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2016 Summary – Service Concepts & Considerations, Designing the new integrated carer support service

SUBMISSION FROM ADAM JOHNSTON, PROPRIETOR, ADJ CONSULTANCY SERVICES

	Section	Questions – Design Considerations	Responses
	General		As someone with cerebral palsy, confined to a wheelchair, with one primary carer, I have to say that little in this document seems different from numerous forerunners. Having checked with my mother, we have rarely interacted with the carers' support services. The one time Mum and Dad did ask for assistance (so they could travel to see ageing relatives in the UK; a trip which did prove timely, as a cousin passed away shortly after their return), this was declined, so we made informal arrangement with a close family friend to support me and my care needs.[1] Again, many similar experiences with services for the disabled have caused me to doubt the bona fides of many policy makers. For example, in the area of employment services, one has long since concluded that the infrastructure exists simply so that a Government

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[1] My consultancy comes out of my own frustrations when dealing with a variety of service providers, the seemingly never-ending need to prove my eligibility, lodge appeals and gather ever growing piles of documents for both procedures. From my experience as a former complaints handler for the NSW Ombudsman, it seemed that a growing number of people just could not cope with the complexity of their interactions with public bodies or NGOs. A combination of literacy, language, health, education and family dislocation often interact to leave people without services. It can also leave many in debt with fines and penalties they do not understand and have little hope of paying. While some people have argued that there will ultimately be a form of e-Government which will make such interactions easier, I do not share that view because it relies on a technical literacy, which in my observation only really exists alongside effective reading and writing skills; see e.g. Jacob, Georg (University of Salzburg, Department for Law and Informatics), *Electronic Government: Perspectives and Pitfalls of Online Administrative Procedure,* Proceedings of the 36th Hawaii International Conference on System Sciences (HICSS'03), 0-7695-1874-5/03 $17.00 © 2002 IEEE, available at http://www.hicss.hawaii.edu/HICSS36/HICSSpapers/ETEPO02.pdf (pages 8-9 Adobe numbering)

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			Minister can stand up in Parliament say "we are doing something for the unemployed," with little regard as to whether what is being done has any positive long-term impact.[2] Similarly, I ask whether carer support services are designed (under whichever model and whatever name) to meet a political imperative, rather than with any real interest to the true needs or desires of carers (or those they care for)?[3]
1.	**Awareness**	1.1 If the proposed model is to achieve a preventative focus, it will be important to identify carers early in their caring journey and connect them to potential supports. For many carers, this occurs within a healthcare setting, where the person they are looking after may be diagnosed with a condition.	We need to be very careful about what we do here. Diagnosis will be a shock for many carers; they may want to go away and think about what they do next. Equally, people will go through stages of denial, acceptance and action at different rates and different times. From personal experience, I have found some service providers only too ready to identify you and your family as needing their services, whereupon they bully their way into your lives, under terms and in ways in which they were never invited.

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[2] See e.g. my submission to the Senate Standing Committees on Education and Employment inquiry into the *Social Security Legislation Amendment (Strengthening the Job Seeker Compliance Framework) Bill 2014* at http://www.aph.gov.au/DocumentStore.ashx?id=b0e07f8c-3f2b-43f0-b6de-3e7f0ceaf38e&subId=301892 as at 29 May 2016. Mandatory employment schemes for people with disabilities, run by charities/NGOs, appear to do little but recycle people through endless training and temporary, subsided employment. Unsurprisingly, the job ends when the subsidy expires. As a result, in my opinion, many Ministers should be held in contempt of Parliament, for misleading the Chamber when they suggest that many programs do like more than fictitiously (and temporarily) move people off unemployment ques.

[3] In the end, all redesign proposals seem to want to fit peoples' lives into neat and tidy boxes. Living is not neat and tidy, yet bureaucracies keep presenting proposals where an individual's or family's life fits neatly into a flowchart or diagram. The ultimate expression of this "fit the person into the box mentality" is actually the National Disability Insurance Scheme (NDIS), an arrangement which trumpets flexibility and individual choice, while in reality requiring people to make applications, submit detailed plans of virtually every aspect of their life and then, after (presumably) obtaining Agency approval, seek agreed services from Agency approved providers. See generally, my submission to the Senate Standing Committees on Community Affairs on the NDIS at http://www.aph.gov.au/DocumentStore.ashx?id=dc64c892-b41d-48b5-9916-7f4b90e71ee3 and the supplementary submission at http://www.aph.gov.au/DocumentStore.ashx?id=c59725d8-263e-48d8-8fb4-60303c4280a8 as at May 29 2016. The NDIS is, in many ways, the antithesis of what an effective support scheme should look like.

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			This was brought home to me when transferring into an Attendant Care Program. This was allegedly going to support me and my mother, allowing us to "age in place" and access more and/or different support services as our needs changed. This sounded wonderful in theory, but in practise it introduced a bully of an NGO case officer into our lives, who wanted to change all our existing services, despite our express wishes to the contrary. Only a few Ministerial letters from me managed to get rid of the toxic woman and her wretched service (which regrettably maintains a major presence on Sydney's northern beaches) out of our lives. This has made me suspicious and sceptical of those advocating awareness and early intervention; one wonders about their true motives and intentions of many organisations, as well as their long-term sustainability and commitment to my needs.[4] These experiences have made me highly reticent about new services like the NDIS. The first of my three submissions to the Productivity Commission's *Disability Care inquiry* highlighted the negative experience and how, if the NDIS was going to achieve anything, it

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[4] NGOs are heavily dependent on grants, donations and other subsidies, such as tax relief. For many, the government grant has become their key source of income. However, when the policy priorities (or the Government changes) what happens then? The answer is that many people get caught out in de-funded services and, urgent appeals have to be made to retain temporary funding while new arrangements are made. Despite this, charities do not seem to change their approach to funding or finance, as I observe in my submission to the Harper Competition Review at http://competitionpolicyreview.gov.au/files/2014/07/ADJ.pdf as at 31 May 2016. I also note the comments of Vern Hughes, *Non-profits lose sight of volunteer heritage,* February 4, 2011, http://www.theage.com.au/it-pro/nonprofits-lose-sight-of-volunteer-heritage-20110203-1afbi.html#ixzz4ABwyiK68 as at 31 May 2016

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			needed to be something other than a major centralised bureaucracy, subsidising the same old charitable suspects.[5] However, sadly the NDIS is proving to be exactly what I hoped it would never be, though I am not surprised by the outcome. The population, as well as our politicians seem addicted to twin notions that both tax deductions and charity are good things. Forty-two years of life have convinced me that the two things are just one activity; namely, the subsidisation of someone else's choices,[6] which will have negligible impact on me if I'm lucky, but are just as likely to have a bad impact on me and my family, as a good one.
		In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner?	Personally, one cannot speak for young carers. However, I anticipate they would be more adept than other groups at using on-line environments than most others. Nonetheless, would such services be accessed? In my own family's case, we learned that you could fill out all the plans and assessments you like; many service providers aim to fit you into their employee rosters and service charters, regardless of what you originally asked for. Consequently, you live your life around

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[5] See my first submission to the *Disability Care inquiry*: http://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0055.pdf ; Second submission - http://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0186.pdf ; Third submission - http://www.pc.gov.au/inquiries/completed/disability-support/submissions/subdr0716.pdf my appearances at the Sydney public hearings were equally ineffectual at halting the NDIS juggernaut http://www.pc.gov.au/projects/inquiry/disability-support/public-hearings as at 30 May 2016

[6] This is a point I took up in a submission to the House of Representatives Economics Committee. Abolishing deductions and handing back bracket creep, amongst other reforms, would greatly simply the tax system. While recognising this would have negative impacts on subsidised activities like philanthropy, the fact that there may be negative impacts does not make the case for continued subsidisation; see http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687 and http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommrep%2F14f05a24-0aaa-4411-85e0-55723e173c59%2F0000%22 (Hansard transcript) as at 30 May 2016

	Section	Questions – Design Considerations	Responses
			their timetables and their needs, which can quickly wear on carer and care recipient alike. Under these circumstances, many people abandon support at the application stage (or don't apply at all) and, this has been well known for some time.[7] Many of the same people probably find it easier to make ends meet informally, or via the so-called 'black economy'.[8] Rather than criticising people for making such choices, it should be read as a telling comment on what is currently offered by NGOs and governments alike. Certainly, when I have met young carers a message that is loud and clear is that they often fear asking for help (either for themselves or those they care for) because records will be generated. People worry about who will end up seeing those records and, what will be done with them? The views employers may take of carers' own health information (or that of the people they care for) has often been an issue raised and, in many respects, while integrating services and using electronic records may sound efficient, many people (including me) continue to be worried about our privacy.[9] Those who have particularly sensitive

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[7] See e.g. *Match making: Using data-matching to find people missing out on government assistance,* The Australia Institute, http://www.tai.org.au/node/1839 as at 31 May 2016

[8] See e.g. Christopher Badjada, *Estimates of the Underground Economy of Australia,* Discussion Paper, UNSW, 1997, School of Economics, http://wwwdocs.fce.unsw.edu.au/economics/Research/WorkingPapers/1997_20.pdf as at 31 May 2016

[9] See for instance, my Senate submission regarding the e-health record (Senate Standing Committee on Community Affairs – *Healthcare Identifiers Bill 2010*) at http://www.aph.gov.au/DocumentStore.ashx?id=76b49657-cf71-4b9c-b340-8d95235c6fbc as at 31 May 2016

	Section	Questions – Design Considerations	Responses
			conditions (such as mental health issues) may reasonably want to keep such matters fairly private; and not seek assistance as a result.[10] Despite this, I do not think these matters should be raised in schools. The curriculum seems to have something added to it every time politicians cannot think of a better policy response. Additionally, many carers are reluctant to disclose personal details or problems. Even with the best of intentions, school-based programs may cause young carers to recoil from the education system. No-one should be forced into a care system, no matter how advantageous others (including *alleged professionals*) may think it is for them. Certainly, in my own life experience, I have recoiled from service providers who have tried to dominate either me or my mother. Neither of us takes kindly to being told how to run our lives.
2.	**Information provision**	While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?	As stated above, a Gateway or portal that was electronic would only be useful to certain demographics. Equally, also as mentioned earlier, the Gateway intervention of some organisations can be bullying and condescending. Carers and those they care for must ultimately have the final choice as to whether they want (or will act) on any information given. Personally, one has never felt the choice has truly been offered; service providers ultimately want you to conform to their recommendations because with that, *they* secure funding.
3.	**Intake**	Given this, when should intake be a mandatory process?	Intake should not be mandatory. This would become another bureaucratic hoop people have to jump through, and it would discourage many from accessing services.

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[10] See e.g. Brittany Taylor, *How e-health records could stop mental health treatment,* The Punch (2010), attached. This important article seems to have disappeared on-line

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			In this, both the NSW Baird Government and the National Disability Insurance Agency (NDIA) should be strongly criticised. To retain any disability services they are currently receiving from the Department of Ageing, Disability and Homecare (now Australian Unity Homecare), there is no choice but to go through the NDIS portal. All services have been outsourced to the NGO sector, which will be funded by the NDIA. Carers and service recipients now have to go through a new series of assessments and planning, in the knowledge that their State Government will offer absolutely nothing in terms of a publicly run 'service safety net'. Single points of entry may represent convenience for bureaucratic flowcharts, but when their use becomes a contingency for service receipt, it is objectionable. You would not expect all train or bus passengers to access transport at a single point and, carers (who will have different needs at different times) seeking services should not be expected to find (or be corralled into) a single point of entry.
4.	**Education**	Given this, how can we encourage carers to access education support?	The last thing carers have time for is another activity – they are often exhausted just getting through every day. Furthermore, in my own case, my mother is a highly educated woman and has a management role in the allied health sector. The last thing either one of us need (or want) is to be told how to "suck eggs" by a social worker.
		If education were to be offered online, how can we encourage carers to participate and complete an education programme?	See my reservations about the on-line environment, expressed earlier. These questions skim over 2 vital issues: 1. Why should any carer or care recipient be obliged to put their details on-line, with all the potential risks that entails? 2. Education, be it on-line or otherwise, requires carers to be able

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			to access respite support. With the population ageing, where are all the respite carers going to come from and, how are we going to be assured of their probity and capacity. The short answer is that this service sector already has a growing reliance on immigration, which presents challenges for domestic authorities in assessing overseas qualifications and suitability. Beyond asking who ultimately pays for this vital checking, in my view, we are missing a real opportunity; this is the option to use far mechanisation and robotics in care.[11] Such technological investment could relieve many of the heaviest and most complex aspects of care, while giving assurance to carers that the one they love would be less likely to be abused, neglected or defrauded. Mechanisation could also free some of us who are heavily dependent on our carers from a degree of our dependency; but I note that those who have obtained exo-

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[11] See e.g.: Sparrow, R., and Sparrow, L. 2006. *In the hands of machines? The future of aged care*. Minds and Machines 16: 141-161, May, http://profiles.arts.monash.edu.au/rob-sparrow/download/InTheHandsOfMachines_ForWeb.pdf; Heather Kelly, *Robots: The future of elder care?* CNN, July 19th, 2013, 03:42 PM ET, http://whatsnext.blogs.cnn.com/2013/07/19/robots-the-future-of-elder-care/; Maureen Dowd, *Silicon Valley Sharknado*, The Opinion Pages | Op-Ed Columnist, July 8, 2014, http://www.nytimes.com/2014/07/09/opinion/maureen-dowd-silicon-valley-sharknado.html?_r=0 as at 19 July 2014. From Ms Dowd's article I note, in particular: "*Vinod Khosla, the Sun Microsystems co-founder, has predicted that algorithms and machines will replace 80 percent of doctors in years to come, making medicine more data driven and less like "witchcraft."*
In a rare joint interview last week with Khosla at his Silicon Valley summit, Google founders Sergey Brin and Larry Page talked about their A.I. (Artificial Intelligence) *hopes. "You should presume that someday," Brin said, "we will be able to make machines that can reason, think and do things better than we can." They have always been interested in robots — they named their operating system Android — and are running "the brain project," described by Brin as "really machine-learning focused." In January, they acquired the British A.I. developer DeepMind, founded by Demis Hassabis, a game designer, neuroscientist and former child chess prodigy*."

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			skeletons and similar technologies have had to base themselves overseas to do it.[12]
		Given this, how can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?	Carers will be happier to access services and, have more time to do so, if they feel the one they love is secure in their absence.[13] I know, for instance, that my mother has given up many professional opportunities like conferences and appointments on accreditation committees, if the work involves overnight travel. I also avoid similar potential work or other opportunities because of the physical, financial and emotional costs to both me and Mum. In the end, no amount of education will make up for the difficulties in obtaining practical support. And, if you wish to travel for any reason, this will more than likely mean a long-winded application process for additional or transferable supports which may or may not be approved. You certainly do not book tickets, hotels suites or anything else, with support approvals pending. As such, spontaneity is not something my mother or I know much about. If Mum and I need to travel, at this stage, we do it ourselves. There will come a time when neither of us can manage that on our own. I have no

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[12] See for example, the webpage of Australian paraplegic speaker and campaigner Amanda Boxtel, now based in the US and Canada, with her walking machine: http://www.amandaboxtel.com/index.html as at 20 July 2014; also see e.g.: News - *This exoskeleton has been approved for personal use,* ScienceAlert Staff, Tuesday, 01 July 2014, http://www.sciencealert.com.au/news/20140107-25786.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencealert-latestnews+%28ScienceAlert-Latest+Stories%29 as at 20 July 2014. I tried raising these issues with the McClure Welfare Review, seemingly with little success (see Welfare Review, attached)

[13] In my view, no system yet designed can achieve this; see my submission to the NDIS Safety and Quality Framework at https://engage.dss.gov.au/ndis-qsf-submissions/1430713127-2/ as at 3 June 2016

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			clear idea of how we will cope then.
5.	**Peer Support**	Given this, how can a peer support model be designed which encourage carers to participate and remain engaged?	I don't think this need has to be formalised. We have some close friends who have known us all our lives. The common link was a child with disabilities. We know we can call on each other in emergencies which is far easier (and faster) than calling a formal service provider.
		Should peer support be a service able to be accessed without pre-conditions or structure processes	Yes, see prior answer
	Needs Identification and Planning	To what extent do you think goal based planning should be used at the assessment stage of the process?	Must we go down this route? There is already a lot of planning paperwork in the NDIS, as an example. How much of this is valuable is highly debateable. Life is uncertain by its very nature and, the further ahead in time one tries to plan, the more riddled with assumptions and inaccuracies any plan becomes. Nonetheless, bureaucracies like plans as they allow managers to tick boxes, while offering a false sense of security that the words on the page may still mean something in 12 months; often they will not. On an individual level, one does wonder why my family and I have to disclose a multitude of details to multiple bodies, for access to the simplest of services.[14] And, it needs to be acknowledged that conducting all these assessments, means-tests and writing plans comes at a significant cost in time and money for all concerned. If this was subject to a cost/benefit analysis, would it pass muster? On many

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[14] I have been concern about the degree of intervention by state and NGOs alike for a long time. See generally, my submission to Father Frank Brennan's Human Rights Inquiry for the Gillard Government at http://www.ncoa.gov.au/docs/submission-adj-consultancy-services-appendix-1.pdf as at 2 June 2016

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			occasions, I do not think so.
		Goal based assessment and planning approaches are common to Consumer Directed Care principles, usually in conjunction with a funded package or financial allocation of some form. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?	Do these funding models work? When I read the *Rethink Tax Discussion Paper,* the relevant observations in my submission were: There are also several notable observations coming out of the *Rethink* Discussion Paper, which deserve serious consideration at this point. If we ended (tax) expenditures, perhaps we could afford to index the tax thresholds.[15] Given my doubts about superannuation, I'd also support a flat tax for social welfare spending.[16] Furthermore, your discussion paper also acknowledges that the Australian tax system has what you call a 'tax wedge'. And this is worsened by targeted assistance for families, whereas "countries with lower tax wedge progression have flatter tax schedules (and yet) some European countries…have universal payments for families with children".[17] In my view, Australian needs to flatten and simplify its tax rates, if we want to be more competitive *and* have an improving

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[15] See The Treasury, *Rethink,* Commonwealth of Australia, 2015, p.37 [44 of 203]

[16] See ibid, p.30. A flat rate social welfare levy may be preferable to the superannuation system (and carers' payments); at least when it is public money, the Parliament is clearly and directly accountable. The same accountability cannot be said to exist in many superannuation funds, or self-directed care/NGO funding.

[17] Ibid

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			standard of living. *Rethink* put the evidence from Europe in front of us, but are we prepared to act?[18] All of this would suggest that targeted spending generates as many problems as it solves. Therefore, it is hard to see how another targeted spending program, be it for carers (or those they care for) will do anything but add to these issues.
		To what extent should self-assessment form part of the future model?	As stated above, you can do as many self-assessments or other reviews as you like, but will any of it be seriously considered? In my case, Mum and I decided to (briefly) look into downsizing and retirement living. We were quickly told that as we were not a married couple and as I was not over 55, local providers would not support us. Equally, to our surprise, while there were communal common, dining and library spaces, on site nursing/personal care was not offered; we would have to arrange (and fund) that ourselves. And, in any event, Mum would be the only one accepted, so we reworked all our plans around staying in the family home indefinitely. It is to be wondered why retirement villages were given a range of development/planning dispensations and were sold as "housing choice". In my experience, the large NGOs who run many of these villages are happy to give you a sales pitch until you raise complex health needs, or make any non-standard requests. While the villages are also legally required to make a percentage of their villas physically accessible to those with disabilities, that appears to be the limit of their

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[18] Taken from my *Rethink* submission, attached

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			interest in exploring markets beyond the atypical over 55's.
7.	**A multicomponent intervention**	Given that this model is seeking to apply preventative thinking, how can we ensure these supports are allocated to those carers who will benefit the most from them? What should be the criteria by which this is determined?	The first question that should be asked is how much will any preventative strategies cost? Add the additional cost of bureaucratic assessment processes and, you have seriously diluted any positive impact. Finally, the case for prevention is not as conclusive as you might think; the cited paper from the Centre for Independent Studies provides an interesting perspective.[19]
7.a	**Multi-component Support: Financial Support**	How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?	As stated in my *Rethink* submission, my preference would be for a flat general tax to supply funds. Making funds client or carer-directed is, in my view, an indefensible cost-shift by government to leave individuals and families with a great accounting headache.
7.b	**Multi-component Support: Carer Mentoring**	When would a coaching programme be most effective for a carer?	In many respects, carers would not need coaching or mentoring had not governments and NGOs virtually conspired to ensure families were left with program administration and financial reconciliation duties, in the name of self-directed care. Carers should be able to take coaching money to pay their accountant and lawyer to manage program administration issues.
		Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors be able to	I am broadly against mandating anything. As stated previously, carers have enough to do already.

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[19] See generally, Helen Andrews, *An Ounce of Prevention? A Toolkit for Evaluating Preventive Health Measures,* November 2014, CIS Monograph, https://www.cis.org.au/product/an-ounce-of-prevention-a-toolkit-for-evaluating-preventive-health-measures as at 3 June 2016. I acknowledge that I am a member of the Centre for Independent Studies.

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		determine whether the carer has the capacity to forgo coaching until another time?	
7.c	**Multi-component Support: Respite support service**	What might these be and how can they be mitigated?	The *Discussion Paper* makes a salient point about the lack of effective evidence for respite, though anecdotally it is seen as useful.[20] What is never talked about is respite from the burden of disability and chronic illness itself. If carers are saving the nation billions of dollars, why isn't this money being ploughed into the primary medical research that could cure the diseases which afflict those being cared for[21] and, conscript many a carer into a role they never planned to hold?
8.	**Counselling**	What other counselling programmes and techniques would be beneficial in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?	On one level, counselling is another "thing" for carers to do when there are already enough things going on. It would be very much a case of personal choice and taste as to whether these services would be accessed. Many carers do not want to divulge their personal struggles to strangers, nor even people they know. Again, as stated earlier, carers also refrain from seeking help, fearing adverse consequences for employment opportunities, amongst other concerns for their privacy.

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[20] See Department of Human Services, *Designing the new integrated carer support service: Discussion Paper,* Commonwealth of Australia, 2016, Page 40 of 72

[21] I have been a long term advocate of stem cell research and related regenerative medicine; see Stem Cells Australia, *Stem Cells in the Hunter Valley, Stem Cells in the Hunter Valley, 20 November 2015* at http://www.stemcellsaustralia.edu.au/News---Events/News/Stem-Cells-in-the-Hunter-Valley.aspx and http://asscrss3.asnevents.com.au/assets/Uploads/Program-and-posters.pdf; and https://www.linkedin.com/pulse/business-stem-cells-australia-daniella-goldberg as at 5 June 2016