A lost opportunity...? Disability, the NDIS and lots of couldabeens...

DIMENSIONS OF COMMUNITY DEVELOPMENT

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Our Consumer Place is Australia's Mental Health Resource Centre run entirely by people diagnosed with 'mental illness'

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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A LOST OPPORTUNITY…?

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As so often, without fear or favour, Leunig asks the right question, usually without asking them… The April 2020 graphic of his wall-calendar has a rather imposing bill-board in a bare desert-like landscape with one single flower and a startled Mr Curly barefooted and as per-usual in confusion trying to understand the message:

WARNING!
THIS IS AN INCLUSIVE SOCIETY!
AND IF WE FEEL YOU ARE
TALKING, THINKING OR BEHAVING
IN A NON-INCLUSIVE WAY
YOU WILL BE
EXCLUDED!

A few decades earlier, in Barbara Kingsolver's in so many ways insightful *Poisonwood Bible* (1998:559), there's the previously 'cripple' daughter Adah of the Price missionary family in Congo, who had been healed from the physical and mental symptoms of hemiplegia when in her early twenties, reflecting on suddenly not being disabled any more… and regret the lost gifts of her 'dis'-ability, or what she understood as her 'different' ability:

> *Don't we have a cheerful, simple morality here in Western Civilization: expect perfection, and revile the missed mark! Adah, the Poor Thing, hemiplegious egregious besiege us. Recently it has been decided, grudgingly, that dark skin or lameness may not be entirely one's* ***fault,*** *but one still ought to show the good manners to act ashamed. When Jesus cured those crippled beggars, didn't they always get up and dance off the stage, jabbing their canes sideways and waggling their top hats? Hooray, all better now, hooray!*
> *If you are whole, you will argue: Why wouldn't they rejoice? Don't the poor miserable buggers all want to be like me?*
> *Not necessarily, no. The arrogance of the able-bodied is staggering. Yes, maybe we'd like to be able to get places quickly, and carry things in both hands, but only because we have to keep up with the rest of you… We would rather be just like us, and have that be all right.*

As well, in a previous *'New Community'* journal issue on *Community and Inclusion* (2018; Vol. 16(4)), apart from looking at how communities and organisations could become more *'inclusive,'* i[1] rather rhetorically asked what it would take communities and organisations to become more *'worth being included into'*…? Shocking as that question may sound, joining Kingsolver's Adah in an honest reflection on the lack of 'sociality' in our culture and the pursuit of perfection, the 'power of one', competition and the continuing drift to self-centredness, individualism and their rather rampantly spreading and worsening bedfellows of loneliness, anxiety and worse forms of mental discomfort, certainly justify asking that question, I think…

The experiences of and reactions to the recent bushfires and floods especially in Eastern Australia and – as i write – to the Coronavirus' rapidly spreading pandemic really don't require us to wonder *again* how the loss of community and of our sense of reciprocity and of the 'commons' came about and what the forces were and are that cause(d) it… The scenes at supermarkets – toilet rolls, for heaven's sake! - and beaches – several thousand people gathering at Bondi Beach in spite of repeated warnings to keep gatherings of humans to less than 500 and stay about 2 metres from one another – just abundantly confirm that and explain why people – probably? – just don't 'get' what ***'social distancing'*** really means in a culture of *'organised egoism'* and that has lost a real and proper sense of 'sociality'.

However, that's the social background against which the *National Disability Insurance Scheme* – the NDIS – came into being… an individualised/personalised 'case-centred' insurance system (rather than a 'social' insurance system), which –

- correctly – assumes that the systems of 'primary sociality' (families – nuclear or extended - and neighbourhoods, for example) can't do the proper caring and support of the young and the old anymore (the reasons for this have been abundantly researched, commented on and both deplored and welcomed and mostly regarded as a sign of modernity if not 'progress');
- and then – incorrectly, i think – 'knee-jerks' its response as an individualised market-based 'service-delivery' system to provide access to such care and provision of what's needed… That's a lot to say in a nutshell, but this is not a publication which intends to unravel the intricacies of the social processes occurred during the last few centuries… So i have to limit myself to the above hopefully illustrative and suggestive - and hopefully not insulting to anyone - remarks

Before further deepening this out, however, and whilst i am still mourning the loss of one of my favourite writers, Toni Morrison, who died about a year ago, let me share one of the most penetrating statements from her Nobel Prize Lecture in 1993, about the power of language and how it contributes to exclusion and oppression…

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[1] Readers will notice that – except at the start of a sentence and in quotes - i resist the capitalisation of the first personal pronoun - the 'perpendicular pronoun' – in recognition of the rather pretentious and simply wrong cultural assumptions in western writing about the centrality of the speaking, writing or thinking author/subject – or more generally, of the individual person – in the entirety of the living and changing context and the complexity of the interconnections s-he reports on.

> *"Oppressive language does more than represent violence; it is violence; does more than represent the limits of knowledge; it limits knowledge. Whether it is obscuring state language or the faux-language of mindless media; whether it is the proud but calcified language of the academy or the commodity driven language of science; whether it is the malign language of law-without-ethics, or language designed for the estrangement of minorities, hiding its racist plunder in its literary cheek — it must be rejected, altered and exposed. It is the language that drinks blood, laps vulnerabilities, tucks its fascist boots under crinolines of respectability and patriotism as it moves relentlessly toward the bottom line and the bottomed-out mind. Sexist language, racist language, theistic language — all are typical of the policing languages of mastery, and cannot, do not permit new knowledge or encourage the mutual exchange of ideas."*

Just add 'ableist' language to Toni Morrison's list and we may start to wonder about our Australian government's repeated rejections of an increase in Newstart payments using the infamous words of *'unfunded empathy'* to justify it … After all, the government had assured us during the election campaign that *'those who have a go will get a go'* and that getting a job was the best way to get off that dreadfully misnamed 'Newstart' program; tell that to anyone between 55 – 65, the largest group of people on that program … 'how good' would it be to offer them a 'new start' rather than a kick in the backside? Add to this that one of the government ministers happily re-iterated former conservative PM Howard's similar misnomer of *'mutual obligation'* to justify the increasingly harsh exclusionary welfare regime we have in this country … But since some government members quite often refer to the 'miracles' which come to them and their family, we should probably just keep our faith in all the goodness which will befall us all … and forget the *Robodebt* disasters at Centrelink (continuing as i write during the Coronavirus pandemic) as well as the 'performance indicators' imposed on staff enforcing compliance onto Newstart recipients… and the mess that is NDIS… (See respectively https://www.smh.com.au/national/this-is-incompetence-families-out-of-pocket-after-centrelink-glitch-20190806-p52eis.html and https://twitter.com/9NewsAUS/status/1159745026429050880).

All of this establishes the discursive platform for this succinct examination of the NDIS first few years of implementation… what is the intended and not-intended impact of the implementation of the NDIS on people with disability, their carers and their (and our) communities? So my concern here is both to inquire about how the individual NDIS 'participants' (and their carers) are faring as well as their 'collectivity', all people with disability, the institutions who continue to be part of the disability care landscape and the overall 'system' of welfare and care on a policy and political level. In brief, the stuff at the core of *community development* concerns for almost ever and central to those of Our Consumer Place since its inception.

A good start is offered by Greg Jericho; he titled one of his recent pieces in the Guardian (Sunday 28/07/2019) ***'Ahh yes, privatising Medicare. Welcome back.'*** He refers to the (barely hidden and then denied) attempts a few years ago by the conservative Coalition government to 'attack' Medicare and force people onto private health care insurance (accusations of that just being a Labor Party 'scare-campaign' notwithstanding; the 'pub-test' for *deniability* has been made a lot easier by the emergence of 'fake news'). Pronouncements by the managing director of private health insurer NIB, Mark Fitzgibbon and meanwhile several other from that same corner, to do away with it entirely chip quite a bit away from that 'deniability', however. Here's an excerpt from Jericho's article:

> Is there any policy issue that the business sector doesn't believe can be solved by privatisation? Especially when that privatisation will most benefit the business run by the person promoting it?
>
> There actually has already been a ***recent quasi-privatising of the health system.*** The NDIS saw the end of the very good care people received from public health groups such as TherapyACT and a switch to having to find private therapists (often those who had worked for organisations like TherapyACT) who are then paid through the NDIS.
>
> I am sure many have benefited from the NDIS, but I have not found too many benefits that would not have been as efficiently delivered by just providing the public health sector with the extra money that now goes into the NDIS.
>
> ***But this is the heart of the argument – the belief that the private sector delivers things better. And yet we know this is a belief better observed in economic textbooks from the 1980s than from reality. The US's largely privatised health system is inefficient and so disgracefully costly that sickness in the US is almost a synonym for bankruptcy.***
>
> We know the current government is committed to reducing expenditure and this of course will have to hit the health system. I suspect this will manifest itself in a push for more NDIS style *"voucher systems"* which is essentially a ***privatisation by stealth and for ever-more "incentives" for people to join private health insurance.***

Couldn't have said it better and more clearly…

So let's walk back a bit and look at the NDIS story so far… My own (and Borderlands') participation in the antecedents of the NDIS occurred through our evaluation of a Victorian pilot project, testing the possibility to make 'Direct Payments' of Disability Benefits to their recipients rather than through the few large existing Disability Agencies. The proposed 'method' for such payments was as follows:

> The model of Direct Payments developed for the trial has the key elements of:
>
> - planning - developing a plan for approval of funds;
> - an agreement about the purpose of the funds and the amount of funds (agreed plan);
> - transfer of the funds;
> - purchases of services and supports;
> - accountability for the funds used; and
> - review.

The pilot ran from 2006/7 under the Labor governments of Bracks/Brumby – certainly not averse to privatisation, private-public partnerships and a stubborn belief that all of this is commensurable with a 'social' conception of welfare and wellbeing - and conclusions from the initial consultation phase involving a group including people with disability, carers and Victorian State Disability Services workers were as follows:

Some of the views of the DPCG (Direct Payments Consultants Group):

- This is an example of acting under best practice.
- It is good to see the Victorian State Disability Plan 2002-2012Plan being implemented.
- This project is likely to make people more independent and it meets all State Plan goals.
- Direct payments have great potential to change the lives of people with a disability as has happened in the United Kingdom with 8% of people using direct payments subsequently entering the workforce.

Some of the typical and central elements – and the weasel-words - of welfare systems under neo-liberalism can be detected; there's talk about *'best practice'* (as if there ever can be a universal 'best' practice…); State *Plans* and individual *plans* (as if 'plans' will eliminate all possible uncertainties and insecurities and if they are done 'individually,' that responds to the necessary 'respect' for people's willingness and obligation to plan for their individual future); the seemingly unquestioned need and desire for *'independence'* (rather than a commitment to sustainable and more realistic *'interdependence'*; people entering the workforce as an unquestioned *'good thing'* (the unshakeable belief that 'paid work' will be the activity everyone is aiming at and – given the 'work ethic' is expected to aim at for achieving a worthwhile life trajectory); accountability/compliance (the most enduring check since the Poor Laws a few centuries ago); people with disability increasing their capability to get involved in community (whatever that means…) and *'daily life at large'.* A literature review Borderlands undertook about similar programs internationally summarised the conditions necessary for success as follows:

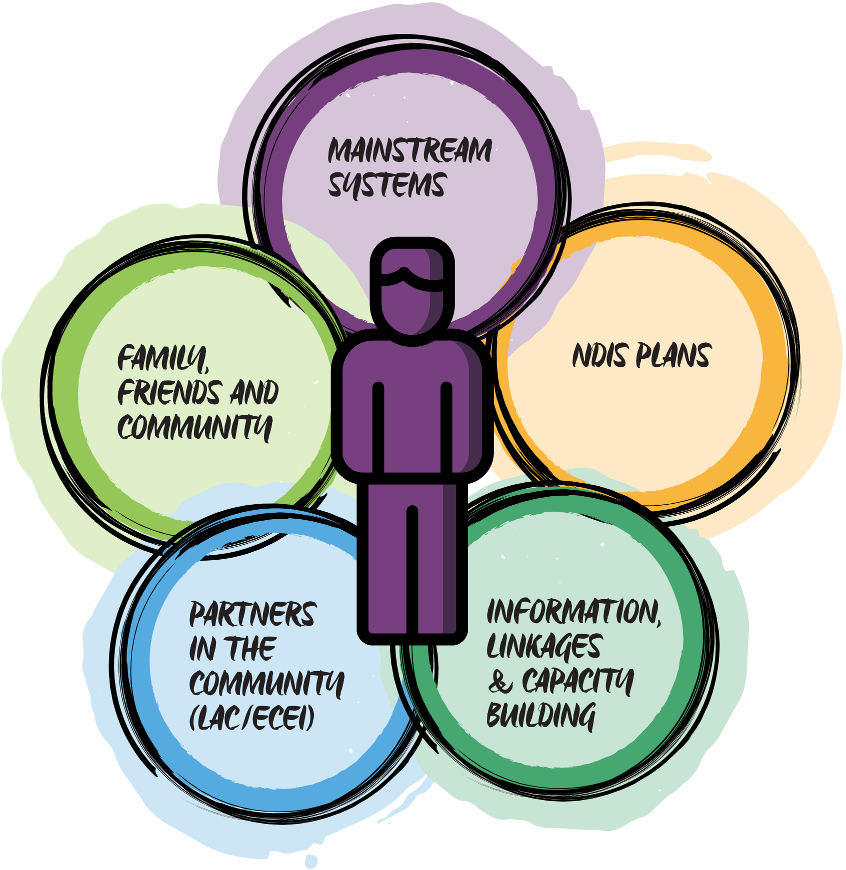
> In determining what makes direct payments work well, it is difficult to differentiate between the effects of overall programmatic change and the changes that result from the specific use of direct payments. The literature indicates that the major structures needed for the successful introduction of programs that allow greater service user choice and control are for a ***legislative and policy framework,*** the development of ***infrastructure supports,*** dedicated staff who work as ***coordinators and facilitators,*** the provision of ***training, guidance and information, transparency and responsiveness of funding*** and a system that encourages ***flexibility and creativity.***

And then, around 2009-10, work on the national system – the National Disability Insurance Scheme or NDIS – started… and it was delegated – surprise, surprise! – to the ***Productivity Commission…*** (see Emily Piggott's article in the New Community (17(2):6-10). By 2013, the first 'NDIS Trial Sites' commenced, including South Australia, where a visiting UK-based expert, Simon Duffy, had the following to say about the initial design, as he witnessed it being implemented in that state (*"Designing NDIS – an international perspective on individual funding systems"* 2013; Sheffield: The Centre for Welfare Reform – www.centreforwelfarereform.org)

> … Australia is being in danger of building the world's worst system of individualised funding. I do not make these remarks lightly, nor for rhetorical effect. In summary, I believe:
>
> 1. The current design does not reflect international or Australian learning about best practice in individualised funding systems.
> 2. The resistance to acknowledging human rights and real entitlements will undermine both the quality and sustainability of the model.
> 3. The resistance to accepting the reality of *rationing* will have the perverse consequence of promoting the worst kinds of indirect rationing.
> 4. In principle, the concept of insurance could be very helpful, but it is not currently being used effectively to guide the design of the NDIS.
> 5. The current design is in conflict with Human Rights and lacks any basic trust in the competency of Australians with disabilities to make their own decisions.
> 6. The proposed model does not do enough to harness the efficiencies that come from shifting responsibilities to citizens and making resources flexible.
> 7. The model is hyper-centralised and risks eroding the responsibilities of States, communities, services and families.
> 8. The current model is designed in a way which will create significant inflationary pressure and will damage social capital at every level.
> 9. The proposed design involved an unnecessarily expensive and centralised bureaucratic infrastructure.
> 10. The current design is not innovative, but bureaucratic, and it leaves no room for social innovation at any level.

So there… that's what you get when you ask the 'wrong' institution – the Productivity Commission - to design a system which then turns out to be rather far removed from the reality of the everyday lives of people with disability and organisations that have been involved in the work with and care for them for a very long time… Responding to several of the already anticipated failures and misfiring of aspects of its implementation, the NDIA has been *'changing the approach to ILC investment and how and when new programs will be implemented…'* (from a December NDIS publication: *Strengthening ILC: A National Strategy towards 2022* - https://www.google.com/search?client=firefox-b-d&q=Strengthening+ILC%3A+A+National+Strategy+towards+2022).

> The NDIS exists within the broader framework of the National Disability Strategy to help participants live an ordinary life. While an individual's NDIS plan lies at the core of the Scheme, the way a participant interacts with family, friends and the community, mainstream services, and NDIS Partners in the Communities (including both Local Area Co-ordinators and the Early Childhood Early Intervention Partners), helps them engage socially and economically. ILC therefore plays a very important role, as outlined in the diagram top right.



But ILC ***does so much more.*** It also provides information and capacity building supports for all people with disability, regardless of whether they are eligible for the Scheme. In that regard, ILC also helps people who are not eligible for an individual NDIS plan benefit from a more inclusive, accessible and connected Australia.

It does this by playing a significant part in ***building the capacity of:***

- ***individuals*** – *making sure people with disability and their families have the skills, resources and confidence they need to participate in and contribute to community.*
- ***communities*** – *making sure mainstream services and community organisations become more inclusive of people with disability.*

And so four 'new' programs are devoted to ***'connecting people'*** and **'invest'** in Individual Capacity Building, National Information, Economic and Community Participation, Mainstream Capacity Building, with grants going for 3 years and being rolled out as i write…

Here's hoping that this is indeed a belated realisation that people with disability are ***'so much more'*** than just individuals and that there's ***'so much more'*** to life for everyone than what a *'services marketplace'* offers and what fits in the imagination of a *'Productivity Commission.'* A good counterbalance is offered by the Victorian State ***Disability Plan 2017-2020*** which is firmly based on Human Rights and the ***entitlements*** they suggests should be offered everyone… (http://www.statedisabilityplan.vic.gov.au/application/files/2314/8062/9382/1610033_Victorian_state_disability_plan_2017-2020_Text_WEB.pdf).

Meanwhile, i'm staring at a ***Self-advocacy for the NDIS (Mental Health)*** Resource booklet of 172 pages published by *Independent Mental Health Advocacy* (https://www.imha.vic.gov.au/) and wonder how the several people with disability I happen to know would feel with the new burden of having to ***'advocate'*** for themselves to receive those services and the assistance they are entitled to in terms of their Human Rights… especially if it takes 172 pages to become adept at this… strange how *'empowerment'* is being morphed into an individualised *'capacity'* for which we then can offer *'resource kits'*… (see also ***Disability Advocacy Resource Unit -*** http://www.daru.org.au/resource-topic/national-disability-insurance-scheme).

Even the government seems to have noticed that 'something' isn't going quite right with the NDIS implementation… A review is happening as i write … which makes me wonder – really – why the number of Royal Commissions and Reviews of all kinds has become really overwhelming… can't we get things 'right' earlier in the process of developing new plans and policies…? For example, by admitting to roadblocks, uncertainties and the need for improvisation given the diversity of needs, situations, areas of living context and a myriad of other differences and diversities that make all and any plans aiming at 'universality' and 'best' practice not just risky but rather ludicrous.

Anyway, here's some detail about the review:

> NDIS Minister Stuart Robert announced a review of NDIS legislation and rules on Monday, in an effort to streamline processes in the scheme. The review – to be conducted by David Tune AO PSM – will inform the development of the government's promised NDIS *Participant Service Guarantee,* which sets new standards for how long it takes people to get their NDIS plan or have their plan reviewed. *"The Participant Service Guarantee will take effect from 1 July 2020 and will have a particular focus on children as well as participants needing specialist disability accommodation and assistive technology. We are listening, and will be consulting with people with disability and their families, the disability services sector, ministers and officials from Commonwealth and state governments and the NDIA as part of this review."*
> ***People with Disability Australia*** have welcomed the review, noting NDIS participants were waiting too long to access essential equipment and get their plans finalised. But PWDA policy and advocacy director Romola Hollywood said people with disability were also finding their plans did not reflect the support they needed. She said action must be taken to create better quality plans, so less people were forced into lengthy review processes. *"We are concerned about any moves towards standardisation of plans, or to implementing generic plans that will undermine the whole aim of the NDIS, which was to provide individualised supports that meet the specific needs of people with disability. We need to see the quality of plans lifted, in addition, to shorter time frames for access and plan development being met."*

Should we wait till the report of the review is out and available…? The contributions to the previously mentioned issue of the New Community seem to urge for a broader investigation and for changes which – really – would not need a 'review'… as Labor's Shorten suggested: ***just employ more qualified staff…!*** To which we would add: ***and invest in communities so they become aware and capable of 'being' inclusive!***

The various contributions to the mentioned New Community issue (Vol. 17(2); go to: ncq&borderlands.org.au to request a copy) are not limited to the NDIS implementation and impact on individuals and the community; they reach further into other aspects of what it means to live with disability and examine other creative and innovative approaches to productively dealing with disability, both as individuals and as a society and its communities.

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REASONABLE AND NECESSARY'– VMIAC 2-DAY CONSUMER CONFERENCE IN THE NDIS (29TH JULY AND 5TH AUGUST 2019)

The VMIAC (Victorian Mental Illness Awareness Council) two-day conference, the first day cheekily subtitled The Good, the Bad and the (un)Reasonable, the second day, The tried, the True and the (un)Necessary took place in July/August last year. A full report of the proceedings is available via VMIAC's website (https://www.vmiac.org.au).

DAY ONE

Proceedings were opened by Dave Barclay, singer, producer, Director and Consumer Consultant, who shared (sang) extracts and scenarios from ***"NDIS: The Musical: The Elephant in the Room"*** (https://www.youtube.com/watch?v=EhnQUrELdeU). Introduced as the 'Opening Keynote Singer,' Dave certainly was adept at engaging the audience based on his lived-experience of mental illness and his (mainly successful) attempts at applying for the NDIS and finally managing to master the art of getting a 'plan' and a 'budget' as well as the required services. He described aspects of this process as *'storytelling, as if you've got something to prove… and being made to feel as if you're a liar…'* One of the worst aspects of the Scheme was that it worked like a *'cookie cutter'* and continued to be *'deficiency-based and -oriented',* a far cry from the *'capability approach'* now generally preferred in working with people with disability.

Jenny Bretnall from ***Independent Mental Health Advocacy*** (IMHA – i introduced their 'resource book' about 'self-advocacy' earlier) started with a 'headline' that *'The NDIS has the right elements but uses the wrong tools to apply them…',* going on to show the often negative tension between the 'right' and the 'wrong' in service delivery:

- The Scheme is consumer-directed including several amalgamated program and practice models all aiming to assist consumers to remain *'independent;'*
- The Scheme is intended to save money for the government: benefit levels are capped; numbers of workers are down and they are less available; there's an intention to shift costs onto unpaid workers and families as 'personal assistant services'; it needs to be pointed out that the NDIS is *NOT* the 'total' and only answer to the needs of persons with disability; rather, it is *PART* of a larger set of systems, including state and local government and NGO resources;

- In spite of its claims, it perpetuates dependence and is too much *'maintenance'* oriented; what we need is help towards the *recovery of people's capacities;* the monies for this have disappeared and it is hence not being looked at (although the ILC now seems to move hesitantly towards funding elements). Most mental illness conditions are *episodic* and the 'maintenance' orientation of NDIS is inappropriate for the nature of most mental health conditions;
- The NDIS puts the onus of consumers to *'prove'* that you have a mental health condition that is 'permanent', grave, etc. thus fulfilling the expectation that the services requested are *'necessary'* and *'reasonable';* the speaker characterised this as *'lots of snakes and not enough ladders'*…
- The Scheme remains discriminatory and is not informed by Human Rights-based entitlements; this is a ***really large hole*** and it's not being taken up in the discussion. For example, the right to refuse medication, ratified in 2008 as a move away from the governing Medical Model of mental health treatments, has not been pursued. Recovery-oriented, strengths-based or other empowerment approaches - based as they are on the Human Rights model as adopted by the Victorian Mental Health Plan – are not being part of the considerations when establishing the Plan and the associated Budgets in the NDIS.

The ensuing panel and audience discussion highlighted some of the problems encountered in the course of consumers' interactions with NDIS;

- Certain treatment decisions are not being allowed because NDIS declares them as not appropriate or accessible; the *'reasonable and accessible'* criteria are often not implemented in NDIS-based contracts; so, for example, consumers wanting to refuse certain treatments because they don't want to suffer from their side effects is deemed 'unreasonable' and alternatives are not considered.
- 'Supported decision making' with the availability of explanations, time to think it over and obtain other information on which choices of treatment are based and which are part of consumer rights, are denied across all areas of NDIS service delivery. Planning meetings and the written plans are often rushed through and often hard to understand, but there's no help available, again, pitting the NDIS against the law and people's Human Rights.
- As mental illness conditions are more prevalent than all cancers combined – with 300,000 (potential) consumers with severe conditions needing support – the NDIS providing for 64,000 is very restrictive and only 21.3% of that number have taken up an NDIS plan…
- The conclusion was that people were urged to *'make the best of it';* learn how to *advocate for themselves* so as to get better outcomes; try to *get out of the isolation* consumers often find themselves in and *link with available supports.*
- One consumer – half-jokingly – described the 'relief when the 'planner' or the 'assessor' declares: ***"yes! You have a disability"***

The remainder of the first day was spent discussing NDIS and access requirements and – especially – homelessness as one of the major conditions defeating the possibility of establishing a meaningful NDIS plan – let alone a budget… Please consult the website of VMIAC for the full report of the conference.

DAY TWO

The proceedings started with Aaron McMurray, a Radical Care Consultant and Inclusive Arts Practitioner; in a detailed presentation, Aaron explained the political-economy rationale behind the establishment of the NDIA and NDIS policies and regulations. He demonstrated what really hides behind the PM's slogan that *'People are our Business',* as the NDIS has fully espoused the capitalist market model and its assumptions: *'I shop, therefore I am'* (with due apologies to philosopher Descartes!). The principle *of personal responsibility for one's own fate* is fully based on a liberal *market model,* but omits many of the other principles of liberal *humanism.* The speaker referred to some of the historical origins of the capitalist approach to the economy, juxtaposing it to elements of more social-justice and equality-based models that recognise the class, race and gender influenced *social determinants of (mental) health.* Aaron also noticed that the latter have been effectively removed from the curricula of most medical and para-medical professional education courses. Privileges – often associated with the positions occupied by rich white men – are ignored or underplayed to the detriment of the value of peer involvement in treatment and service delivery.

Indigo Daya, Human Rights Campaigner and Strategic Projects Manager at VMIAC, wondered whether the Consumer/Survivor movement had been knocked off-course by the emergence of NDIS and the impositions associated with its implementation? Reminiscing about her own trajectory as a consumer, she found support in Community Mental Health sector – in her case, the Prahran Mission – that gave her hope as she negotiated her way from de-institutionalisation through rehabilitation to recovery… she would just walk in, meet a support worker, participated in groups, drop-in centres offering 'hearing voices' groups, thus getting respite from the mental health system. Indigo wondered where all those opportunities in the community sector have ended-up, offering an alternative (or complement) to the clinical sector and supporting the consumer movement… Soteria houses, hearing groups, arts collectives, open dialogue programs… we seem to have lost these safe spaces already before the NDIS was established but certainly they will disappear even more as the market model of the NDIS will take hold.

Indigo made a powerful call to *'grow our own movement'* as consumers; do we really *'want a seat on their table'?* she asked, when 'they' do their reviews; it often makes it worse for consumers as 'they' don't listen. She quoted Audre Lorde's wise words that *'the master's tools will* ***never*** *dismantle the master's house' and suggested that 'we build our own table, with our 'menu', our invitees and using our own style… and we need more than our own table… we need to grow our movement based on a shared and collective vision for consumers and how they are to be treated in society.'*

Matt Ball was video-streamed from Adelaide; he is a consumer and was elected Australia Mental Health Nurse of the Year in 2017. His presentation *'Re-awaken: a Manifesto for Compassionate Change'* certainly hit the mark for many attendees and did so in many ways; initially found to be 'treatment resistant,' he eventually declared himself 'un-mad' and forcefully argued against the medicalisation of mental health by the NDIS. His story meandered through his experiences of becoming 'un-mad' and the questions he posed himself during that process; against the 'risk-avoidance' imperatives imposed on consumers, he started sky-diving and engaged in other avenues to *'reconnect with the world'.* At a camp in Scotland – *Environments for Recovery* – consumers invited workers in (rather than the other way around); the operative word guiding that experience was *'autonomy; we created environments that were OK for us and not the other way around… the place was quite isolated, we lived in huts, catered for ourselves, axes were lying around everywhere to cut the wood for fires… so the question of safety and all other questions to do with living together occurred with all participants rather than to participants…'*

So the question for the NDIS needs to turn towards consumers themselves: *'what do people want for themselves?'*… The danger of the NDIS is that it has been restricted and limited to finite resources rather than being predicated on supporting mutual learning, mutual power to discover all our potential. To make his point that mental health needs to be *'demythologised',* Matt referred back to Laing who posited that *'sanity equals determinism and totalitarianism'* and the NDIS could lead *'to the death of the soul and of our freedom.'* We need to be allowed in the peer movement to affirm our own responsibility and the NDIS (and its operatives) need the patience to sit with us. We collectively organised a Many Voices Festival in Adelaide which we thought of as the beginning of a new way of how NDIS could work by ourselves. We used peer support in a different way, telling the NDIS what it is that we want to do and get and not the other way around. We need to take the authority, hence the call for *Reawakening, for connection, for compassion, dreaming and feeling and action.*

Asked how far we can go pushing boundaries, his answer was that there were no pre-set boundaries for meaningful action… *'I am not the label you have given me… we need to tell one another our new story… the NDIS has no legitimacy on its own… we need to take and make the rules…' These are the elements of the 'ReAwaken Manifesto for Compassionate Change: We deserve the best psychiatric hospital in the world; respite should be available under the NDIS regulations and offer mutual support by peers; and radical crisis responses are our 'emotional CPR'…'*

The afternoon was devoted to sharing experiences and practical attempts at 'productively' dealing with the NDIS. Kristin Gillespie acknowledged the importance of 'community' and connection between NDIS users and has started a Consumer Facebook Forum: *The NDIS, Psychosocial Disability and Mental Illness. 'Consumers need to be in the driver's seat'* in interactions with NDIS; initially, a Facebook group with well over 50,000 participants included consumers, carers and practitioners but did not really respond to consumers' needs. What was needed was a site which offered information not available elsewhere in a language consumers understand; it is about knowledge sharing and being connected, using our own experience to help one another and to get through the processes when we try to get what we want and need. It's a site for two-way translations between the NDIS and consumers. It was agreed that the NDIS will remain a rough journey unless people are appropriately supported; it's incredibly hard to get what we need but once through with the plans and budgets it gets better. The Victorian Mental Health sector - which used to be great - has been decimated which could add more distress and VMIAC was called on to become a stronger advocate and offer training for this.

The following session invited service consumers and 'producers' to exchange experiences of their respective engagements in the *'NDIS services marketplace(s)';* as already remarked, it was pretty much a *'snakes and ladders'* experience as reported by representatives of mutual self-help groups and peer-support networks. The final session i was able to attend was led by Galadriel Scott, a consumer and mental health practitioner who has set up a *'consumer-led NDIS Service Provider Organisation,* ***"Gladyandco,"*** *at The Recovery Hub* in Mooroolbark, an outer-east suburb of Melbourne (https://www.facebook.com/gladyandco/). They provide support services through NDIS packages from Box Hill to the Yarra Valley area. Whilst the need is enormous, they started with a small service and have been *'learning as they go';* they have opted to remain 'small' because getting big makes things much more complicated.

The NDIS is difficult to deal with; there are always errors occurring but you can use some of them creatively. NDIS personnel is overworked and really don't know anything about mental health. Still, there is scope to develop innovative enterprises in which consumers and peers are involved; it takes some patience, but there is scope. The conference concluded with two sessions run by VMIAC personnel attempting to launch a 'Consumer-Led Vision for Change' and – via a participatory process – develop a *'Consumer-Survivor Declaration'.*

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Meanwhile, several pieces of research have been published and one really has to say that the picture is not very positive; to start, a University of West Australia ***White Paper*** calls for a ***fit-for-purpose disability system;*** (https://www.uwa.edu.au/projects/six-years-and-counting-the-ndis-and-the-australian-disability-services-system). It starts ominously: the NDIS is not working for everyone and change is needed now. The research analysed 63 reports written on the NDIS since it was first launched in 2013, painting a damning picture of how the system is currently being managed and arguing that a significant part of the problem is the lack of an industry plan focused on reforming the *Australian disability services system as a whole,* rather than the NDIS as a standalone element.

Combined with a short-term approach to problem solving, the approach has resulted in a system that only works for some service users and providers.

> *It is increasingly evident that it leaves major gaps in terms of responsibility allocation and funding capacity between state/territory and the Commonwealth governments in critical service areas such as housing, health, education and employment. It also leaves states and territories to pick up the bill when people with disability are diverted to other health and welfare systems due to supply breakdown.*

Some fundamental assumptions underpinning the way the NDIS had been developed and rolled out have not been questioned and are causing problems. Some assumptions are explicit, such as around the existence of a functional market, some are more implicit assumptions about the efficiency of the sector. As one author of the report suggests in an interview with Pro Bono News:

> *"The expectation was that after six years we would start to see competition driving efficiency and reducing prices, that is based on the assumption that the existing system was inefficient and was overcharging, and what we're seeing is the opposite,* ***prices have actually gone up.*** *So that assumption is implicit but it's never challenged."*

The white paper, designed to describe a way forward, warns there is a significant risk that ignoring the mounting evidence could cause *"destruction"* in terms of the system's capacity to deliver appropriate and fit-for-purpose services and supports, increasing difficulty for people with disability and cost for governments. It cautioned that people with disability were *"the shock absorbers"* for any volatility caused by poor policy and practice.

Some of the issues highlighted included: a breakdown in pre-existing inter-governmental and intra-governmental service structures; increased uncertainty preventing investment and expansion by service providers; significant workforce issues; and pricing based on funding availability rather than sound data on needs and costs of services. While the system worked well for some people, the concern was that it didn't work well for everyone; one of the authors suggested:

> *Our concern is that, as much as we want to have support for disability, we actually have to build it so it aligns with those mainstream services,* ***not create a completely separate model of governance.*** *While it sits as it does, it is quite separated and isolated, which is inefficient and also results in poor service outcomes for many people.*

The paper is calling for the development of an industry plan and local decision-making framework as a priority.

WHAT ARE THE ISSUES?

- The NDIS is not working for many it is intended to support
- The 2018/19 $4 billion+ underutilisation and clear signs of unsustainability in the disability services sector confirm this reality
- The roll out of the NDIS was always going to be difficult and mistakes were always going to be made. Good leadership means that we learn from this experience and modify our approach in a timely manner
- A significant part of the problem is the lack of an industry plan focused on reforming the Australian Disability Services System not just the NDIS, combined with a short-term approach to problem solving—changes being made are not positively modifying the system itself they are tinkering with band aid solutions
- We now have a significant body of evidence in 63 separate reports, primarily focused on the NDIS, written since 2013 relating to problems and potential solutions across the system
- People with disability are the shock absorbers for any volatility caused by poor policy and practice—they are the ones that ultimately feel the impact of systemic challenges
- There is a significant risk that being unresponsive to the gathering of evidence will cause destruction in terms of the system's capacity to deliver appropriate and fit for purpose services and supports, increasing difficulty for people with disability and cost for governments.

WHAT DO WE NEED?

- Leadership must accept the challenges and have the courage to drive forward in new ways where experience tells us what we are currently doing is not working
- Leadership must accept that the successful implementation of the NDIS requires a fit for purpose approach driven by a culture of clarity, certainty, accountability, collaboration and flexibility
- A comprehensive industry plan and responsible investment funded out of the savings from underutilisation, to guide the development of industry and support government decision making, and which utilises the decades of experience & capacity that exists nationally to ensure the whole system works
- A national governance model and policy framework allowing for policy and investment to be informed collaboratively by all involved in the system including people with disability, governments and provider peak bodies
- A local decision-making model providing fit-for-purpose allocation of resources and capacity to make decisions in the community where those decisions have to be lived with
- Transparency of outcomes to ensure we are all working toward a future where people with disability are receiving fit for purpose services & supports and are maintaining decision making capacity and agency.

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People With Disability Australia (PWDA), is calling for the federal government to develop a national jobs plan that will look at *"every barrier, and every part of the employment picture;"* only 53% of working age people with disability are in paid work, so PWDA is launching a $100 million plan to help more people with disability land and keep a job. The plan includes a fund set up to transition people with disability out of sheltered workshops and into open employment that pays a decent wage and for the NDIS to move away from supporting sheltered workshops.

This has been an ongoing issue for disability advocates as people in sheltered workshop can receive wages as low a few dollars an hour. So, the plan calls for a national advertising campaign to tackle disability discrimination in the workplace and increased funding for ***Job Access,*** the government program oriented at disability employment. Compared with other OECD countries, Australia ranks 21 out of 29 in employment participation rates for people with disability.

Jeff Smith, CEO of PWDA CEO said: *"We know that many people with disability find that outdated attitudes, a lack of flexibility and accessibility can make getting and keeping a job incredibly hard. We believe that the measures outlined in our plan will contribute significantly to removing the barriers people with disability face, and make it possible for many people with disability to enter and stay in employment."*

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A next report derives from the National Disability Services' (NDS) Annual Market Survey, one of the more important sources to understand and monitor the changes in the Australian disability sector. (see the full report; the following are excerpts from the ExecutiveSummary https://26f05b23-e9e4-4e1c-b157-4d9d821c7e81.filesusr.com/ugd/aa1ed8_f0c2e3ba9bf54313884b0ae668e9274f.pdf)

The survey provides insight into ***service providers' perceptions*** of the NDIS, the operating environment for the sector and financial sustainability. The 2019 survey found the operating environment for the sector, particularly prices, have improved on previous years. However, there continues to be uncertainty and concern about the sustainability of organisations within the NDIS. Provider perceptions of operating conditions for the disability sector have improved. Just 38% of providers in 2019 say that conditions have worsened in the last 12 months, compared to 55% in 2018. Providers increasingly feel NDIS reforms are heading in the right direction (up from 47% in 2018 to 55% in 2019).

However, the disability sector continues to be characterised by uncertainty. Three quarters of the sector feels the operating environment is uncertain. In particular, providers describe a turbulent operating environment with frequent policy changes and inconsistencies from government agencies. At present only 19% of providers feel the NDIA is working well with the sector and only 22% feel the NDIA has respect for providers. Provider relationships with the Quality and Safeguards Commission differ by location. This reflects the State by State NDIS roll out. Providers operating in New South Wales and South Australia (the first jurisdictions to come under the remit of the new regulator) are more positive than others -36% agree that the Commission is working well with providers, compared to 21% of providers in the ACT, Northern Territory, Queensland, Tasmania and Victoria, which transitioned mid-2019.

Administrative burden associated with assisting participants and families navigating the scheme continue to be a challenge. Most providers report supporting individuals to navigate the NDIS as it is perceived as too complex for participants to navigate alone or without adequate independent advocacy. *Only 15% of providers agree there is sufficient advocacy available for the people their services support.*

While confidence in the NDIS is improving and recent pricing changes appear to have brought relief to parts of the sector, a high number of providers are still unsure they can operate within the NDIS as it is currently configured. Some indicate this is a result of pricing levels, while others suggest significant delays in payments are causing financial precarity. Half the providers who responded are worried they won't be able to provide NDIS services at current prices – 52% agree in 2019 compared to 58% in 2018. Again, longer-established organisations were significantly more likely to indicate they are concerned about the NDIS pricing structure: 58% agree with the statement, compared to 37% of organisations established after 2015.

Just over half (53%) of organisations said they are worried about their ability to adjust to changes due to policy; the concerns about pricing and administrative burdens referred to above may be contributing to this uncertainty. Reports about financial sustainability have remained consistent since the previous survey in 2018, though only 54% of organisations report making a profit in the last financial year. A smaller proportion of organisations report they have considered leaving the disability sector in 2019 compared to the previous year (11%, compared to 16% in 2018). Small, medium and large organisations are more likely to report they are actively growing their organisation, compared to very small organisations. Of the organisations responding to the survey, 17% are sole providers, and as such are unlikely to be focused on growth.

How is the disability sector faring? Large organisations said they are worried about their ability to adjust to changes in the policy environment, compared to 53% of very small and 49% of small organisations. Looking at the need for improvement by organisation size, generally small, medium and large organisations were more likely to indicate there are business capability areas they needed to improve, compared to very small organisations.

The 2019 survey again found concern over ***collaboration*** in the sector. Some respondents indicate collaboration appears to be increasing, particularly in the last 12 months. The majority who answered our qualitative item on collaboration view this as being restricted by the introduction of a competitive market for disability services. There are significant differences in collaboration across organisations depending on age of organisation, and organisation size. Organisations established prior to 2015 generally report taking part in more collaborative activities.

RECOMMENDATIONS

The report makes a number of recommendations for improving the NDIS:

- Either resource the NDIA to ensure adequate staffing, thereby addressing time delays, inconsistencies in advice between staff and locations, or outsource functions to appropriately qualified non-government providers.
- Provide more training to NDIA staff around communication with the sector and changes in rules and regulations, thereby helping to rebuilt trust between the NDIA and the sector.
- Investment by government in independent advocacy to provide high quality independent advocacy (which will also lift excessive administrative burden from providers).
- Continue to monitor and improve pricing structures.

Overall, this report paints a picture of a sector that continues to be precarious and frustrated with the reform process. There is a clear call from the sector for consistent and reliable information and communication, along with a recognition of the large administrative burden placed on the sector while the NDIS takes shape. Without addressing these issues, the vision of the NDIS of increased choice and control for eligible Australians with disability is at risk.

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Fran Connelley (whose book 'Workplace Culture and the NDIS' was released in November 2019 and is available from www.fcmarketing.com.au) says that from first-hand experience, there is a second "shock absorber" in this sector – and in many places it is at a critical breaking point. ***It is the disability workforce itself.*** The NDIS has fundamentally changed the nature of work in this sector. As a result of the new funding model, disability organisations are expected to deliver a quality customer experience within the framework of a transactional business model geared towards fast delivery. ***The reality is that the disability customer or NDIS participant is not looking for a transaction. The NDIS is not Medicare.*** They are simply looking for someone they can trust to deliver a quality, personal service. However, the new funding model is, in effect, ***"pauperising"*** the people and service providers it relies on to deliver that promised service. As Michael Chester, head of service operations at UnitingCareWest, remarked in his interview for my book:

> *"I believe that we have an obligation to keep the issue of the working poor on the radar for everybody… for politicians, the NDIA and every provider in the sector. If the current trend continues, we have the possibility of a new working poor emerging in the ranks of disability providers around the country."*

And she goes on to report: in practice, the NDIS business model is fundamentally at odds with the nature of the support service its customers were promised: ***a high quality, individualised support service that offers choice and control. Trying to extract a consistently high quality human experience from a transactional, high volume, low touch business model is almost impossible.***

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A report released last September from the Australia Institute's Centre for Future Work, Precarity and Job Instability on the Frontlines of NDIS Support Work, found significant stress, instability and lack of support for frontline workers:

> *"A disability services program that organises support in the same manner as digital platforms organise fast food delivery or taxi services, is not likely to achieve the high standards of respectful, individualised support that the NDIS's architects hoped for."*

It's not just frontline workers. In the course of my own research for the book, I found on a number of occasions that dedicated frontline team leaders and service managers would actually breakdown when asked the question, *"What's the greatest personal challenge in your work on a daily basis?"*

To expect a consistent, high quality customer experience within this business model is not only unrealistic, it's also unfair to the hundreds of passionate support workers who genuinely want to make a meaningful difference in their work. Regular hours, a reliable income, access to the necessary skills training and quality on the job support should be an easy business case. Particularly when you consider two compelling facts:

- *The sector needs to attract another 90,000 full-time employees in order to meet the increased*

demand generated by the NDIS. 71% of these are expected to be support workers.
- *The Royal Commission into Violence, Neglect and Exploitation of People with Disability is already underway.*

However, the NDIS pricing model actively works against attracting new, high calibre talent into the sector and delivering a quality service. The Australia Institute's report concluded: *"It is unrealistic to expect that agencies can provide the critical infrastructure essential to the development and maintenance of a high quality workforce, on the basis of tiny 'margins' built into NDIS unit prices."* The reality of the NDIS is that the current funding model does not make any provision for adequate skills training, professional development or on the job mentoring. This is not simply because of the NDIA's price guide. It is exacerbated by the fact that disability organisations are spending unpaid time helping anxious families and individuals navigate a bureaucratic transactional model implemented by people who very often lack sufficient training or first-hand disability experience.

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Another report, this time from *UNSW Sydney* (19/08/2019), is based on the examination of the deaths of 901 people with disability, drawing on published state and territory data from 2007 to 2018. (https://www.ndiscommission.gov.au/sites/default/files/documents/2020-02/findingsreview-deaths-people-disability1.pdf)

Across all samples, ***the median age at death was between 20 to 36 years lower than that of the general population, with the majority of deaths reported considered to be "unexpected".*** Luke Michael reported in The New Daily (14/02/2020) that the report was requested by the NDIS's *Quality and Safeguards Commission,* to obtain an Australia-wide insight into the deaths of people with disability, and identify how best to reduce these risks on a systemic level. The report identified a number of areas of poor practice that contributed to the spate of premature deaths.

> *These included failure to comprehensively support client access to preventative health measures such as recommended vaccinations, annual physical examinations and dental appointments," the report said. "Despite observed high rates of lifestyle related risks such as obesity and hypertension, a significant proportion of people whose deaths were in-scope for this review had not been supported to access the services of dieticians or exercise physiologists prior to their deaths.*

The report noted that people with known health risks – such as dysphagia, epilepsy, recurring respiratory infections or cardiac conditions – were not referred in a timely manner for specialist help. They said it was unclear to what extent health and disability services were supporting people to effectively communicate their health concerns. They also identified systematic problems around health and disability staff training and expertise across the country: *"For example, even in cases where the person had a mealtime management plan in place, multiple cases of staff not adhering to the plan were noted as a contributing factor in choking deaths."*

The Council for Intellectual Disability (CID) said the findings of the research were shocking; their senior advocate, Jim Simpson said that the report was a stark compilation of evidence on inadequate health care and disability support, which caused people with disability to die far too early. He said CID has been very concerned about ***the lack of proper focus on good health care by the NDIS and the safeguards commission;*** practice standards were to be the bedrock requirements that disability providers needed to meet.

> *It is not adequate that the commission is only planning new standards in relation to mealtime supports for people with swallowing problems. For example, standards should also oblige service providers to support people with intellectual disability to have annual comprehensive health assessments. These assessments are covered by Medicare and have strong research backing for leading to better health promotion and identification of hidden health problems.*

NDIS funding must be reformed, it was suggested, to give people with complex health needs access to a health facilitator, to deliver appropriate health supports within NDIS services.

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CONCLUSION

It would be beneficial to return to Simon Duffy's findings on p. 5… they were made in 2013… (!) Lots of the rather questionable outcomes of the implementation of the NDIS could certainly have been prevented or alleviated if heed would have been taken from the findings and the implicit and explicit recommendations.

'Going back to the drawing board' would probably be the most sensible thing one could suggest… and that drawing board should not be in the offices of the Productivity Commission… and one should include the entire disability policy and program landscape in the re-drawing and not just those who do or want to play the 'market'… and one should certainly include in the thinking and the policy re-jigging the community-based and voluntary agencies, organisations and initiatives… and, obviously after all of that, re-think the care and support approach within a community development and 'inclusion' philosophical and practical framework…