



Purple Orange

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Naming values, and the values of names?

This article first appeared in the Purple Orange blog on Wednesday 27 March. Click [here](#) to visit.

Being immersed in two projects funded by the NDIS Practical Design Fund, it has been harder than usual to keep up with the rapidly developing NDIS scene. However, the recent government announcement that the NDIS will be known as DisabilityCare Australia warrants a response, however late.

The announcement seems to have come as a surprise to many, including us, though we have been told the disability sector peak bodies were briefed on the process and given the opportunity to comment.

It is no surprise that some people might see the upside of a word like “care”. At its broadest level it carries meaning about compassion, about connection, and who doesn’t want some of that in their lives. The British media yesterday reported the UK government’s response to a public inquiry about health, concluding that the National Health Service needs more compassionate care. I can entirely see how a comparable sentiment may have brought the word “care” to the list of possible names for the NDIS.

But this is a word that has layers of meaning, making it a problematic choice for the scheme’s name. And I encourage people not to make the mistake of assuming that name selection is a minor issue, a sideshow that has little consequence given the other important considerations about the scheme’s

design and implementation. The name is a brand, intended to convey the values of the scheme. As such it is the first and most telling signal of the scheme's culture. More on this later.

The difficulty of using the word "care" is well summed up in the following excerpt from Craig Wallace's opinion piece on the ABC's Ramp Up:

"Instead of choosing a name that speaks to a new world, of rights, choice, inclusion and control, with people at the centre, we have a moniker that puts people with disability to one side - as people to be cared for. It spells more of the same."

Hitting a similar vein, the National Council on Intellectual Disability posed the question, "Where is the language of the UN Convention on the Rights of Persons with Disabilities?"

Further, one Facebook contributor to the debate suggested the only way the use of the word care could be less unacceptable would be if it were applied to every Commonwealth Government department, for example the Department of Infrastructure and Transport Care, the Department of Prime Minister and Cabinet Care, the Department of Foreign Affairs and Trade Care etc.

In its defence, the Commonwealth Government might argue the name DisabilityCare Australia was a good fit with existing public funding brands like Medicare. Understandable, then, that the government might wish to build a brand stable. However, there remains the question on whether it is the right name for its target beneficiaries – people within the disability community.

In this regard, and in addition to consulting with disability peak bodies, we understand the government commissioned a series of focus groups comprising people living with disability and their families from a range of communities around Australia, and that there was good support for the name DisabilityCare Australia.

If this was the clincher (and it would have to, because the "brand stable" argument isn't enough by itself to justify the adoption of this tricky word "care"), we might seek to deepen our understanding as to the nature of the focus group participants. One might reasonably assume the focus group membership was derived using sampling techniques typical of market research companies, so that the focus groups bring a range of perspectives typical of Australia's disability community.

If true, fair enough, but focus groups are typically small so there are limits on what a focus group can tell you about trends across a broader population, especially the complex, multi-layered population called the disability community. But let's just stay a little longer with the focus group issue.

I don't know the focus group research agency's identity so I am drawn to this next question: what did that agency truly understand about disability community demographics? It may have known enough to look for focus group participants with, among other things, perspectives covering person and family, metropolitan, regional and rural Australia, and the differing causes or types of disability. But this isn't enough. However small or large the consultation, a demographic we cannot afford to overlook is the range of experiences that different people have in accessing support. What I mean by this is there are people within the disability community who have had differing types of experience with the disability service system. This includes people who have been "done to" by the system, rendered passive service recipients, neglected or worse, and where the notion of care has become synonymous with an absence of control and choice, of being mis-served by paid carers who don't.

It is not unusual to find that this particular demographic of painful service experience comprises people with greater degrees of disability and vulnerability, with less voice heard. These are the people who arguably have the greatest moral stake in the new system, because they are often the most distant from good life chances. These are the people we might hope can make the greatest advances in their life chances as a result of the changes.

If this is true, and I believe it to be, then because of the damage done in its name to some of those with the greatest stake in the success of the new system, the word "care" should not have made the long-list of naming options, let alone the focus group shortlist, let alone being anointed as the chosen one.

The NDIS reflects a set of values the government wishes to advance and uphold; values around control, choice, participation in community life and participation in the economy. For values to truly come alive in any field of human endeavour, every decision and every action needs to be coherent and consistent with those values. Otherwise, the values will die the death of a thousand cuts, where a sequence of misaligned decisions and actions, however well-intentioned, serve to wound the intended values-based culture.

Ultimately, the success of the NDIS hinges on its capacity to live out the stated values, to express a values-based culture that advances people's chances of a good life. Every decision and action taken will either contribute to, or undermine, the emergence of that values-based culture. Choosing a new name for the scheme is one such decision. Because of the complex and diverse perceptions of the word "care", including for some people a profound negative emotional weight, it doesn't present itself as an obvious choice to encompass the scheme and its values, and I don't think the prospects are good for its rehabilitation.

I remain hopeful that the government – indeed the various governments including bipartisan support – truly wish to see a paradigm shift in the way people living with disability are supported, in line with our nation's commitment to the UN Convention and the values underpinning it. If so, choosing a name for the NDIS warrants further reflection, in the hope that a different name emerges that better captures the values we want the new system to live by.

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Contact the New Minister and Shadow Minister

Earlier this year the State Government and opposition announced changes to their cabinets.

Labor's Jay Weatherill announced MP Tony Piccolo would take on the role of Minister for Communities and Social Inclusion, Social Housing, Disabilities, Youth and Volunteers. A few weeks later, the then newly appointed Opposition Leader Steven Marshall announced MP Dr Duncan McFetridge would be the new Shadow Minister for Communities & Social Inclusion, Volunteers, Disabilities, Social Housing, Youth, Mental Health & Substance Abuse and Suicide Prevention.

The Minister and Shadow Minister can be contacted via the details below with any ideas and concerns you have about the disability community, especially given the changes currently being explored in disability support and individualised funding.

For more information about Tony Piccolo you can visit his website at www.tonypiccolo.org. His site includes links to his blog, mailing list subscription and upcoming events. Alternatively, you can contact Mr Piccolo via the details below:

Address: Light Electorate Office, 148 Murray Street, Gawler, SA, 5118

Telephone: (08) 8522 2878

Fax: (08) 8523 1392

Email: light@parliament.sa.gov.au

For more information about Duncan McFetridge you can visit his website at www.duncanmcfetridge.com. His site includes links to his newsletter, Blog and Facebook page. Alternatively, you can contact Dr McFetridge via the details below:

Address: 4 Byron Street, Glenelg, SA, 5045

Telephone: (08) 8294 6711

Fax: (08) 8294 9712

Email: Morphett@parliament.sa.gov.au

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JFA Purple Orange Workshops

JFA Purple Orange is holding a series of workshops in Adelaide from May through July. The workshops explore how people living with disability can move towards a good life, especially given the changes to how disability support is funded.

All workshops will be held from 1:00pm—3:30pm at Our Space, 104 Greenhill Road, Unley, Adelaide. The workshops are free to attend (cancellation policy applies) and refreshments will be provided.

These workshops are for people living with disability and their families who are able to engage in an ordinary workshop format. A separate workshop will be held in September for people who may need extra help with learning. Contact us for details.

[CLICK HERE](#) to visit our website and download a flyer and registration form.

The SA Government Department for Community and Social Inclusion has contributed funds toward this program.

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Values Based Leadership Development Workshops

This is the first of two projects funded by the NDIS Practical Design Fund. It involves a two-day workshop for service agency staff, run in each of the five NDIS launch sites – Tasmania, Barwon, South Australia, Hunter and ACT. We felt this workshop was important because values are essential to the way service agencies connect with people living with disability and their families.

The workshop is intended to serve as a 'primer', equipping participants with a set of ideas about the different ways that values need to be seen in the ways agencies undertake their work. The material includes the development of a set of questions participants can take back to their agencies to get a conversation going about the values that currently drive the agency's work, and how it might strengthen key values in practice.

All five events were fully booked with waiting lists, suggesting this topic feels important to agencies. After the final event next week in Canberra, we will be reviewing the program, including participant feedback, in readiness for a report to Government.

This project is guided by a Steering Group comprising a range of perspectives including people living with disability, family, and service agencies.

This project is independently managed by JFA Purple Orange and funded by a grant from the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. The opinions, comments and/or analysis expressed in this document are those of the author or authors and do not necessarily represent the views of the Minister for Disability Reform and cannot be taken in any way as expressions of government policy.

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e-Market Consultations

This is the second of two projects funded by the NDIS Practical Design Fund. It involves a series of consultations around Australia, exploring how an e-Market (similar for example to eBay, TripAdvisor, Gumtree and Amazon) could provide an opportunity for people to find information about products and services relevant to people living with disability.

We are running a total of [how many] consultations around Australia, with over [how many] registering to attend. Most of these consultations have been completed, with the final events running next week in Darwin and Canberra:

- Darwin, 8 April, National Disability Services NT Conference Room, Level 2, 43 Cavenagh Street, 10:00am-11:30am
- Canberra, 12 April, Nature Conservation House, 153 Emu Bank, Belconnen, Burrai Room, 12:15pm-1:45pm

Flyers and registrations forms are available [HERE](#).

If you can't get to these events, you can have your say via our online survey [HERE](#).

So far contributors have included people living with disability, families, service agencies, government officers, IT professionals, academia and others, raising a range of opportunities and issues.

All the feedback then goes to our Co-Design Group who will be centrally involved in developing a report to Government, detailing what people would want from an online platform, together with any practical issues. This group includes people living with disability and service providers.

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Riverland Disability & Ageing Expo

Last month JFA Purple Orange participated in the DIRC 2013 Riverland Disability and Ageing Expo held at Barmera.

The expo provided a valuable opportunity to chat with people living with disability and their families about some of our key projects and initiatives including:

- the Julia Farr Youth Mentoring Program - an innovative program in which a group of young adults living with disability mentor children and adolescents also living with disability.
- our workshop program tailored towards people living with disability
- the Julia Farr Housing Association.

Contact us on admin@purpleorange.org.au if you would like information about any of the above projects and initiatives.

The day was a success with many people visiting our stall. Thank you to everyone who visited us.

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Connect with us

Did you know JFA Purple Orange has a Facebook page? You can connect with us online at www.facebook.com/JFAPurpleOrange. Our page is a hot spot for news, events and information about issues relevant to people living with disability, their families, support networks and the wider community.

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We value your feedback!

At JFA Purple Orange we are working hard to make our communications as accessible as possible. If you have trouble accessing any part of this e-newsletter please contact our Information and Communications Officer Susan Peterson at susanp@purpleorange.org.au, phone (08) 8373 8333 or call 1300 857 327 (cost of a local call from most phones). Additional information

on the work of Purple Orange can be found on our website www.purpleorange.org.au, and in Robbi's [Purple Orange blog](#).

Please [CLICK HERE](#) to unsubscribe from the JFA Purple Orange e-mailing list.