Submission to the Productivity Commission Inquiry into the Longterm Care and Support Needs of People with Disabilities – by Vela Microboards Australia

We are cautiously optimistic about the opportunity for changes to the long term care and support arrangements for people whose lives are affected by disability-related challenges that may flow from the present Inquiry. We are optimistic because we deliberately and consciously choose to believe that our family members and friends can and will have fulfilling, meaningful lives grounded in rich, reciprocal relationships that enable them to make positive contributions to the communities and societies to which they belong. But we are also cautious because our individual and collective personal experiences remind us that achieving systemic change of any significance is ALWAYS much more difficult than it seems. Finding the right words to express the intention and desire behind a new system is but a fraction of the work needed to implement and run it successfully. If an NDIS simply delivers more capacity within what is essentially something similar to the current system, little will be gained and a great opportunity will be lost.

In making this submission to the Inquiry, we want to share some of our collective learning from the past four years of working and learning together in largely voluntary capacities. *Vela Microboards Australia* is a family-led initiative auspiced by Perth Home Care Services Inc that is bringing a proven Canadian approach to Australia. A Microboard is a small (micro) incorporated non-profit community organisation (board) that forms around one individual who has disability-related challenges. The intent of a microboard is to help create and ensure that the person at the centre of the microboard lives a good and meaningful life grounded in reciprocal relationships characterised by making many decisions for themselves.

Microboards first emerged in Manitoba in the mid-1980s and have since found their most enduring and systemic expression in British Columbia where over 600 microboards now exist. There are also microboards in other Canadian provinces, in the USA, in Ireland and in England. In Australia, we describe ourselves as ‘a community of learning and practice’. We have deliberately taken a slow and considered approach to starting microboards here. We are committed to ensuring that what we create is significantly different to options and approaches that are currently available in the disability sector, and that it will endure for the long term. We have also consciously chosen to include families and individuals from regional WA in the inaugural group because the Canadian experience shows us that microboards can work in regional areas ALTHOUGH there are significant challenges associated with establishing them and making them work in less populated areas.

Because each microboard exists for the benefit of a single individual based on reciprocal relationships, this approach is a truly person-centred approach that deserves to get some significant profile, consideration and support in any revamped disability system. We assume that all individuals – no matter what level or type of disability may affect them – are capable of exercising self-determination in both large and small decisions in their lives. Over the past four years, we have collected evidence that supports this assumption from our own work and experience. We have learned that the vast majority of service agencies do not share this assumption in how they work and in fact they find it very difficult to accommodate individuals whose families and friends attempt to relate and work from this assumption. Despite this, we remain committed to this approach as a way that truly respects and acknowledges the full humanity of all individuals and enables them to exercise self-determination in ways that are highly consistent with the UN Convention on the Rights of Individuals with Disabilities.

We have also learned that bringing positives changes to individuals and their families is a gradual process of challenging and surfacing operating assumptions and ways of thinking which is best facilitated by family members and individuals who 'walk the talk' of self-determination and reciprocal relationships. This will require changes to the current system which systematically preferences 'professionals' employed by agencies and arms of government over and above the knowledge, experience and learning of individuals and families.

In Australian society, stories about disability are typically anchored in a 'tragic story' narrative. This is the dominant disability narrative whether such stories are shared in sector forums, around kitchen tables, in support groups or through media representations. In our experience it is a narrative that unwittingly and unintentionally marginalises individuals with disabilities and contributes to dehumanising them. Typical representations of this dehumanising are evident in behaviours such as speaking about the person in their presence as if they are not present; making decisions without consulting or asking the person in a way that they may understand and/or respond to; treating gestures and vocalisations as random and devoid of meaning; and running 'community tourism' programs that occupy people with disabilities without enabling any meaningful community or relationship engagement for the people involved. The tragic narrative and its associated assumptions do not serve individuals or their families well, but are difficult to shift. In our experience to date, gentle and caring mentoring of families by other families in relationship with them is proving to be the most successful way of helping to change such attitudes and assumptions. Few senior managers in the government sector or service providers seem to appreciate the difficulties associated with effecting such changes or the time, resources and support needed for such changes to occur. Quick fixes and fast changes are routinely expected despite their repeated failure to deliver.

It may be helpful to provide a positive example of what we have learned and how this demonstrates both the need and opportunity to do things differently. Some of people with whom we are working to create microboards are individuals who are typically labelled 'non-verbal' (among other things) due to their lack of verbal communication skills and capacity. We have learned that such people are in fact very good communicators and we have adopted the term 'uniquely verbal' to recognise this. They each have their own unique language consisting mostly of vocalisations, gestures, signs, pictures, facial expressions, and eye, limb and body movements. With each of the uniquely verbal individuals with whom we are working, we have recognised their unique languages and we have intentionally engaged in learning their languages. In each case (without exception) this has created profound shifts in our thinking, in our relationships with them, in the balance of power between them and those of us with verbal capacity, in their capacity to make decisions for themselves and in their ability to attract and make friends with other people their own ages. As with learning any language, this takes time, conscious and intentional work and comprises many mistakes along the way. It is difficult to speed up the process, yet it is fundamental to any person-centred approach or any attempt to increase the opportunities for people with disabilities to be more self-determining in their own lives.

The current Inquiry offers a remarkable opportunity to address and change the systemic marginalisation of people with disabilities – especially those with developmental and/or communication-related disabilities. It offers an opportunity to recast the dominant disability narrative as a more hopeful and positive story. It offers an opportunity to contribute to Australia becoming and being a society which places a much higher value on care – with the care of people with disability-related needs being simply one facet of the much broader change in attitude towards care that this country desperately needs. Creating an NDIS system which preferences and relies on professional and paid support over and above supporting grassroots community-building initiatives that incorporate care will create a system that will not stand up to the rigours of foreseeable future challenges – most notably the supply of affordable staff in paid roles (even leaving considerations of the quality of such staff aside). Any cursory examination of human resource projections in human services industries provides sufficient evidence of this as a coming reality. Finding ways to support and value caring within communities – both financially and in other ways – is a critical future need that this Inquiry's recommendations can positively influence.

The premise behind national equity in services described in the draft report is positive and some of the options where an individual and/or family can create a personal plan and self-manage their supports sound great. We are aware, however, that in regional centres the opportunities for real choice are often more limited than the options available in bigger cities – whether the choices are for self-managed or agency managed options. In many cases it may look like there are several choices, but the reality is that this is often not the case in regional, rural and remote areas, especially when the quality of services is considered. It is evident is that when agencies attempt to stay person centred and be responsive in the way they work with clients with disabilities, they tend to be deliberately smaller and very intentional in the way they work. In regional centres such as Albany and the lower great southern region of WA, the economic viability of agencies is heavily reliant on numbers of clients, a factor which creates only a limited number of agencies that are accredited DSC providers. This again limits the choices available to individuals and families wanting services, and we wonder how an NDIS or similar system would address this issue. If there is to be a federal NDIS bureaucracy similar in size to Centrelink or Medicare, it is difficult to see how it could be responsive and personally focused when these features are not currently available in the WA state system, despite the WA sector being widely acknowledged as one of the better systems in Australia.

Recognition of other workplace issues is critical to the sustainability of care and it is pleasing that this is being looked at in some detail. One comment in the draft report is: ". . . one of the most important services is relatively straightforward personal support in which empathy and responsiveness of the carer is the most important feature." Anyone who has been on the receiving end of "personal support" would not describe their typical experience as characterised by the "empathy and responsiveness of the carer". A great deal of intention is required to provide personal care and support in such a way. Personal support done well does not have to be bound in systemic complexity but supporting another human being respectfully and skilfully can be complex. We certainly have concerns about a large and bureaucratic system having the capacity to maintain any kind of quality control over variables such as support workers, agency practices, working relationships between different government departments such as Health and the disability sector, Mental health and the disability sector etc. The present state based system struggles with this at the ground level. Monitoring standards and practices is a rigid and inadequate means of ensuring quality now and we wonder how this will be done more effectively in a federal NDIS system. Ultimately a significant shift of real power to individuals and their families is probably the best means of instituting quality control. Individuals in receipt of the support need to be empowered in this regard.

The flexibility around self-management sounds really good but without specifics it is an opinion based on a general idea. The devil will be in the detail as always.

Another issue with a national body concerns the capacity for innovative and alternative approaches to supporting a person with a disability to be considered, piloted or trailed. Such initiatives (Vela Microboards Australia is one example) are necessary to move the sector from a predominantly medical model of care to a more socially-based self-determining style of support for individuals. This is a very big shift that as we have detailed, is not widely practised at this time. We fear that a national approach may potentially create additional layers and political machinations which could make this more difficult than it is currently.

Finally, while we agree that direct funding options are likely to be a positive element in an NDIS model of support, we are aware that direct funding has not been a panacea in other parts of the world. The challenges of finding, paying and managing support staff are often considerable and may be beyond the capacity of many individuals and families. It is imperative therefore, that direct funding options exist alongside, and are congruent with, agency-based and 'shared management' arrangements that give greater control and autonomy to those in receipt of services.

Vela Microboards Australia
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