Sienna, R&R_

She described how this had not been easy because of the attitudes of the Department of Education, who requested that her daughter go to a special school. Based on this experience, she said:

I believe there is so much more awareness required out in the community with regard to access...I want and need my daughter to access as much opportunity as possible to enhance her quality of life...we go hand in hand...however one day I know I will not be there for her...so I feel responsible to pave the way forward for others so that perhaps like minded folks will come out and speak up and make life the little bit more bearable for others walking beside us.

_Sienna, R&R_

In the ‘Investing not Spending’ stream, another carer said:

My kids, including my two disabled ones, are members of this society, and valuable ones. They belong, and have a right to belong, and to be valued for what they bring to life. We are not some poor dears - yes, we struggle, although none of that is because of their disability as such but because of the under-funding and bureaucratic nonsense we have to put up with.

_Heike, IS_

We can see from these comments that funding is much more than a simplistic ‘dollars and cents’ issue. It is a matter of recognising and respecting the value of all members of society and investing in making society as inclusive as possible for people with a disability or illness.
and their carers. For many carers this would best be achieved by redirecting funds away from service providers and other stakeholders and giving it directly to carers and the people who are in need of care. This may take the form of individualised funding packages or it may simply involve more adequate social and financial support for people with a disability and their carers in the first instance.

The following section discusses contributions to the forum that related directly to accommodation options

4.3 Accommodation

I do not want this 2020 forum to be lip service I would like to see something come out of this, us family carers are putting comments in because we need assistance, not because we are bored and have time free. We are in desperate need for change, because sooner or later we will not be around to continue the endless tasks that are required by our role and who then will provide this care.

It is time for the Government to open their hearts, and minds to these pleas and learn from family carers, because they have a lot to share through their resilience which would help this country to be so much stronger.

Sienna, R&R

Problems carers identified in relation to accommodation were generally expressed in terms of lack of facilities, lack of choice, a one size fits all approach, access problems, and lack of flexibility. In response to these problems, carers put forward a number of possible solutions, including the establishment of purpose built supported accommodation facilities, the provision of individual funding packages, and the provision of long and short term respite beds.

Some of the ideas about accommodation that participants contributed to the forum included apartment-styled accommodation for young adults with a disability (Greg, AC); little villages with individual living units for some people with a disability (Sue, AC; Care Manager, AC); and retirement village style accommodation to cater to disabled people whose needs range from low to high. By far the most popularly received style of accommodation, however, was that of the clustered residential settings, which Lyn Allen discussed in her article at the beginning of the ‘Accommodation Choices’ stream.
4.3.1 Supported accommodation facilities – clustered residential model

Many carers supported the idea of clustered accommodation settings as a preferred type of supported accommodation for their disabled child. Carers identified a number of benefits of the cluster model. Many said it would suit their children who have a disability and enrich their lives by enabling them to have companionship with their peers while still having the support of their family (Joy, AC). One carer said:

Personally my 30 year old son would enjoy and benefit from living in a small and I repeat small villa/cluster type supported accommodation with his mates.

suzanna, MC

This carer called for a state-wide forum on supported accommodation and emphasised the need for a shift away from crisis driven supported accommodation to planned transition. Another carer, who agreed that the focus needed to shift away from crisis, said:

I also believe that a SMALL group home in a SMALL cluster would suit my son and that the economies of scale that are afforded by cluster is the most responsible model to the taxpayer.

Catherine, MC

A person who has cared for their son with a severe intellectual disability for more than 30 years expressed concern at what they understood as the suggestion (in the original article in the ‘Models of Care’ stream) that they should expect their other sons to take care of him when they are no longer able. Being able to transition their son into supported accommodation was their preferred option:

I want to see him settled out of home in the local area in a small family-managed cluster setting with his friends, all of whom have a disability similar to his own. I expect to have significant input in this arrangement, as do all the parents involved.

Sarah, MC

Many carers identified an urgent need for supported accommodation so that they are able to plan for the future care of their child. For many carers it was about being able to choose the best option for their family and for their circumstances. In identifying the need for
immediate planning and implementation of accommodation choices, such as the clustered residential model, a carer of almost four decades said:

We need to transition our person with significant disability into such accommodation in the next decade before we are in our 70’s and 80’s. The person then will be set, we continue to care but from a distance, and we get some freedom in our last decade or two.

*tristesse, AC*

Another carer said:

Many of our group are very enthusiastic about the cluster type of accommodation because it would provide a sense of independence in a safe environment and would also enable social interaction.

*Anne, AC*

Other carers discussed how the cluster model would be an enormous improvement on group homes:

Most group homes have approximately 4 people in them and it is to be expected that in many cases not all will mix well. Whereas, with a group of approximately 20 people, there is more opportunity for social interaction and friendships to be formed. Families have also found that there is also a strong caring bond within these groups which can only serve to strengthen these small intentional communities.

*Caring Carer, MC*

In returning to the issue of representation, some carers identified reluctance or failure on the part of advocacy groups to advocate for what carers are asking for and referred to calls for cluster accommodation as a case in point. On carer said:

They claim to be our representatives but we still don’t have the services we need, or they are openly advocating against what we keep telling the government we need. The point in fact being the overwhelming need and desire for cluster accommodation which the advocacy groups condemn and label “institution”.

*Jen, R*
In this context, some carers made a point of distinguishing the model from old style ‘institutions’:

A cluster model would be a happier environment, be more open to family visits and interactions on site, provide safety in numbers and because more than one staff member would be on shift 24/7 staff accountability would be increased. More people would be able to access accommodation than they do now.

*Charlie, AC*

Another said:

The world has moved onwards and few would encourage or settle for mind numbing institutions with dormitory living, little social engagement and basically loss of hope and little or no choice.

The movement from these institutions of the past was borne out of a humane response to individual needs. It was a good thing. It is irrelevant to the debate on future care, because no-one is asking for the return of this.

The family home can be as mind numbing as an institution, it is the opportunity and support to flourish as an individual that should be leading this argument, not the size of the roof.

*nell, AC*

Support for RASAID’s model of supported accommodation was also expressed in the ‘Representation’ stream, with one carer calling for Carers Australia and state carers associations to add their support to this cause. This carer said:

Such models will provide mini communities which can be staffed with permanent not casual staff, in far less numbers that transit through group homes. We parents will support the governments and walk side by side with them, as they walk side by side with us implementing these havens to the best we individually can offer. Some will offer more practical support in concepts, ideas, others may be in a position to ‘purchase’ with a refundable bond on the exit of the person
with ID or whatever the dependency. Different models undoubtedly will be necessary for the plethora of differences, but hey, this is achievable, with foresight and planning and will go a long way to providing "peace of mind" to we Representatives of our loved ones who cannot REPRESENT themselves.

*tristesse, R*

Supported accommodation is clearly a need that governments can support families to attain for their children. The benefits to people with a disability and their carers of knowing there are supported accommodation facilities to move into cannot be underestimated.

But supported accommodation is not the preferred option for all carers, such as those who would prefer for their child to remain in their own home with limited assistance (webstar, AC). As one carer pointed out, what works for one person may not be suitable for another and they suggest this underlines the importance of carers/parents lobbying for the particular needs of the person they are caring for (Jen, AC). At present, however, many carers are frustrated that their calls for more supported accommodation facilities have not been heard.

The message in regard to accommodation is that there is no one-size-fits-all. One carer suggested that individualised funding packages would enable carers to have control over the current and future care and accommodation arrangements of the person for whom they care:

> I believe that individualised funding packages where the person/family has control of their own funds allows for families to better plan and cater for their own particular needs best and to plan ahead knowing the $ you have whether it be in a cluster housing or a more individualised environment.

*Kevin, AC*

Individualised funding packages are ultimately about shifting control to the person with a disability and their family carers. Some carers may choose supported accommodation while others may choose to assist their children or loved one to remain at home.

The message that one size does not fit all also pervades people's needs and their ideas in relation to services and service delivery, which is the topic of the next section.
4.4 Services

Will they sit and weep when they read our contributions?
Will they do something meaningful to overcome the discrepancy between the orgs and lack of services?

tristesse, H&W

If I had one message to send to governments it would be LISTEN to our hearts and hear the cry of a carer, send us services that work not legislation that never makes it past the paper its written on. Stop talking about what we need, take action it’s long over due.

webstar, AI

Problems carers identified with services related to funding, access, and lack of flexibility and accountability. Many carers expressed frustration that the services available are unable to meet their needs. Some of the specific problems with services include funding packages that exclude certain groups of people with a disability, lack of services in certain areas, and lack of respite facilities that cater for certain conditions. For example, one carer questioned why so much of the funding for people with autism spectrum disorders goes to early intervention and school services, which they suggest are insufficient in any case, and so little is offered once they turn 18 and leave school (Junior, R&R). Another carer also said that older children and adults with autism are being forgotten in all the new Autism Packages (Siddiver, R&R). Others identified a lack of funding for particular services, such as speech therapy, and lengthy waiting lists. A number of carers identified a need for better access to information about entitlements to services. The importance of being able to access assistance before reaching crisis point was also a common theme.

On the basis of their experiences with services, carers made a number of suggestions about what should be done to produce better outcomes. Because the kinds of services that affect carers and the people for whom they care are many and varied, so too are the kinds of ideas they put forward to address them.

One carer said that Home Care did not have a back up after hours service if a care worker is not able to attend a service for some reason, and they called for greater flexibility in being able to nominate the preferred service givers of cleaning, for example, because Home Care refuse to do those sort of tasks (Sophie, A). Other carers described not having various requests to Home Care met (Faye, A; invisible, A). One carer described the “palpable” difference in level of service they received after moving to a lower socio-economic area and suggested that carers in poorer areas need to be educated as to their rights and the responsibilities of services so that they are able to self-advocate and complain about lack of professional service (faye, CP). One carer who said that too many bad experiences could
damage carers’ confidence suggested that each service should provide a feedback form to show them if their services have been helpful or painful.

For some carers there was a clear link between misdirected funding and insufficient services. In regard to the need for supported accommodation, one carer of a disabled son said:

After 25 years of high level hospital care (in our family home) I should have confidence in regular respite and the knowledge that a supported accommodation bed awaits my son if and when I can no longer carry on with the Herculean task of his care. A novel idea - spend the money wasted on ‘talking’ about service provision and spend it on actually providing disability services.

_Catherine, O_

One carer who expressed concern about more money being spent on research to find out what carers already know, and have been saying, said:

To me it seems all the carers are saying the same thing in a different way - that the research has ALREADY been done, and it is time to stop wasting VASTS amounts of money on MORE research. If the money spent on researchers & consultants was instead put toward offering the types of services and equipment the carers have already repeatedly told you they need, there wouldn’t be such a shortfall in the funds available.

_Shelley, H&W_

One carer, whose son’s speech therapy service was recently closed and who is now on another long waiting list, said:

It’s just more evidence for the desperate need for an individualised self-directed service such as In Control where we - as parents - get to decide what our children need. Not mindless dictatorial bureaucrats.

_Faye, A_

For many carers these kinds of problems with, and lack of funding for, services was an argument for cutting at the middle man and directly supporting carers to get what they want from the service system.
4.4.1 Self-directed services

One contributor to the ‘Carer Populations’ stream took issue with the terminology of ‘carer populations’. They suggested that it is not a phrase that carers would use but, rather, one of bureaucrats and career policy workers who they say no doubt use it “to describe cohorts of people who need to be surveyed, consulted with, delivered to, and then evaluated to see if they are using what ‘we’ provide for ‘them’”. This person suggested it is symptomatic of the larger approach that views services not being taken up as a problem of ‘communication’ and ‘access’, rather than the product of a system that is designed to meet its own needs first. They said:

Instead of focusing on “carer populations” as the unknown Other, carer advocates should talk about “us”. We know who we are, and what we need. We don’t need to be constantly consulted - we need to be resourced and empowered to get what we want from the service system. This revolution in services is now sweeping the UK, where self-directed services give people a real voice in shaping the service they want and the money to back it up.

Vern, CP

In identifying the flaws in the ‘access to services’ model, which they say produces problems of people not knowing what is available or where to get it, this carer highlighted the need for a new model:

We need to turn this around, as is now happening in the UK, so that we start with the needs of each carer and their loved one, allocate a budget to cover their support needs, and then allow the family, with the support of professionals, to prioritise what they need and then purchase it from their allocated personal budget.

Families do not need to be able to handle the administration or finances of this process. That is a furphy. These jobs can be handled for families by an agency or broker. The important thing is that the prioritisation of support is done by the family, not by a service provider, and that the family directs where the support will be purchased from.

Vern, A
A number of carers agreed that the current service model served the needs of service providers rather than those for whom the services are meant. This led many to call for a new model of service delivery similar to that of *In Control* in the UK, which was the topic of Vern Hughes’ original article in the ‘Models of Care’ stream.

In response to the trend toward non-government services dictating when a carer can access respite, rather than being able to book on an as-needed basis, one carer said:

>This choice and flexibility has been eroded away over the past few years and the government really needs to act. Services should not be meeting their own needs first. The government should have a list of guidelines for non-gov agencies to ensure they are meeting flexibility criteria - this should be compulsory and if they fail to meet these standards don’t fund them.

>The long-term answer is having the option of a funding stream such as “In Control” whereby the non-gov providers would be redundant for those who would choose it and the days of having our lives dictated by these services would be over.

*faye, A*

But not everyone responded favourably to the idea of self-directed services. One person who has been a carer for a person with an intellectual disability for almost four decades said:

>I don’t want personal handouts to try to manage and find the appropriate places to use....too tired, get it, too tired to undertake more management and advocacy, I want genuine (GENUINE) organisations and more created to take responsibility for our person with ID, because we and others face the time when we will be too old and frail to do so.

*tristesse, S*

While self-directed services may be the preferred option for some carers, others simply want more and better tailored services and support to access them, as the above comment suggests. Indeed, the need for government investment in infrastructure and support services such as supported accommodation is certainly as important as the issue of who controls the funds. In order for carers to be able to get the best out of the service system, services need to be available and accessible.
4.4.2 Flexible and accessible respite

A number of carers identified problems with respite, such as lack of availability and flexibility. One referred to a lack of available respite and services in the area where she lives and cares for her autistic son (Michelle, R&R). The mother of a son with schizophrenia described being unable to find a respite facility able to care for her son and, as a result, having to leave him at home by himself with the support of a neighbour and a case worker on week days. When she returned home she said that her son had regressed and it took him a year and a half to recover (Lynne, R&R). Another carer described their experience of being unable to access appropriate respite:

I recently had to make a rush trip to hospital on a weekend (cellulitis)-rang a respite service provider and from a total of six nights, the provider provided care for one night only. I had to call on friends and family to fill the gaps-none of these people had had any experience in looking after a disabled adult.

*John, O*

Carers put forward a number of suggestions as to how respite should be improved. They identified the need for a more flexible respite system that is able to meet the needs of all carers, including self-carers. The following comment from a forum participant aptly captures what is required of respite:

Respite needs to be able to meet the needs of every Carer. All Carers including self carers need to be recognised, respected and supported with more hours and greater flexibility for respite. That is respite to care for the person while a Carer takes a break and respite for the self carer to support them to maintain their independence, this would be social support which includes accompanied shopping etc.

*Helen, R&R*

There also needs to be flexibility in the kinds of respite that is available. One person discussed the need for respite to be flexible by permitting the carer to save up their days or weeks entitlement over a few years so that they are able to take a long holiday of at least a month every now and then. They said:

If you do not use your respite entitlement then you should be permitted to accumulate the days towards a long block and not be forced to source 2 or more facilities.

*Tristesse, H&W*
For many carers who are ageing and caring for children with an intellectual disability, an extended period of respite is preferred:

My husband would like a year of respite to fulfill his life’s ambition to be a grey (in his case, bald) nomad and to go around Australia in a campervan. I would like us to take six months and see Europe. We are in our fourth decade of care giving, but we can’t imagine how either will ever happen.

Sarah, H&W

One carer said that they need 12 weeks annual leave to coincide with school holidays, curriculum days and public holidays, and four weeks Family Leave that is flexible enough to accommodate specialist availability, clinic waiting lists and virus “schedules” (Rainbow, H&W). Some carers suggested that carers be provided with annual holidays, including funding for a support person to attend if the carer takes the person for whom they care, and that respite be available to all carers regardless of their age (Sienna, R&R). One carer said that their main need is to have a holiday for a night or two with their dog and the person they care for, and for someone to be there to ensure he is okay while they sleep (Care Manager, H&W). Another carer highlighted the need for weekend respite services, which they said would enable them to attend family gatherings and reduce some of their isolation (Bernie, CP).

Other forum participants identified the need for in home respite and other support services. One carer said they would prefer respite in their own home after having a bad experience with the hospital respite bed system (Care Manager, H&W). Similarly, another referred to the need for trained personnel to provide in home care for her husband so they can have a break. They said:

Why when we have set our homes up (at our own cost) to be as practical as possible for caring for our loved ones and our loved ones are secure and happy in their home environment have they to go into a respite centre.

szanderki, S

For a mother who home schools two children who are on the autism spectrum, a house cleaner and a regular baby sitter would help by enabling her to have fun from time to time (Donna, H&W). Another carer relayed their experience of having suggested that an organisation arrange a night shift for two paid carers to go from house to house turning people with a disability to enable carers to have an uninterrupted sleep once in a while, only to be told that this would require too much coordination. They said:

To me it was simply a different time of day for one shift, once in a while, not a whole new service requiring a dedicated coordinator/administrator.

Rainrtr, H&W
This is suggestive of the service system putting its own needs ahead of those of carers, who in this case had actually been invited by a service provider to suggest ways they could provide a better service for their flexi-care respite.

In order to increase the pool of resources available, one carer suggested that the charities sector be invited to accept more applications for respite and other carer needs (Care Manager, R&R). Another person suggested a ‘Neighbourhood Help Framework’ whereby people would be encouraged to register to help their disabled neighbours and their carers with tasks such as shopping, gardening, cleaning, outings and personal care (Arthur, MC). This idea was described as idealistic and unrealistic by other carers (Tristesse, Sarah, Jen, faye, Catherine, Carers Alliance, MC). Another suggested that there might be something to learn from the model of respite care offered by Alzheimer’s Australia (Joscelin, H&W).

4.4.3 Supported accommodation

Some carers were explicit about the need for accommodation models to fill the gaps in the current respite system. One carer who described the pain of having to “relinquish” their nine-year-old son because of a lack of out of home respite, said it was equally distressing to find that there was no permanent accommodation for children whose care is too challenging for one family. They identified the cluster style model of accommodation as discussed by Lyn Allen in the ‘Accommodation choices’ stream as a solution:

The government can’t go on pretending these children don’t exist. They need a home they can call their own that’s appropriate for permanent care where their family can still be involved in their lives if able. Lyn’s model sounds ideal.

Pam, AC

Some carers identified ways in which respite could also be offered in cluster style supported accommodation of the kind discussed earlier. One suggested a shared model of accommodation support as a more permanent respite type system that would be available on negotiated days according to the needs of carers (Tracey, AC). Building on this idea and that of the cluster model, one carer suggested that one of the rooms in a cluster development could be set aside for shared respite and that this would help to ease the person with a disability into supported accommodation that they are likely to be moving into at a later date (Jen, AC). Similarly, another carer said more respite care needs to be available and accessible for a good number of years prior to a person needing full-time supported accommodation:

Again it is my view this is important as it gives an idea to the intellectually disabled of what is to come and would make it an easier adjustment when permanent accommodation is needed because it is harder for persons of special needs to adjust.

Margaret, AC
Another carer suggested a short term respite centre similar to but less intimidating than a hospital environment as a way of preventing carer burnout and overload (Care Manager, AC).

One important aspect of meeting the needs of carers, especially in the areas of respite and supported accommodation, is to ensure that paid carers and support workers are properly trained, available, and able to provide the kinds of support that carers need.

4.4.4 More and better quality paid care workers

A number of carers identified an urgent need for the Government to develop strategies for increasing the pool of paid care workers, who are well trained and reliable (Deborah, H&W). Increasing the wage of paid carers was identified as one possible strategy (Rainbow, H&W). One carer said:

Perhaps we could encourage more caring people into the profession by offering a more substantial and fair wage. Better wages = more carers = less pressure on existing carers (both paid and unpaid) = better care for people with a disability = reduced ‘costs’ in the long term.

*Shelley, H&W*

Another carer referred the shortage of paid care workers and called for a better and more accountable system of paid care workers. In particular, they proposed that a register of Paid Care Workers be established, similar to the nurses’ board of registration. They said such a register should include a list of workers’ qualifications and that it would empower carers to be able to access quality paid care workers (Sienna, R&R).

One carer suggested that case managers and care workers should have the opportunity to work under the supervision of a senior worker in their first year of work. This same carer also said there needs to be a reduction in the case loads of case managers so they can do their work properly. They also said there needs to be an increase in the pool of people who can become paid carers and that this could be achieved by making the system of training more flexible (Rainbow, H&W).

One participant suggested that meeting respite needs must be explored in the knowledge that the pool of respite carers is small and shrinking, which means that hiring respite carers will be a luxury that less and less people can either access or afford (Concerned Researcher, H&W). In reply to this, another participant did not accept that the workforce of respite carers is dwindling and said that we should investigate how other countries have been able to find workers in adequate quantities (Sarah, H&W).

The next section deals with the ideas presented to the forum in relation to financial assistance for carers, some of which have been touched on already.
4.5 Financial assistance

If anyone in a position to make changes read[s] between the lines of these articles they will surely know that love alone is not enough. Love does not stop us living in poverty, feeling desperately alone and it won’t stop us from growing old, sick or making our loved one well. If life was that easy we would not be writing in this forum. We ask for help to do our job because we cannot do it alone.

*trish, H&W*

Many carers commented on their financial hardship and why they are in desperate need of more financial support. The following comment from a carer of 19 years, who reflected on Australia’s relative material wealth and budget surpluses, encapsulated the sentiments of many carers:

Ensure that the work of unpaid family carers is adequately remunerated. If I were in the paid work-force I would be in a senior role and therefore reaping the benefits of my pay. However, carers are punished by receiving an income support payment that is equal to or even less than a quarter of the income of an average male income. It is simply not appropriate that on top of all the caring responsibilities, unpaid family carers have to struggle to make ends meet.

*Rainbow, H&W*

Similarly, another carer under the subject heading of ‘National Disgrace’ said:

How can Australia call itself a developed country when being a Carer = poverty? It is a national disgrace when one parent has to give up work to care for a disabled child 24/7 and receives little more than $100 a fortnight (Carer Allowance) in support.

*David, FS*

Forum participants put forward a number of suggestions as to how to improve the financial assistance available to carers and, as with the above comments, they presented a strong case for doing so.
4.5.1 Increase in income support to carers

The idea that income support for carers should be equivalent to, or greater than, that of the minimum wage was popular among many carers. As one, a full time carer of two children with complex and chronic medical conditions, said:

If it is at all possible to increase a carer’s income support to the equivalent of the minimum wage or to develop a system whereby carers can build up superannuation for the future then I say push for it every way possible.

*Kerry, FS*

Another carer even put forward a suggestion as to how to guard against unscrupulous people who may commence a relationship with a person with a disability purely for the purposes of collecting the Carer Payment. They suggested this risk could be addressed by a close examination of the true nature of the relationship and the length of time it has existed. This person also suggested that many carers would be happy to provide the evidence to prove they are eligible recipients (Glenis, FS). Another carer said:

Personally, I would like to see Carers receive at least double the minimum wage, with a superannuation scheme on a par with that enjoyed by our MPs. Sadly, most Carers do not get to retire, except in the most distressing circumstances.

*tired and grumpy, FS*

Similarly, another carer said that full-time carers should receive at least the full-time employee minimum wage as well as superannuation benefits and that this should not affect any payments to which the person being cared for is entitled (Val, FS).

It was also suggested that there be a major review of the Carer Payment:

For a parent to leave a full-time position to look after a child with a disability the carers allowance is way not enough. I believe that the carers payment should automatically be given to carers who have to stay home full-time to look after the child because of their disability.

*Angie, FS*
Another carer also said a total rethink of the Carer Allowance is a must:

To put it in perspective - the amount does not even fill a tank of fuel in a car for a week. I know that I do not expect the Federal Government to pay for my weekly outings in the car but I use this example as the lion’s share as to where it goes.

West Aussie, FS

This person also said that the annual bonuses must stay. Another suggestion was that the Carer Bonus be provided twice a year (Care Manager, FS).

4.5.2 Increase in the income threshold for the Carer Payment

A number of carers commented on the unfair nature of the threshold for the Carer Payment:

The fact that the Carer Payment is means tested much lower than other Government payments is very unfair. The threshold for other payments is between $110 and $150K, the threshold for the Carer Payment is $65K - how unfair is that? Especially considering the additional costs of caring for a child with a disability. Even more unfair is the fact that having more than one child with a disability does not increase the threshold.

David, FS

In reply to this, another carer said:

Why is a working couple on up to $150,000- able to receive more in Child Care support welfare payments per annum than many, many carers receive when their income is up to two thirds less than that? I find it particularly discriminatory. Especially as it was stated by a leading politician at the time that those on $150,000- per annum were ‘hardly rich’.

deborah, FS

It is unfair, one carer suggested, for governments to look only at the income earned and not the expenses that carers have when determining their eligibility for payment (angie, FS). Another carer who receives the Carer Allowance for two children who have disabilities said:
I feel it is unfair that it is so hard to get any other payments such as the carer payment and that it is means tested when so many parents with children with disabilities can’t work full time or even part time and are disadvantaged because of one income only that may be just over the threshold for any other allowances when we have to pay out twice as much for therapy etc our children require.

de, FS

One carer suggested the payment system needed to be flexible enough to accommodate individual requirements and preferences, rather than assuming that one size fits all (Shelley, FS).

4.5.3 Simplification of paperwork and application processes

A common complaint among carers related to Centrelink paperwork and the time and emotional strain involved in completing it. A number of carers described the distress of having to re-apply to Centrelink for payments, even when their children have had a disability from birth that is not going to suddenly change or improve (Michelle; Rainrtr; Lynne, MC). In relation to entitlements for people with progressive disorders, one carer of a son with Duchenne muscular dystrophy said:

I agree, there should be some training of stakeholders so they don’t ask insensitive questions or require identical paperwork to be completed periodically - surely they could receive enough training to understand which disorders are chronic with no likelihood of remission or cure.

Rainrtr, MC

This carer expressed frustration at the small window of opportunity for post-school options having to be completed in year 12, which they suggest does not take into account people whose condition may be degenerative. They said:

It seems that the govt expects that disabled persons may get better and need less support (by confirming diagnosis frequently in paperwork) - but it has no concept that many will get worse and need more support, than a singular opportunity before the end of high school to request support.

Rainrtr, MC
Making the process of applying for government payments and respite easier would for many carers make their lives easier (Stacey; Drizzle, R&R). One person who cares for their elderly mother said:

It is particularly galling to have for example, the people I spoke to about getting the carer’s payment - about $90.00 per fortnight - blithely telling me I had to collect up myriad forms of ID for both myself and Mum, along with photocopies, and make an appointment at the local Centrelink. I estimate that the private care I had to organize so that I could go back to my home and find documents, go out and get photocopies, and make two trips to Centrelink cost us about $320. So before the first carer’s payment even hit my bank account I had spent the first two and a half months of it on getting the payment. This is crazy, and speaks to a much bigger lack of understanding and respect for carers by the various bureaucracies involved.

*Helen, R&R*

One carer suggested that it should be possible for carers to apply for funding for their needs online because it would save a lot of time in travel (Donna, AI) and another suggested that there be e-government services for carers (Care Manager, A). Another carer who expressed concern about carers having to go to government offices to attain funding, suggesting that this would be difficult to manage while caring for a child with a disability, called for better use to be made of email when applying for funding (Sienna, R&R).

Some carers expressed frustration about the power of Centrelink to exclude some carers from certain entitlements by failing to accept that many of the forms of care they provide constitute caring duties. In regard to the power of Centrelink to confer disability and carer status, one carer said:

Why does Centrelink then have the power to decide that we are not Carers? or that a person does not have a disability, or that the Permanent Disability a person was born with, recognised by Professional[s], needs to be reviewed every year. Why does Centrelink have the right to override Medical opinion that a disability is lifelong and permanent?

*Tracey, R&R*
This carer also said:

Providing Care for another person does include taking them to appointments, taking them shopping, cleaning, cooking, washing clothes why does Centrelink not recognise the tasks that other Government agencies recognise as Caring? The Government recognises and employs Support workers to assist people to complete these tasks because without support many people would be neglected and unable to remain in the Community.

But when completing a Centrelink form these roles are identified as not being Caring duties?

*Tracey, R&R*

Another carer said:

Her issues of diet and hygiene that I assist with do not count by this Government as caring that qualifies for the Carer Allowance.

*careworn, R&R*

One carer who described feeling demeaned by being made to complete incomprehensible forms and having to subject their loved ones to demeaning medical scrutiny, only to have their claim for Carer Allowance disallowed, said:

In 2020 I hope Governments are truly recognising Carers with meaningful and readily accessible Allowances provided in a respectful, dignified and timely manner.

*Potaroo, R&R*

These comments perhaps add weight to calls from some carers for a review of the Carer Allowance and other carer entitlements or, at the very least, of the criteria that is used to determine the kinds of duties that are and are not classified as caring.

Simplifying the paperwork is really a matter first and foremost of respecting and recognising carers and ensuring that processes through which they must go in order to access their entitlements are flexible and able to be adapted when they do not apply to the circumstances of applicants. This may be as simple as deciding that certain forms do not need to be filled out or that certain questions on certain forms are not relevant to a
particular carer and the person for whom they care. As one carer said:

Carers are EDUCATED people, I wish the system would treat us the way in which we deserve and realise we don’t fit into a pre-determined multiple choice questionnaire. Words cannot adequately express what our reality is - they should spend 5 minutes talking to us, meet us or even watch video footage as individuals rather than 16 months of meaningless paperwork.

*EW, H&W*

### 4.5.4 Tax deductions

Calls for tax deductions for carers were also common in the forum. It was suggested, for example, that family carers either be given targeted income support to pay carers or that the employment of carers be made 100% tax deductible (Fiona, H&W). In commenting on the need for the financial expenses associated with caring to be tax deductible, one carer suggested that there could be an annual Carers Expenses claim form so expenses incurred over the year could be claimed and reimbursed to the carer (Tracey, FS). This person also put forward the suggestion that another tax payer be able to contribute to a carer’s superannuation and receive a tax rebate. Another carer said:

I am a mother to a young son with Cerebral Palsy. He has significant mobility and speech issues. We spend thousands on physio, speech, OT and other non mainstream therapies, not to mention the thousands we spend on equipment.

It would make life far more easier for us financially if his therapies and equipment (which we mostly fund ourselves) were 100% tax deductible.

*Cash Strapped, FS*

In referring to the frustration of finding that representatives from organisations who receive funding to support families have their information sessions paid for, while family carers have to pay for their own attendance, one carer said:

I would therefore like the Government to allow all Carers, who self fund what I class as our Professional Development, the opportunity to claim back such funds either through their Tax Returns or establish a pay back grants system for Carers Australia wide.

*Worn out Westie, ET*
Increased financial assistance is undoubtedly one of the most pressing needs among carers. This section shows it can take a variety of forms, the most fundamental of which is that of an increase in the Carer Payment and Carer Allowance. It is also important that the paperwork and application processes that people are required to complete in order to apply for funding are flexible enough to respond to the needs and circumstances of different carers.

Supporting carers who wish to or are already in the workforce, as was touched on in relation to increasing the threshold for the Carer Payment, is also a way of enabling carers to improve their financial situation and security. This is the focus of the following section.

4.6 Employment

But are we ‘crying to the wind’ for something which will not arrive? Are you, ‘powers that be’, listening? Or is this forum a farce?

Nell, AC

Yes, yes. Yet another study that shows that us Carers are overworked, underpaid, stressed out and on the brink of falling apart constantly. We all know this. How many more studies do we need? Just do something about it.

Cynical, H&W

While not all carers are able to enter paid employment, many would like to but find that there are inadequate support systems in place to enable them to do so. Some of the problems facing carers in regard to paid employment relate to lack of flexibility in regards to eligibility for the Carer Payment, lack of care options available during certain hours, and inadequate leave entitlements for carers in the workforce. In regards to carers having a choice about whether or not they enter paid employment, one carer said:

I really believe that carers should have a choice, Centrelink should not attempt to force them to re-enter the workforce but if a carer chooses to work or study there would be support mechanisms in place to do so.

I honestly believe the government does not want to create further respite places because of the huge cost involved. Well guess what you can’t have it both ways, if you insist on forcing some to work then you have to pay. But more importantly
Carers should have the right to choose to work and access services so they can do so.

*webstar, CW*

Barriers for carers in or seeking paid employment include inflexible and unresponsive workplaces and a general lack of support for carers in the workforce. As one carer, whose spouse was suddenly affected by a “life limiting condition” and who now has the responsibility of meeting debts they took on as a dual income family, said:

There is an urgent need to better understand the issues faced by working carers such as myself compelled to work not just to meet our current financial commitments, but also to ensure a future for my kids, while ensuring that my husband’s health & wellbeing is looked after.

*Geetha, CW*

Another forum participant suggested governments have a role to play in making it more attractive and practicable for employers to employ carers.

### 4.6.1 Incentives for employers to employ carers

One carer put forward some suggestions as to how to increase the attractiveness of carers to employers. These included Carer Fixed Term Leave, for which registered carers could apply with the confidence that their job would be kept open for them when they return; a Temp Staff Back Up Scheme, whereby the Government would subsidise employers for costs incurred in securing staff to work for up to four weeks per year to enable carers to take leave to fulfil their caring duties; an exemption from Payroll taxes for those who employ registered carers; access to out of school hours and after school care; and no limitations on the number of hours a child over two can attend long day care, if the parent is in paid employment on the days of attendance (Gina, CW).

### 4.6.2 Flexibility in Government Payments

One of the major disincentives for carers entering or re-entering the workforce are the conditions of receiving the Carer Payment. Numerous carers called for more flexibility in hours that carers are able to work before payments and entitlements are taken away or reduced (Cynical, FS). Some carers said that the time it takes to travel to and from work should not be included in the 25 hour limit that carers are able to work before having their payments affected (Time Traveller, FS; Felicity, FS). One carer said:
Rejoining the workforce is daunting and I didn’t know if I was going to manage it. Even six months down the track, I am not sure that I am managing. The Carers pension does not allow you to work more than 25 hours per week. What if you get a job for 28 hours per week and realise that you cannot manage. All that paperwork again.

_Cynical, CW_

This suggests that there is the need for greater flexibility in the Carer Payment, so that carers are given the opportunity, within reason, to see whether or not they can manage, without the constant fear of having their Carer Payment stopped should they slightly exceed the 25 hours. In order to assist carers with the costs of re-entering the workforce, it was suggested that the normal weekly Carer Payment be continued for a set period after a carer had obtained employment (kate, AI).

A number of participants in the ‘Financial Security’ stream described how the system disadvantages carers who are able to work. For example, one carer said that because they earned $400 per year over the Centrelink limit her husband, who is no longer able to work, cannot collect any benefits (Glenis, FS). They said:

We would be happy if he could receive a health care card, without any other Centrelink benefit. The system at present only allows people to receive either everything or nothing. I try to keep working, to survive independently for as long as possible, and to keep life as normal as possible for the family. It is hard to swallow that we are actually disadvantaged by trying to be responsible.

_Glenis, FS_

At the other end of the spectrum are carers who receive the Parenting Payment, one of the conditions of which is that they must look for three hours of work per day or have their payment stopped. One forum participant said this policy should be scrapped, especially for people who are in the situation of having all their time and energy taken up by caring for a child with a disability (Lynda, FS).

4.6.3 Accessible respite and support services

For some people it was a lack of respite suitable for their loved one that made it difficult for them to stay in the workforce, or guilty for doing so. In particular, one carer described being unable to find a respite place for her husband who is of working age and who has a brain injury (working carer, CW). Another carer described their fear of having to leave the
workforce because of a lack of post-school support services for her young adult son who has high support needs (Rosemary, CW). One mother said that being able to work between 10am and 2pm would be ideal because she had to provide constant care to her son before and after school, as there are no after school services for him (Rainbow, H&W).

Inability to access respite or supported accommodation was an issue for some family carers working in the paid workforce. One carer described trying to access Emergency Respite to help her with caring for her disabled children after suffering a prolapsed disc in her back. She said:

When I explained that my Husband had had to return to work they refused to help me saying that “emergency respite cannot be used for working carers.” They basically refused to help me because my Husband was at work. How totally inflexible and unreasonable to refuse such a small amount of help in such circumstances.

*Faye, CW*

Other participants said that making home care more accessible could enable some carers to join or continue in the workforce (Cynical, CW; Geetha, CW).

One person who works part-time as a GP in order that they can care for their autistic son said that the availability of supported accommodation could allow them to work full-time:

If my son was in supported accommodation, I could work full-time and deliver a valuable service to the community. I am sure there are hundreds of other families who also could be providing important contributions back into the community if they had appropriate accommodation for their family member.

*Jeffrey, AC*

At present, a lack of supported accommodation also means that this person is restricted from accessing the financial and social benefits of full-time participation in the workforce.

The following section discusses some of the rights and entitlements that participants in the forum called for, which do not relate to any one in particular of the already identified areas. Indeed, to the extent that the need for greater recognition and rights for carers is an overarching theme of the forum, the ideas discussed in the following section can be seen as relating in some way to all of the areas already discussed.
4.7 Rights and other entitlements

Will any government ever have the decency and integrity to actually act and bring Australia in line with other developed nations in regard to the rights of people with disabilities and their Carers?

*Faye, R*

In response to the original article in the ‘Recognition and Respect’ stream written by Pam Webster, the President of Carers Australia, there was some discussion in the forum about the possible need for legislation on carers’ rights. Forum participants also called on the Government to contribute to carer superannuation, to assist carers to purchase insurance, and to provide a certificate of service to carers. Participants also made a number of suggestions regarding other entitlements, in the form of discounts and vouchers, and their needs in relation to health care, information and social connection. Others identified a need for greater community awareness of the lives of carers.

4.7.1 Legislation

People were divided about the importance of legislation and its ability to bring about recognition, respect and other entitlements for carers. More specifically, one carer in response to the original article by Pam Webster expressed concern about the proposed national carer legislation, suggesting that it may be a way of “putting carers in a pigeon hole”. They also suggested that requiring carers to be involved as partners in health and community care services may disadvantage or punish carers who are not good at being partners with these agencies (Care Manager, R&R).

On the other hand, some people suggested that legislation on carer rights would help to ensure that recognition and respect for carers was automatic. In particular, one carer said legislation is an important part of ensuring that the relationship a carer has with the person they care for, and their right to be involved in discussions and decision-making related to their carer role, is recognised by health care professionals. They said:

> It should be clear to hospital health staff that the carer needs to be involved in all plans related to ongoing care and also that the particular knowledge the carer has must be part of the planning process.

*Faye, R&R*
This participant also said:

We need comprehensive disability and carer rights legislation in Australia. A bill of rights for disabled people that encompasses the rights of carers. We need legislation included under HREOC (Human Rights and Equal Opportunity Commission).

\textit{Faye, L}

This participant said the Government needs to ratify the optional protocol for the United Nations convention on the rights of the disabled and said that it was shameful that some parents of children with disabilities leave Australia because they have no rights to inclusion in society (Faye, L).

Legislation was seen by some forum participants as one way of being able to protect and enforce the rights of carers in the paid workforce. One carer related their experience of an employer – an unnamed Federal Government Department – denying their requests for part-time hours so they could care for their elderly mother. They expressed concern that, while the Government may recommend flexibility in the workplace, without any mechanism to enforce it employers can ignore it. They said:

Instead of yet another ‘committee’ or ‘enquiry’ it is time the Australian government stopped lagging behind other countries and introduced a ‘Carers Rights Act’ as recommended by its own HREOC. The necessity for an ‘Act’ to ensure carers’ rights has been recognised and been in place in the United Kingdom and Central Europe for some time!

\textit{Public Servant, CW}

Other carers agreed that legislation was vital to ensure that carers have the right to flexible work hours (Lisa, CW). Also in regard to carers in the workforce, one carer who described the different circumstances in which carers may need to take leave said:

Flexibility, with the safe guard of a ratio of carer’s leave available without the need for a medical certificate would be a positive move forward. The current carer’s leave entitlement is inadequate - leave entitlements need to be expanded.

\textit{Lisa, CW}

The ACTU in its original article in the ‘Carers in the Workforce’ stream also called on the Federal Government to consider increasing the amount of dedicated carer’s leave available to employees.
4.7.2 Government contribution to carer superannuation

It is well recognised that many carers have no, or very little, superannuation because their caring duties have prevented them from entering the paid workforce. As such, many carers believe the government should in some way account for this. One carer said:

I think if government was genuine about its regard and appreciation of carers it should make a contribution to the superannuation of long term carers. I know they do not want to risk inflationary pressure of carers kicking up their heels and purchasing new clothes etc but if long term carers (say over 20-25 years) of caring for a very high needs patient (those who would otherwise be in very expensive supported accommodation with massive staffing costs) sacrificed their financial security along with their own hopes and dreams the least the govt could do is contribute to their retirement so that at the end of their lives they at least would not need to live in abject poverty.

_I live in hidden poverty, FS_

Another said:

I believe all who are in receipt of carers allowance and/or carers payment should benefit from government contributions directly into their superannuation fund. The eligibility criteria for these benefits is rigorous and should be enough to determine eligibility for taxation/superannuation support.

_Lisa, FS_

This person said that one idea could be for tax concessions or rebates to carers that could be paid directly into their superannuation fund.

4.7.3 Insurance for carers

One carer suggested that the Government assist carers to purchase life and permanent disability insurance, either by making it fully tax deductible for registered carers; paying for coverage of up to $1 million per carer for registered carers; or by bulk buying and making the purchase of reduced cost insurance available to carers (Gina, H&W). Another carer who has been caring for their intellectually disabled son for nearly 35 years said:
My suggestion is the Federal Government incorporates a type of disability insurance (for significant ID disabilities and other significant disabilities) into the National Health Fund (Medicare), so every mother who bears a child does so knowing that if she draws the ‘short straw’ there will be financial assistance through all life stages for the affected child through to adult years lifelong, and assistance for the mother/carer.

Tristesse, H&W

This same carer, and a number of others, also identified the importance of parent carers of people with an intellectual disability, who will be dependent on them for life, being able to access support services from the inception of their role (Tristesse, AI).

4.7.4 Carer identification and certificate of service

One carer who referred to their experience of being woken on the hour every hour from midnight to 7am most days commented that they would receive 30% penalty for working at that time, if they worked in the transport industry. In relation to the overdue need for recognition and respect of carers, they said:

How this could be achieved is simple - On the State Drivers Lic or Vehicle Lic incorporate the words CARER on the border surround. On a National Standard incorporate it on the individuals Medicare Card a similar notation. Have a bumper sticker.

West Aussie, R&R

In response to this, another carer alluded to the value of this form of carer identification:

When we attended appointments etc with our loved ones we would be recognised as the one who needed to be told vital information to perform our caring role with utmost efficiency.

kim, R&R

One carer suggested that the word ‘Carer’ could be included on a person’s Medicare or health care card to prompt doctors and pharmacists to be proactive in offering information (Care Manager, ET).
Other carers suggested ways of respecting and recognising carers that may at the same time help them to re-enter the workforce after their caring role is over. One person said:

I believe that the Carer should have a long service aspect to their care say 2 weeks benefit for every year of caring plus the government should issue a certificate of service that states that a grateful government recognises us for our efforts and work on behalf of the nation. This could be used as a reference for those young enough to re-enter the work force. It would at least make re-entry to the “other” world a little less stressful.

*country dave, R&R*

According to this participant, this would help carers to address the attitudes of Centrelink and prospective employers who may treat carers as though they have bludged off the system and fail to appreciate how much money their caring has saved governments.

These ideas about long service and a certificate of service for carers were met with agreement from some carers. One carer said:

I have been doing voluntary work however it is difficult to find paid work which recognizes the skills and experience gained through being a personal assistant for my child for the past 6 years. To receive a Certificate from the Government recognising the time taken caring would be brilliant.

*Sienna, R&R*

One carer suggested that the budgets available for families who have sustained a long period of caring, such as 30 years, to access supports for a loved one, should be dramatically increased and many times the size that it was in the first or second years of care (Vern, S). Similarly, one carer expressed frustration about the lack of recognition given to the long-term carer as distinct from the short-term carer, and case workers failing to take into account the length of time they have been in the caring role, and the severity of their child’s condition. They said:

Longterm carers, those caring for someone with complex needs and carers of multiples should be recognised and given priority over those who find themselves newly appointed to being a carer, caring for someone with lesser problems and caring for singles.

*invisible, R&R*
A certificate of service, or some form of carer identification, could provide solutions to this kind of problem. It could be shown to service providers and Government Departments and, potentially, enable carers to be treated with the level of understanding and recognition that is appropriate to their years of service as a carer. This is not to suggest that it should be used as a tool to treat some carers better than others but, rather, to ensure that those who are supposed to assist carers are aware of the stage of caring that a person is at and are able to tailor their service and support accordingly.

4.7.5 Discounts, concessions, bonuses, vouchers and rebates

Numerous strategies by which to reduce the cost of living for carers were put forward. These related to government subsidies to cover the increased costs of caring, increasing the Centrelink rent subsidy, providing mortgage assistance to carers, free equipment, free parking at hospitals, increasing the Medicare rebate for carers, vouchers for carers to access services for their own health and wellbeing, and a computer and internet subsidy to reduce isolation.

One carer said there should be a permanent bonus scheme to all family carers receiving the Carer Payment and Carer Allowance to help with the increased costs of caring. They also said these same carers should be provided with a discount card to pay for exercise classes, massage, petrol, large items, clothes, shoes and hair cuts, as well as a ‘celebration bonus’ as a way of celebrating their role in the community. They said this bonus should be given directly to carers so they have a choice as to how they wish to spend it, rather than being at the mercy of service providers (Sienna, R&R).

After describing the physical effects of years of lifting her son who has cerebral palsy one carer said:

My suggestion, is that the government should make available to the carer, as well as the person being cared for, a concession card that would enable reduced costs for massage, chiropractic and prescription drugs, so that the carer can look after themselves in order to remain well to stay in the caring role.

Loz, H&W

A number of carers agreed with this idea. One said that vouchers for chiropractic, massage and gym would help improve the health of carers (faye, H&W). Another said that the Government ought to provide the lifting equipment that carers need to prevent them from doing damage to themselves (Gaye, H&W). Another carer suggested that formal training for family carers in aspects of care should be available and funded, as is the case for carers in residential and community care. They said:
It is good that training is given in financial areas, making a will, etc. but what about manual handling, medication, use of oxygen, dental hygiene, wound care, and so on.

*Concerned of Adelaide, ET*

*Also in relation to training for carers, another forum participant said:*

If paid care workers are protected by Occupational Health and Safety regulations, how can we justify the failure to guarantee similar protections for those who provide care without payment? If paid carers receive training on how best to perform the physical or behavioural management requirements of the care role, how can we justify the failure to offer similar training to family carers who undertake a much more intensive and long term caring responsibility?

*Deirdre, S*

*Along similar lines, one carer identified a disparity in entitlement to aids between those being cared for in nursing homes and those being cared for by an individual living in the community. They said:*

Carers are saving the Government pots of money so all aids supplied by the non-government sector should be made available to people still living in the community and being cared for by an individual.

*Gaye, A*

*One carer suggested that all people with physical disabilities should receive a Mobility/Access Allowance separate from the Carer Allowance and/or Payment. They said this payment should not be means tested and should be at a minimum the level of the Carer Payment. This person also suggested that the government look at ways to reduce the costs of power wheelchairs and other items (Gina, A). One carer, who suggested that the Medicare rebate be increased to 50% or higher for carers, said:*

We have spent over $50,000 in 2 years since our son was diagnosed on medical treatments, therapies & special diets. We have received no help from the Gov’t with this & if we could claim back more through medical it would be a big help, especially since we have run out of money & are now re-mortgaging our house to pay for his treatments.

*asdmum, FS*
This carer said it would be an investment for the Government to support the therapies and treatments available to children with autism spectrum disorders because in the long run it will mean they stand a better chance of being able to live an independent life.

One carer said they would like to be able to make modifications to their home in order to create some space between themselves and the person they care for, but said they could not afford it and could not get any financial assistance from the Housing Department. They suggested a subsidy for carers to make home modifications would solve a lot of problems (Care Manager, AC).

As an incentive by which to encourage greater accessibility to commercial and public community facilities, one carer said:

There are government subsidies for rain water tanks and many other habits of good citizenship we are trying to foster, why shouldn’t there be a rebate system for businesses and owners of premises to provide wheelchair access? In some cases it means fixing a 4 inch stoop/threshold, but this is an effective barrier for exclusion.

Raintr, A

Similarly, another carer said it would be a good idea to subsidise or give tax deductions to businesses and services who cater especially for people who have trouble being included (Care Manager, IS).

Forum participants called for Government leadership on a range of measures to improve access to the community for family carers and the people for whom they care. Some of these measures included more disabled parking spaces and monitoring thereof, more disabled toilets, more funding for taxis, more buses with accessible ramps, legislation to make supermarkets provide assistance with shopping if needed, discounts or free entry for carers when accompanying the person they care for, funding for wheelchair accessible vehicles, fuel discounts, and scholarships for family carers to study (Sienna, A). One carer suggested that scholarships at all universities be offered to carers and also called for flexibility in respite for carers who are studying (faye, ET). Another carer said:

Hi, I’d like to see financial support to enable carers to study courses of their choice in order to provide a means of income into the future. I would also like to see decent support systems in place to enable them time out in order to undertake study.

webstar, ET
In response to experiences with Centrelink not providing accurate and adequate information and support, some carers suggested that carers be referred to a financial adviser to help them sort out their financial situation. While one person suggested that these financial advisers and counsellors be connected to Centrelink, another said they needed to be independent of it (Frustrated, FS). In regard to the need for information about legal matters affecting carers, this carer also said:

Suggestion only - a system that allows a one-off and follow up appointment may be all that is necessary to put a lot of carers at peace of mind and in an informed situation. Perhaps a back up advice line (eg telephone support).

*Frustrated, L*

This carer said that financial and legal advice should be free or substantially subsidised.

### 4.7.6 More home visits from doctors

Carers of all types and for various reasons often have trouble transporting the person they care for to and from doctors’ appointments. One carer identified a need for more easily accessible medical and health care for people who care for their loved one at home, including more home visits from GPs, rather than waiting for a crisis and ending up at the hospital emergency department. They described their experience of being unable to easily access nursing or other assistance to care for their elderly mother after she came home from hospital (Helen, R&R). Another carer of two children who are in wheelchairs also identified the need for more flexible services for carers, such as home visits from doctors for carers and people with disabilities (Faye, H&W). Similarly, another carer said:

we need more doctors and ones that will come to our home as some of us find it hard to leave their home to go and see a doctor.

*Lyla, H&W*

For many carers, knowing what services are available and how to access them was a big problem for which they proposed a number of possible solutions.

### 4.7.7 Quality information resources

Some carers described frustration at not being able to access information about services and entitlements that the person they care for are eligible for and suggested that there needs to be a central body through which carers can gain this information and access the services to which they are entitled (LeahD, MC). Such a resource could take a variety of
forms, such as a telephone number, website or local community drop-in centre.
One carer said:

Also it should be MANDATORY to give written referencing information referring to support groups/relevant organizations/ courses/ research institutions/legal/ financial services etc. This information should be provided to Psychiatrists/Counsellors/psychologists by state or regional government facilities, and issued/updated quarterly or twice yearly. These should be local area or region specific. These should also be displayed MANDATORILY in the waiting rooms of clinics both private and public AND given out to carers upon admission of a person to Psychiatric hospital. It should have specific coordinator(s) for this role, possibly part of a larger Carer Support Coordinating unit.

*Frustrated, R&R*

Another carer suggested that there be a one-stop-shop where carers can call to find out what services are available, to save them having to spend hours on the telephone merry-go-round only to find that no service exists (Cynical, R&R).

In the event of illness or a medical emergency, carers often do not have the option of waiting for a respite bed to become available, and not being able to access emergency respite at short notice can mean they put their own recovery in jeopardy. A carer who described having to leave hospital on the same day as their operation, because they were unable to access short term emergency respite for their disabled son, said:

*There needs to be a central number carers can ring to access help when they are ill or need an operation.*

*trish, H&W*

Another carer who said they moved from the country to the city in order to try and access better assistance, but to no avail, reflected on what would have helped:

*I wish now there was a helpful website for carers that included where to go for practical assistance and perhaps even the offer of a starter pack for carers including things you might come across including the management of grief and loss…*

*Care Manager, L*
One carer proposed that suburban shopfronts be established that would provide support groups, counselling, time out space, meeting places, information, and help with filling out forms. This person suggested that such drop in centres could be staffed and run by organisations such as Carers Australia as an extension of their existing services (Potaroo, MC). They said that suburban drop-in centres would be one way of making services more accessible to carers as well as alleviating some of the isolation that many carers experience (Potaroo, A). Another carer urged the government to provide funding for family carer retreats that are open and available to carers of all ages and can provide an opportunity for carers to support each other and exchange ideas and strategies (Sienna, H&W). Another carer said that the brother who she cares for would like there to be a weekly talk back radio show on the ABC for disabled and handicapped people (Care Manager, H&W).

4.7.8 Permanent online carers’ forum and other support networks

A number of carers said they would like the online forum to continue, saying that it is a valuable resource that provides an insight into the difficulties faced by carers (David; Joscelin; Frustrated, O) as well as a way for carers to connect. One carer said:

As mentioned in other posts I would also like to see this website continue after the end of August. I think it is a useful tool for Carers to exchange ideas, information and decrease some of the isolation that Carers feel. It’s the first time that Carers have been able to actually have [a] say so it will be a shame if that is short-lived and doesn’t continue.

faye, O

Another agreed:

I would also like to see this forum stay open to be a source of information for ‘researchers’ as well as mandatory reading for the politicians and bureaucrats who have so much power over our lives. It is important for carers to know we have a voice and to be able to share information.

invisible, O
Another said:

This forum should be continued. In my short experience as a carer, I have found that talking to other carers in a similar situation is much much better than talking to so-called health professionals who have never lived with what we live with.

_Vicki, O_

Another carer of two autistic sons said:

I welcome the greater use of web forums, teleconferences, videoconferences as a cheaper alternative (my opinion only!) to getting Carers together in person.

_Cathy, O_

One carer called for a permanent website similar to the _Carers Virtual 2020_ summit covering many of the topics mentioned on it, such as details about where to access services and equipment and how to get funding for them (Care Manager, A). Another said that if it could not be permanent the _Carers Virtual 2020_ should be an annual event in order to keep track of changes and improvements and the value of the forum (Frustrated, S). Carers Australia informed the summit that a permanent forum for ongoing discussions is under construction and will go live on its website on October 20

_http://www.carersaustralia.com.au/_.

Another carer had a slightly different idea for a website:

I would like to see a site called “FIRE US THE CARER QUESTION” and then have a team of specialists around Australia provide answer back to the person who asked. In addition - input from carers who have dealt with a person in need of care in a similar or like role can add their comments as well.

_West Aussie, ET_

Participants also put forward other ideas about how to help carers stay connected to society:
Local Carers clubs, telephone clubs, on line chat rooms such as the one that I set up to combat my isolation (www.carershaven.org.au). Anything to help the Carer stay connected with society, even if it has to be a new part of society.

Cynical, H&W

This person also suggested that a telephone counselling service that proactively contacted carers to talk them through any of the emotions that may be eating away at them would also be helpful. Some carers supported this idea. One said:

Counselling is [a] great idea too...it is difficult for family carers to get to appointments so a phone call asking how we are going and being there to get things off our chest...would be a great idea.

Sienna, H&W

This person also suggested that the Government should put more money into toy libraries. Another carer called for a 24-hour carer helpline and a “laughter line for those days when we just cry and try to hide this from our loved one” (Joscelin, H&W). Another carer described how being able to use chat lines to connect with other carers was very useful during the seven years they cared for their father who had dementia and Parkinson’s disease. They suggested that a computer and internet subsidy for carers could alleviate some of their isolation (Brian, H&W).

4.7.9 Increased community awareness of carers

Some participants said that achieving recognition and respect for carers involves creating awareness about what carers do. As a carer who questioned the practical value of legislation said:

It is attitudes that need to change in order for us to receive the respect that we deserve. You cannot legislate for respect. I cannot see how any legislation is going to make my day to day life any easier.

Cynical, R&R
Another carer said:

Most people turn a blind eye to the work that family carers do or do not exactly know this needs to be promoted more and the community need to be educated.

*Sienna, R&R*

Another carer said:

Maybe with raised awareness of the complexity in the lives of carers, society would be willing to invest more in helping us. It could happen to anyone at any time, it is not just about children with disability or dealing with elderly relatives.

*working carer, CW*

This may point to a need for some kind of campaign to raise community consciousness about the way in which social structures are often a further disabling force in the lives of people with a disability and their carers, especially if their rights are not recognised and upheld.

As this section shows, carers identify a range of rights and other entitlements that they are at present lacking. It is clear that forum participants believe there is much more that can be done to support carers in their caring role. It is perhaps best to leave the last word before our conclusion to a carer who said:

Carers and people with disabilities live in hope, faith and with dignity and are proud of what they have achieved with their limited resources and support. Are your governments proud?

*Greg, IS*
5. Conclusion – the way forward?

I really appreciate the time its taken to set up a forum such as this but my plea to the government is please don’t let this be yet another session of empty words that fall on deaf ears....... now is the time for change, the real question is will you take up the challenge?

webstar, S

My fear is this forum is an exercise in ‘letting off steam’, so ‘powers that be’ prove me wrong, and do something valuable for us...support us to prepare for whatever position we find ourselves in, the beginning, middle, or nearing the end of our care.

tristesse, S

In concluding this report we would first like to acknowledge the carers and others who participated in the Carers Virtual 2020 summit and who have provided us with a window into their lives. We recognise their expertise and thank them for sharing their ideas about what needs to be done for carers and the people for whom they care. It has not been possible to make reference to every post and/or all of the issues raised by participants in the forum. We have sought to balance the need to reflect the content of the forum with that of focusing on what carers say needs to change.

This report has highlighted a number of areas identified by carers as being in need of change. Our objective was not to attempt to quantify the number of posts that supported a particular idea, although we have observed that certain ideas were quite popular among forum participants. We have also identified key themes that underpin the different ideas and directions put forward by carers.

People’s ideas and suggestions for change are rooted in their experiences of lacking voice, choice, control, recognition, respect, investment, inclusion, access, flexibility and availability in a range of areas that impact on their lives. People’s solutions in regard to all of the problems they identified in the forum revolved around the principle that carers have the right to have a choice in regards to all aspects of their caring role.

Many carers said they are offended by having their voices represented by paid professionals and some called for an end to this practice. Several forum participants said they do not feel that their views are represented in the present carer advocacy environment. Some argued that the unwillingness of these organisations to lobby for supported accommodation facilities, like the clustered residential model, as well as an overhaul in funding arrangements are two cases in point. The idea, supported by some carers, of
carers being represented by a carers’ union was also discussed. On the other hand, some carers recognised the important advocacy work of existing carer organisations and called on them to lend their support to various initiatives. The strongest message to emerge in these posts is that carers must be recognised as the experts in their needs. Their lived experience and the knowledge it affords must be given equal, if not greater, weight as other ways of knowing about carer needs.

Funding, particularly the need for an overhaul in funding arrangements affecting carers, which could take the form of individualised funding packages and investment in people with disabilities, was the second area discussed. An overhaul of funding arrangements was identified by many summit participants as providing the solution to a range of problems. It is for this reason that participants called on carer associations and advocacy organisations to heed their calls and lobby for change in this area. In the view of many carers, governments must seriously consider bypassing service providers and directly funding carers in the form of individualised funding packages that will enable them to source and be in control of their own solutions. The level of support for the UK In Control model is notable.

The need for a shift in the mindset from spending to investing in inclusion underpins many of the directional changes that carers are calling for as well as the specific ideas they put forward in the forum. Investing in people with a disability can take the form of increasing financial assistance available to them, creating education, training and employment opportunities for them, and/or creating the social conditions and funding and services infrastructure under which they can reach their potential and gain independence. It can also take the form of putting in place the (supported) accommodation options and arrangements that would enable them to transition from the family home as smoothly as possible.

The third area we discussed was that of accommodation, most notably the supported accommodation model of clustered residential settings, which was popular among a number of forum participants. Many were of the view that supported accommodation facilities, along the lines proposed by the cluster model, are worthy of government investment and support from advocacy organisations and the broader community. Parent carers of adult children with a disability were particularly in favour of this accommodation setting and urged the government to invest in this area now so they can begin to transition their loved one into this setting before it is too late and crisis point is reached. Some carers also suggested that this accommodation model could be suitable for short and longer term respite. An overhaul of funding arrangements and a move in the direction of individualised funding packages would, in the opinion of some, enable carers to take control of accommodation arrangements.

Carers identified a number of services as being in need of improvement. A common complaint among carers is that services do not meet their needs and, as with funding, many participants called for flexibility in services and an overhaul of the way in which they are funded and delivered. One of the problems carers identified is that too many services and systems supposedly in place to help them take a one-size-fits-all approach. Self-directed services, ways to address gaps in funding and respite, the provision of supported accommodation, and the need to increase the pool of paid care workers were some of the ideas that were discussed. Comments to the summit clearly show that it is not enough merely to acknowledge the ‘diversity’ of carers. This fact has to be translated into practice through the provision of flexible services that are responsive to people’s needs.
Carers put forward a range of ideas about how they could be better supported financially. These included increasing the income support for carers, increasing the threshold for the Carer Payment, simplifying the paperwork and processes of applying for payments, and tax deductions for caring-related expenses. A very strong case was made for increasing the Carer Payment on the basis that its current level is simply not enough to cover the costs associated with caring. Some participants also called for a rethink of the Carer Allowance in accordance with the increasing cost of living. Some carers highlighted a disparity between the Carer Payment and other Government payments in relation to the means testing threshold.

On employment, forum participants identified a number of measures that could be taken to support carers entering and those already in the workforce. These included various incentives for employers, greater flexibility in Government payment conditions, and more flexible and accessible respite and support services. More supported accommodation facilities would also benefit some carers wishing to enter the paid workforce.

The final section of the report discussed rights and other entitlements that carers identified. These included the possible need for legislation, government contributions to carer superannuation and assistance to purchase insurance, a government issued certificate of service for carers, more home visits from doctors, and better and more accessible information and networking resources for carers. A range of other discounts and rebates that could be offered to carers were also identified, all of which would enhance the ability of carers and the people who they care for to participate in society. Some carers also identified the need for greater community awareness of the work carers do, and suggested that better recognition would improve the likelihood of carers being respected and enabled, rather than disabled, by society.

In summary, as we stated at the outset, we are not in a position to make recommendations on the basis of ideas presented to the Carers Virtual 2020 summit. Our modest objective has been to report on these ideas. One of the strongest and undisputed messages conveyed by carers who participated in the forum is that change has to begin now. As many of the comments throughout this report show, carers are desperate and many are in crisis. To this end, we urge readers of this report to take heed of carers’ frustration about not being listened to, recognise the reforms they are calling for, and act to ensure that their voices do not, yet again, fall on deaf ears.
Don’t wait: Carers say listen and act now

A report on the Carers Virtual 2020 summit