Making Care Count in a National Disability Care and Support Scheme

Submission to the Productivity Commission’s inquiry into a National Long-term Disability Care and Support Scheme

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INTRODUCTION

Personal

As care and support involves the interface of public and private spheres, it is relevant to describe some of my background here. Married, and a father of two children, I have lived with quadriplegia since 1978, as a result of a non-financially compensatory accident. I have worked in paid and voluntarily systemic, individual, citizen advocacy, and advocacy development; in direct service provision; in ministerial government advice; and in adult guardianship jurisdictions as Tribunal member. I have degrees in human services, social science and hold a PhD in philosophy. Author of *Euthanasia And Disability Perspective* (2010).

The Inquiry

I respond to what was previously called the National Disability Insurance Scheme (NDIS), then called the National Disability Long-term Care and Support Scheme (CCS). I will use NDCSS throughout to refer to this proposed scheme.

The subject involves both the notions of social insurance and care. Consequently I suggest Joan Tronto's (Tronto, ethics of care framework as relevant to this submission, as a proposed ways forward.

The Inquiry is an important initiative, both for its potential to contribute to significant positive change for people with disabilities, and for the threats it would represent if it delivers 'more-of-the-same' inadequate approaches to meet their needs. Some 56% of respondents to the government's Shut Out report reported that services were barriers to them. *Fundamental* change is needed. Change that goes beyond assuring there is more money for disability services. It is commendable that some key people have commenced this process.

However, the Terms of Reference to the Productivity's Inquiry would have benefited from early 'deep and wide' representation from the disability sector and its allies. With 'deep and wide ' representation I mean specific areas of expertise in physical, sensory, intellectual disability and mental illness, including people with formal expertise in disability-related disciplines, and representation from specific cultural backgrounds.

As it is, and while not dismissing the direct personal life experience of disability of some of the members of those working parties, the reports that have shaped the inquiry were largely done by experts in financial, banking, actuarial, and competition policy fields. Not primarily by experts in disability, or in how to be of good service. A more balanced, representational approach, reflecting the primary interests of people with disabilities and carers from the beginning would have resulted in a more comprehensive terms of reference that include all issues that are vital to them, whereas it presently does not (Amendments to terms of reference, 2010). Consequently the community consultation is now being conducted within a restricted framework, where the primary stakeholders had inadequate participation in framing it.

It is important to reflect on this background because of its implications, such as on primary motivations for this Inquiry, and on its implicit views of disability and therefore its proposed solutions. If the 'problem' is seen mostly as an economic issue, situated in the 'market', then certain solutions will be offered. If primarily seen, on the other hand in the light of fundamental human needs and rights, in protecting and advancing the position of one of our society's most vulnerable category of people, other solutions might be proposed.

The underlying mindset to this Inquiry is that of economics. The Parliamentary Secretary for Disability Bill Shorten says his disability portfolio is essentially an economic one. The very first exploratory report was an accounting exercise, assessing the economics of the idea of an NDCSS. The Productivity Commission is a body that investigates issues in the light of health of the national economy. Its commissioners are economists. The government's interest in this Inquiry is inevitably shaped by its realisation that a fast-growing disability population is a huge pressure on its Treasury through pension- and other payments and in funding growing disability services. Hundreds of billions of dollars are at stake over a likely 20 - 40 year life of a new public levy-based revenue source, and success or failure to have it implemented. The disability services industry is looking for ways in which to be financially sustainable.

Both their interests are substantial and they represent legitimate concerns about financial viability. Among interested parties in an NDCSS some interests overlap, some involve tensions. My question here is, how dominant are the roles of the interests of these powerful parties in the pursuit of this NDCSS and how does this play out in the interests of the much less powerful people with disabilities and carers, where their needs are not primarily economic? While these interests are not transparent we might be shadow boxing about whose needs are actually to be served by an NDCSS.

> “... the market (...) is a valuable institution if used in the service of society, but a horribly destructive one when elevated to the level of a supreme rationality, a wonderful servant but a dangerous master” (Aly, 2010).

A conflation of the needs that various interest groups have, seems to me a reasonable explanation for reasons why this Inquiry constructs people with 'severe and profound disability' as those in highest need; why it does not overtly adhere to a social/ecological model of disability; and why it does not wish to look into the underlying problems of the disability service system that it says is dysfunctional. How you see a problem, is how you will arrive at solutions.

For example, if you believed that those in highest need are constructed by being the highest-cost category measured by frequency of core interventions in their lives, you would make that group the eligibility focus of your inquiry. In turn this means that only a medical view of disability to describe them is needed. In so doing you might be counting only those things that are measurable as needs while making things like high vulnerability by, say people with mild intellectual disability to exploitation, abandonment and even imprisonment (10-14% of Australian prison populations have an intellectual disability or mental illness) not count for eligible support.

It has been argued since that constructing the eligibility for an NDCSS as now in the terms of reference was originally a mere statistical exercise in getting an idea of costs. But the fact is that it does not say that in the Inquiry's terms of reference and that is the reality before respondents to this Inquiry.

As underlying belief systems and interests, even when unconscious or opaque, drive the construction of problems and their solutions, it is clear then what the importance is of solid philosophical underpinnings for this Inquiry. It requires an overt understanding and agreement on fundamental issues such as what is disability and what is need.

I suggest the need is for sufficient, sustainable revenue sources that are structured to fund care and support approaches towards the fundamental needs of vulnerable people with disabilities, ones that are effective in advancing and protecting their interests in being safe and secure in their lives, work, accommodation and recreation, as part of a web of supportive relationships. In other words, sustainable lives of people with disabilities in which they can flourish. A truly participative process of working towards that aim would in itself mean transformational change for people with disabilities.

I propose the following points as important to an NDCSS, which is not presented in any order of importance.

Crucial elements of an NDCSS

1. **An overt central belief system about disability as arising from interactions between impairment, values /attitudes & environment;**
2. **Orientation towards fundamental human needs (see Maslow's hierarchy, Max-Neefs' work), and factoring in of vulnerability arising from the above-mentioned interactions, in assessing individual needs;**
3. **Factoring in the emerging and future socio-economic-environmental impacts of climate change on already vulnerable people with disabilities;**
4. **Active, genuine, creative & supported grassroots participation in administration and monitoring of an NDIS, as in service approaches funded by it, including openness about all interests involved, and having them all at the table, where power discrepancies are acknowledged and compensated for;**
5. **Ongoing support for capacity building of people with disabilities, families, carers, disability services and advocacy groups towards genuine and skilful participation at all levels, effective service, and strong, independent disability advocacy;**
6. **Adoption of Tronto's framework of care to this National Disability Care & Support scheme as constituting: Attention to need; Taking responsibility for that need; Doing so competently; and Responsiveness to these caring actions in a two-way participatory fashion - a relationship . This model to be applied and modelled in NDCSS/disability services organisational structures and practices, extending to its workers, carers and clients. A culture of care.**
7. **Active exploration of service anomalies and strengths in a forward strategy towards quality in being of service, where the nature of quality is articulated;**
8. **An overt, ongoing positive public narrative towards an NDCSS worth having and in the course of its implementation. This would be a story that says a positive contribution to the character of our nation is made by all as we genuinely care for and support people with disabilities (which indirectly benefits carers also), and where the public 'insurance premium' is an insurance strategy against inadequate care and support when**

impairments are acquired. Impairment is a normal part of life. Disability is not, as we all act in creating or ameliorating it;

9. **Strong safeguards to the integrity and quality of an NDCSS and for people with disabilities, including strong independent advocacy; meaningful ongoing participation in functioning of NDCSS at all levels; complaint mechanisms; monitoring, independent evaluation and renewal of an NDIS;**
10. **Retaining what is best and transforming what is not good in service approaches, within a flexible, decentralised NDCSS structure, under a common values structure and agreement on needs (as distinct from demand);**
11. **A strengthening of support from NDCSS funds to disability/human service studies research centres under that common values/needs umbrella, not a new national research centre. The first is a better strategy towards a rich and diverse research environment, wide in scope;**

Further Issues covered in this submission

12. **Individual funding**
13. **Interface with aged care**
14. **Two tiers?**
15. **Paradigm change**
16. **Openness**
17. **Utopia**

1. An overt belief system

> Reaffirming the universality, indivisibility, *interdependence* and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination... (UN Convention on the rights of persons with disabilities - Preamble)

An NDCSS should be based on an *overt* values foundation. I propose that it adopt a disability definition that views ***disability as resulting from interactions between impairment, social values, practices and beliefs, and the environment.***

Further that it acknowledges the resultant belief of the lives of people with disabilities as interdependent, where individual autonomy is based on relations with others.

Such values and beliefs are fully compatible with the UN Convention on Rights of People with Disabilities, as the respect for 'independence' of persons that it refers to, is part of the facts of life as interdependent, involving degrees of dependence, and transient experiences of 'independence'.

> As current Finance Minister Lindsay Tanner wrote, when in opposition:
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> *Relationships are the missing piece of the political puzzle. As we struggle to adapt to the domination of the bottom line and to constant economic, social and technological change, the factor invariably omitted from the equation is human relationships. … The shape of our future society will be determined by the health and strength of our human relationships. Our economic progress depends on*

the relationships that sustain our economic activity. … We must refashion our entire approach to organizing our society, and put relationships at its heart.

Tanner ,L., 2003. Crowded Lives. Pluto Press. Australia.

2. Orientation to fundamental human needs

The nature of needs is blurred in the Issues Paper, where it conflates 'needs' with 'demand.' Watch 'need' morphing into 'demand', as if it's one and the same, in this passage: “...unmet need is hard to estimate, not least because the concept of 'unmet' demand is difficult to define. A measure of unmet demand requires a judgement about what constitutes an appropriate or reasonable level of service provision as the benchmark for assessing the shortfall of existing service provision.” (Issues Paper, p. 44)

‘Demand’ is an economic concept where 'The Market' responds with supply to rational consumer choices and or actively creates 'demand' itself through marketing. However The 'Market' is not good at making judgements about human needs, or environmental ones for that matter. Its construction of human behaviour and needs has given us recently the near global collapse of the financial system, and a thoroughly unsustainable planet. So, the number of people sticking their hands up for disability services, regardless of their efficacy in meeting needs, would appear to be an indicator of 'need' under this Issues Paper’s construction.

Clearly, what people need is not always the same as what they want. And the needs of one party may override another’s. Some parent/carer groups want institutional care for their disabled children, as the Four Corners program 'Breaking Point (Four Corners, 2010) showed clearly. “I need residential”, said a distraught family carer on this program when actually talking about the needs of her child. Carer/parent stress can of course be great, and their needs should be addressed. But a funding scheme that puts the needs of people with disabilities central should address needs of both these parties separately. Good support for the carer in their caring role, will often benefit both carer and person with a disability – just as good care and support for the person with a disability benefits their carers.

Some of my friends who are in demanding family care roles find their caring roles hard *and* rewarding, but complain that their greatest source of stress is the service system that serves its organisational needs first within its operating budget that it has tendered for, and won, in the market-based purchaser/provider funding model.

Special, segregated education is no longer widely accepted as providing well for the needs of its students. Segregated, congregated accommodation support, or institutions, social activities, respite and sheltered workshops likewise fall short of meeting fundamental human needs, such as of facilitated by inclusion, of belonging, and human development.

As I write this I realise that it is close to 30 years ago that the United Nations International Year of the Disabled (1981) signalled an intention for people with disabilities to fully take part in the life and development of their societies. But in 2010 governments are still funding service models that act contrary to that aim!

Segregated/congregated approaches invest in long-term expensive infrastructure, and it is questionable that having a funding-of-demand approach, disregarding how these approaches may meet fundamental human needs of people with disabilities, is even economically efficient. I hasten to add that I do not propose funding eligibility should be tied to economic efficiency of services in this way.

> The basic assumptions of neo-classical economics - of 'Economic Man', weighing economic costs and benefits and making choices which maximise his utility based on perfect information - are fatally contradicted by most caring decisions which rely upon altruism and sacrifice of personal interests to the interests of another... The economy of care which underpins the economy of paid work and production has its own laws and circulations, but its guiding principles contradict the founding assumptions of neo-classical economics: rational man who maximises his private utility. Carers make decisions that shape labour market participation, production and consumption - indeed which shape the official economy based on motivations where costs are a minor player. These decisions are instead related to love, reciprocity and a complex economy of relationships, community and family where 'gain' derives not narrowly from individual utility but also from obligations, love and responsibility that can not be measured in dollars or individually, and often can't be predicted. Perfect knowledge about effects, events, costs and benefits rarely accompanies care decisions.(Pocock, in Fine, 2007:152).

The NDCSS is a needs-based scheme. Therefore it needs an articulated agreement on what the needs are that it aims to meet and for whom.

Such an agreement is central to the effectiveness and efficiency of an NDCSS, as without it, it may simple attend to a category of people with disabilities who represent the highest cost to government, or to those with the loudest voices. Highly vulnerable people may not appear on its radar as in need of care and support.

Clearly ‘what are fundamental needs’ and consequences of deciding what they might be, requires further in-depth *engagemen*t in working parties with 'grassroots' people with disabilities as well as with family carers and those in paid care roles. Engagement of a sort that we have seldom yet experienced, despite many inquiries, consultations and 'having-our-says.'

Perhaps we talk about “meeting” needs for a reason. It is an inherently interactive, social process, requiring personal engagement with people and their needs.

> “Along the path of life I have learned much (…) about the importance of relationships. Relationships can either transform our everyday lives and/or socialise us very effectively in narrow, passive, recipient ways of being disabled” (Newell, 2005).
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> Notably, my late friend and colleague Christopher Newell, travelled a path from being a worker in a sheltered workshop to being a disability activist and scholar, professor and Anglican priest.

I suggest that the best of the scientific body of knowledge about what constitutes universal human need be explored as relevant to constructing assessments and services, as well as each person's unique needs.

Maslow's hierarchy of needs and Max-Neef's work on fundamental human needs, seem good starting points for exploring universal needs. Maslow’s hierarchy includes needs as relevant to the body, including health; for safety and security, including work and accommodation; for belonging and social relations; for esteem (valued status) and respect; and for self-actualisation. Max-Neef, an economist who distinguishes needs based on what it is to be human from economic 'wants', described fundamental human needs as subsistence, protection, understanding, participation, leisure, creation, identity and freedom (Max-Neef, 1992).

Further, I suggest that the degree of vulnerability to threats to one's health, safety, participation as a valued member of society and so on, must be a prominent part of assessing needs for care and support and who should be eligible. 'Severe or profound' medical categorisation of disability makes little sense when defining disability as interactions of impairment, attitudes and environment.

It does not follow that a high level of impairment necessarily correlates directly with vulnerability. People with a low level of intellectual disability, or where, say, visual impairment or amputation is combined with another socially devalued status, such as Aboriginality or belonging to an ethnic minority, vulnerability can be very high. 'Early intervention' and 'periodic mentoring', as suggested in the Issues Paper seem inadequate responses in such situations. Substantial support, funded by an NDCSS may well be required for them.

> Vulnerability has serious moral consequences. Vulnerability belies the myth that we are always autonomous, and potentially equal citizens. To assume equality among humans leaves out and ignores important dimensions of human existence. Throughout our lives, all of us go through varying degrees of dependence and independence, of autonomy and vulnerability. A political order that presumes only independence and autonomy as the nature of human life thereby misses a great deal of human experience...” (Tronto, 1994:135)

In order for the ethic of care, as proposed in this submission, to work to the advantage of people with disabilities, and of carers, and safeguard against perversions of 'care', this exploration of and wide agreement on the nature of needs is essential to any NDCSS.

I suggest Maslow's hierarchy of needs and Max-Neefs' work is examined for it suitability as a reference point to the needs that NDCSS-funded approaches of service would meet.

3. Climate change impacts

Where the present negative social position of people with disabilities is bad enough, developments predicted for the near future pose even greater threats to this already vulnerable group.

Highly likely climate change and biodiversity-loss scenarios make it imperative for a highly resilient care and support system to be in place and an NDCSS design should factor in these threats. I am referring to the combined effects of imminent climate change and energy shortages. The unprecedented loss of biodiversity also carries significant risks to humans. Former Prime Minister Kevin Rudd has described this unprecedented phenomenon as the greatest moral challenge of our time, and he was right.

Many reports point out a high environmental-social-economic cost to human-caused climate change. The combined effects of global warming, energy shortages and socio-economic disturbances will impact most heavily on those most vulnerable now. People with disabilities are like the canary down the coal mine in that respect and need appropriate safeguards against these threats. Since government spokespersons have repeatedly referred to the character of our nation being reflected in how it treats the most vulnerable among its people, we should expect to have agreement on that.

A report commissioned by the Western Australian Disability Services Commission states that *“one of the key issues will be to determine which formal groups will be supported in their demands for* *adaptive strategies and mitigation policies. We would argue that lessons from history teach us that it's highly likely that climate change adaptation will become a class issue - where those with resources will be able to create their adaptation and mitigation responses, and those who do not have the resources, will suffer. This will be an important issue when considering the federal government's future agenda on social inclusion"* (Stehlik & Costello, 2008, p.11).

Possible future scenarios of an Australian society under inordinate global socio-econo-environmental stress include that of an even more highly self-interested and utilitarian nature than today's, where people with disabilities become liabilities and burdens that can be discarded. This scenario would only constitute an incremental change of present dominant values of the market, and a medically constructed view of disability as financial and physical burdens. Therefore working towards viewing people with disabilities as possessing the same intrinsic worth as that of any other, and their welcoming acceptance in community is the best practical safeguard to their wellbeing that we have.

As goodwill for public expenditure on disability support would wane under such adverse conditions, trying to safeguard resources for this purpose, including perhaps through a public levy, is important, if not essential. But such efforts must be coherent with regard for vulnerability and commitment to capacity building.

Stehlik & Costello refer to the need for using *measures of vulnerability and capacity building* in strategies towards amelioration of climate change effects on such vulnerable groups – the understanding of which it says: *"remains less than well developed in the Australian context as regards specific pre-existing vulnerable groups" (p. 6).*

Recognising vulnerability and building capacity for actually belonging in community are therefore vital components of care and support for people with disabilities.

I suggest working parties to examine how measures of vulnerability could be developed and applied in assessing individual need alongside recognition of the impacts of impairment, within an understanding of the social/ecological model of disability.

4. Participation

The NDCSS is premised on the National Disability Strategy's focus on economic and social participation. Whereas participation is important, and while recognising that, in social interactions during participation, other needs can be met, participation as a goal should be put in a context of fundamental human needs. When doing so it becomes apparent that needs like safety, security, protection, belonging, and human development encompass a broader set of indicators of fundamental human need then participation. These are based on an extensive body of research whereas the basis of declaring participation as a central need for people with disabilities is unclear. Of course participation is contained in the UN Convention but nowhere in it does it say any nation cannot expand on that understanding.

Participation is also of relative importance, depending on the ability to participate meaningfully. People with severe behavioural and cognitive impairments can however still experience belonging in supportive caring relationships. And every person has their own developmental curve, much of which may not always be apparent to others. An NDCSS should therefore be able to fund approaches that go beyond measures of need as constructed solely by social and economic participation.

Having said that, participation is obviously a good worth advancing, certainly also in the framework of care that I suggest as valuable to an NDCSS. As the NDCSS is grounded in participation it should model it at all levels.

An NDCSS should build in high levels of real participation for its users and such participation should:

- allow direct involvement in decisions made about eligibility, service responses, service policies and practices, in such a way that does not take over the life of the person;
- recognise and ameliorate power imbalances;
- be creative in enabling participation;
- build capacity for genuine participation.

WHERE

A In overseeing operation of NDCSS

B In monitoring, evaluating, renewing NDCSS

C In ensuring greatest responsiveness to needs in NDCSS-funded 'services'

D In developing research priorities

HOW

A By being represented* on the NDCSS governance structure

B By local opportunities to participate in service policies and practices

C By having access to strong *independent* advocacy

D By having easy access to complaint mechanisms

E By decentralised, low-bureaucracy structure of NDCSS

F By fully participative, transparent approach to decision-making on who is eligible for what.

- *By "being represented" I mean expertise as in lived experience of disability from various socio/cultural backgrounds and allies in relevant fields, where such voices are not diluted by representation from unions, business, media and so on, but with a clear focus on disability.*

5. Capacity building

If the NDCSS is to be a contributor to fundamental positive change in the lives of people with disabilities then it must involve a set of beliefs about disability and people with disabilities that is different to how it currently appears to construct it.

It will mean services based on an understanding of the causes of disability as arising from interactions between impairment, environment and attitudes, of people with disabilities with inherent value and developmental potential. Where supportive, caring community is both a necessary environment for support as well as an outcome of such support.

This view of disability involves a greater understanding of service in relationship, where there is active participation by people with disabilities and their carers in the service process, policies and practices.

It can involve greater control over resources to pay for a service and manage it.

It also involves greater diversity and regional participatory advice under a common understanding of what disability is about.

These ways of doing things require broader availability of skills and understanding that are commensurate with them. Therefore an NDCSS ought to invest in capacity building processes and draw on the expertise that is already there in such capacity building in Australia.

Capacity building is a big subject with many levels of application, from personal, to organisational, to community. A working party of people, networks and organisations with a track record in this area should be established to develop approaches relevant to an NDCSS.

6. Care as a framework

This care framework (Tronto, 1995, 1994) describes care as a political ethical framework, where care is constructed in four stages. If 'care' is to mean anything concrete in the inquiry towards a care and support scheme, then this now 25-year old theory, seems highly commendable as a practical application, relevant to doing things in 'new' ways :

Attentiveness to need;

Taking responsibility for that need;

Attending to the need competently and;

Responsiveness to the care given.

This framework connects abstract policy to the daily lived experience of people with disabilities and that of carers. However, to use a 'care' framework will be challenging to many in the disability movement, given its long-held and legitimate concerns and sentiments about its applications.

> ... it is obvious that care is a process, that judgments made about care arise out of the real, lived experiences of people in all of their variety. From this standpoint, we must reformulate our account of human nature (people qua people are interdependent rather than independent), of what activities count as centrally human (...), and our values, rethinking what we expect from our collective institutions (Tronto, 1995).

For good historical reasons, 'care', like 'dependence', and 'vulnerability', is a suspect term to many people with disabilities. It is important to note that this framework of care is far removed from negative experience of one-way, parochial care, expressed in institutional care or care as a charity, which really are perversions of care, and are closely associated with a medical model of care of people with disabilities.

Care as constructed here fits with notions of social justice, rights, participation and inclusion. It continually connects the daily lived experience of disability to abstract constructions like rights. It enriches currently limited constructions of inclusion and participation, and thereby gives them power. It is a dynamic that clearly puts the interests of people with disabilities first while providing more positive linkages with those of carers, government and services.

Eva Kittay is the mother of Sesha, a young woman with severe cognitive impairment.

In “a society which defines and confines all meaning and worth in terms of production, profit, and pervasive greed,.”(Trent, 1994, 277) the intellectually disabled will be exploited. In such a society, their caretakers will also be exploited and will have the opportunity to become victimisers as well as victims. The change from institution to group home can help, but the form of the residents will not alter their poor care its residents receive if the care givers are as abject as their charges. In such a society, care will be minimal, and callous caretakers will be inevitable.” (Kittay & Kittay, p. 269).

Care applies to the private sphere as it does to the public. Its four stages are a practical framework in how to best support someone in need. It also can be applied to policy formulation and to staff relations within disability services and government departments. The prerequisite is of course to be clear about whose need we focus on and how we construct needs. I stress again therefore the importance on being clear on what fundamental needs are.

Care is not peculiar to some people only, like people with disabilities. We are all interdependent people. Dependent on care as a newborn, as a child, when ill, disabled or in frail age. Care relationships are a normal, and essential, part of life. A society that supports care will be a more caring society. In a caring society people with impairments will be less disabled. Carers will be better supported. Paid care will be a valued job and better rewarded. Just as we all contribute to the currently disabling forces in our society and communities, so can we be forces for enablement.

I propose a working party that explores the merits of applying Tronto’s care framework to each aspect of an NDCSS, its policies, practices and organisational structure, and to those it funds.

7) Quality of life and quality of service

Assessments of 'quality of life' are problematic as the closer one examines it the more fluid it becomes. It has been criticised for having the potential to degenerate into judgements about quality *or* life.

A quality of life approach suggested in the Issues Paper measures quality of life by objective and subjective measures, relying on self-reporting of wellbeing. But there are obvious difficulties in getting reliable self-reports from people with cognitive impairment or mental illness. It is possible of course that reporting is done through others, calling up more questions and needs for safeguards. At the very least more community debate about quality of life measures as outcomes of services is needed.

As suggested above, another approach is to look for the presence of those things in a person's life and in services, that are known to contribute to the meeting of their fundamental human needs. Coherent with the relational nature of the proposed vision, disability definition, values and needs within acknowledged interdependence, observable things would be positive relational processes, as well as other signs that indicate that fundamental human needs are likely to be met. Evaluation methodologies of this kind exist and are being applied.

Building on these indicators one would then design service approaches, based on the said ethics of care framework that incorporate these characteristics in their organisational structure and functions, maximising their coherence with their purpose and vision.

It follows that one would be able to evaluate such service based on organisational characteristics and processes as well as by direct rapports from its service users.

A necessary counterpart to finding out what causes our problems is to look at those things that constitute quality in being of service, and incorporate those aspects in an NDCSS. Quality of service is constituted by the extent to which a response to a need is adequate, based on values and beliefs about what contributes to a good life.

Again this is an exploration that must involve direct engagement with people who receive service, as well as involving the literature and those in Australia who have been involved in developing implementing and safeguarding high-quality service approaches based on relational models. There is much to be learned from a number of such, often low-profile, organisations.

Quality of service differs in different states and territories. Whereas Western Australia is by no means perfect, comparatively it has a better coverage of needs than most other regions. It also has a long experience of local area co-ordination and individual funding. An NDCSS should not mean that things that currently work reasonably well are discarded.

8) A positive story

A NDCSS should be progressed on a positive disability story. A story that is about the contribution to the character of our nation as one that invests in proper care and support of its most vulnerable citizens.

It should not portray people with disabilities or carers as victims or saints, or people with disabilities as burdens, or super heroes. If it’s about assisting people to lead ordinary lives then that is what the story must tell.

Many people with disabilities have learned to live within limits, dictated by impairments and found creative ways of living with them – often quite well. Their lives often contain the relational values and practices that contribute to community among people. These ways of living are actually strategies for sustainable lives where individuals can c\flourish. Is that not what all of us need?

Tronto's Care framework applied to being of service contributes to a more caring, less disabling society.

9) Safeguards

NDCSS risks being a proposal for a large national bureaucracy.

Bureaucratisation, inflexibility and distantiation from the people it aims to serve will make an NDCSS ineffective in meeting needs. NDCSS ought to examine Centrelink, Medicare and the National Superannuation scheme for their strengths and weaknesses for example. Centrelink's difficulties in communicating with its customers, Medicare's waiting lists and Superannuation Funds insecurity in its dependence on the global market come to mind as major weaknesses against which to provide safeguards.

NDCSS safeguards should include:

- Overt anchoring in disability definition, vision fundamental human needs, and grassroots participation as discussed;
- Modelling NDCSS and services on care framework within organisational structure, policies and practices;
- Facilitation of the practical ethics of care in the organisational structure and functioning of an NDCSS as in the services it funds;
- Overt and frequent use of a positive disability story;
- Facilitation of development and exercise of strong, independent disability advocacy;
- Facilitation of development and exercise of effective complaint mechanisms;
- Facilitation of development and exercise of effective participation mechanisms;
- Effective and independent in-built monitoring, evaluation and renewal of NDCSS and services it funds at regular intervals;
- Decentralisation and localisation of eligibility assessments and service delivery under a common values umbrella;
- Maintain multiple funding sources as a strategy that contributes to the resilience of revenue for purpose of meeting the needs of people with disabilities, under a common view of disability umbrella;
- Attention to conditions in rural/remote locations and cultural diversity;
- Build in vulnerability criteria in eligibility assessments alongside nature and degree of impairment;
- Flexibility in maintaining multiple sources of funds under a common values umbrella;
- Maintain and develop diverse approaches to meeting needs under one values umbrella;
- Capacity development for people in administrating their individual funding packages;
- Simple, non-intrusive measures to guard against abuse and neglect of persons and abuse of funds in person-centred, individual funding packages;
- Identifying and drawing on those service approaches that work well;
- Safeguards necessary against two-tier service structure of those eligible for NDCSS and those not;
- A new national disability research institute under NDCSS auspices should not be progressed as this could impoverish research scope. Instead existing diversity of research centres should be supported;
- The development of each of these in a genuine participative manner by primary stakeholders.

10) Taking responsibility for 'dysfunctional service system'

Even though there is scant data about the reasons for the majority of service approaches that are failing many people with disabilities, this NDCSS Inquiry does not propose to look for them. The reports that it mentions in its Issues Paper that supposedly do this already are not cited in it. These reports actually do not identify underlying problems in services. The NDCSS campaign by the Disability and Carers Alliance, also overtly discourages any investigation into what are the underlying causes for the dysfunctionality of services that are the very stated rationale for the inquiry.

Cited service deficiencies, such as being under-funded and crisis-driven are merely symptoms, not underlying reasons. If we treat the symptoms we would just need more money. If we want to treat the causes we need to first understand them.

From my own experience, in that of friends and as observed in my work, reasons for services that do not meet needs well, or even create disablement, include:

- negative attitudes by service and care providers;
- organisational efficiency-needs trumping service user needs;
- non-participatory top-down management;
- high staff turn-over; inadequately trained staff;
- managerialism, where it is thought that management expertise is all one needs in any area of endeavour;
- over-professionalisation where service user expertise is not valued;
- bureaucratisation;
- top-heavy management structures;
- distance from the lived experience of service users;
- disabling organisational values around medical, segregation/congregational, economic market models;
- and more.

Wills and Chenoweth for example, mention outcomes of pervasive managerialism in disability services as resulting in “compartmentalisation of of the various components of support to the extent where service outcomes are reverting to the counting of “bed days”, 'community access hours' or the number of available 'carer support days' – a long way from what constitutes an ordinary life” (Wills,R & Chenoweth,L., 2005:55).

How can we achieve transformational change when we do not face, acknowledge and take responsibility for the underlying reasons for service that is not what we need? Just more money, or even individual funding models will not change this. It takes a values change to where 'being of service' means care. Without it we will just have more of the same dysfunction.

Not looking at the underlying reasons for the 'broken system' is akin to going to one's garage with the complaint of unevenly wearing tyres, and where the mechanic suggests a 'paradigms shift' for your car by fitting it with four new tyres. Without proposing to look at the wheel alignment or your driving habits. Cost effective? Meeting your need for quality service and outcomes? Not likely.

The current state of affairs has not come out of nowhere. It is in large part the result of government and services' policies and practices. It is now time for these parties to acknowledge this fact and publicly accept responsibility, in order for us all to move forward.

Not looking at the underlying cause of the system that is 'broken' is to ask tax payers, when it comes to voting for an extra levy out of their pockets, to accept this without knowing exactly why the current system is no good, and consequently with no real strategies to make it better. This does not present as an obvious strategy for electoral success.

I suggest the Inquiry investigates underlying problems in disability services, as well as identifies the best. There are examples of good service practice to draw on too.

11) Disability research

High quality of disability research is in the interest of people with disabilities. It is proposed for an NDCSS to fund “Research into best practice and prevention strategies to drive effectiveness, efficiency and reduce long term costs.”

It is unclear why it is in the best interests of people with disabilities to have a centralised research centre of this kind.

Disability, and human service research in Australia is important and deserves to be better supported for the contributions it could make towards inclusion of people with disabilities. A research focus as suggested for an NDCSS body includes some aspects of what such research may explore but is not broad enough to fulfil that aim.

It would serve that interest better if existing and emerging centres of disability research received better support and funding, under an umbrella of an agreed set of values and beliefs about disability as advanced in this submission.

Diversity of research (centres) contributes to richer research. Independence of research contributes to quality of that research.

ADDITIONAL COMMENTS

12) Individual funding.

Individual funding has been made a centre piece of an NDCSS. Of course, in itself it does not constitute a fundamental human need. It is a possible tool towards meeting them. The elements of greater control and choice over a service can work both ways, depending on the motivations for individual funding and the underlying values and beliefs about disability of those using them, and funding them.

If individual funding is seen by governments and services primarily as a way to make dollars go further than this may be a misconception of the cost of individual funding, as well as be a motivation that is at odds with an aim of meeting the person's fundamental human needs.

Individual funding should be an option but should also be fully safeguarded against possible abuse of the primary person and of the funds involved. At the same time such accountability measures should be sensitive to privacy needs.

Individual funding can involve levels of administration that a recipient may not want to, or be able to take on. Support should be available for people to embrace that level of administration and control that fits their situation. Book keeping, hiring, managing, and firing of staff is not something that's for everyone. Capacity building for those who want to learn how to do this should be available.

I suggest that the Inquiry explores the knowledge and expertise of those organisations that have a track record in supporting people with disabilities and their families in such ways.

Some are concerned that widespread adoption of individual funding will lead to a weakening of the viability of the service industry. Whereas some of that concern may involve anxiety about job losses, another part is legitimately concerned with loss of services' infrastructure.

We should not do what we did with de-institutionalisation of people with mental illness and abandon them to their autonomy in choosing to be 'free' in an uncaring society.

In our individualistic society, where a capacity for freely-given care has been eroded, formal services represent an important last resort. And they have their place. Good services will always be needed.

Change towards a greater application of individual funding models should be done carefully and should incorporate easy opportunities to go back to using a service if that best fits the needs of that person. A mix of services and individual funding should be found that is to some extent flexible. Of course flexibility will have its limits because of the solidity of service infrastructure. Any change should be evolutionary, and prioritised to highest needs.

13) Interface with aged care

Life has no sharp boundaries between being a 'younger person with a disability' or being aged with a disability. Disability is disability, no matter when acquired or experienced over a lifespan.

The preferred option would be for NDCSS funds to be available across a whole life span, no matter when disability is acquired. This may depend on the size of revenue obtained from a public levy in combination with other revenue sources.

It appears an anomaly for a person with a disability who is eligible at a certain age for NDCSS-funded benefits, under a certain values and beliefs umbrella, while a person with a disability on the other side of that dividing age line would be subject to receiving care and support based on a different view of disability. Certainly there are enough reports in the aged care area that the situation there can at best de described as uneven.

I suggest that the Inquiry pay attention to ways of enculturing both sides of that dividing age line to the same set of beliefs and values about disability as proposed in this submission. It would not matter that needs on either side of that line would be funded from different sources, as long as of course adequate resources were available.

Doing so would be coherent with a long-standing pursuit of a whole-of-government approach to supporting people with disabilities.

14) Two tiers?

It is important to give thought to the possibility that an NDCSS might give rise to two tiers in disability support, for at least two reasons.

If the NDCSS would define eligibility as for those with a 'severe or profound' disability then large sections of the disability community would be excluded from its benefits.

Those who would need core intervention, and would likely not participate in the job market, would be one tier. Those who could participate in the job market would be the second tier and not be eligible for NDCSS benefits while still carrying a level of vulnerability that warrants care and support.

Presumably those in that second tier would need to rely on existing income-tax based government revenue, and other sources, for assistance.

That highlights the need to safeguard such existing revenues to be protected from governments cutting back on them because we now have a public levy which takes care of the most costly category of people.

It also highlights the need for a common view-of-disability across different revenue sources and the provisions they fund.

15) Paradigm change

> There is long history of professionalised disability service models, over some 200 years. Each one has been followed by another. “What strikes one about these accounts is that each chronology seems to follow a similar arc or trajectory. A call for change or reform is bolstered by optimistic predictions of improved outcomes. It is followed by a period of gradual, often ambiguous policy changes that are undertaken in pursuit of the recommended reforms, while usually maintaining at least some fiscal support for the discredited model. Finally there is a period of reassessment which recognises the unfulfilled promises, discovers some unintended consequences and bemoans the persistence of the same problems that the reforms had hoped to remedy. … A new reform slowly emerges as the answer to all our problems. (Ferguson & O'Brien, 2005)

Much has been said by those advancing the NDCSS about the break-through, fundamental, and revolutionary change in disability service, it would bring.

We do need a paradigm shift. A change in underlying values. A rising prevalence of disability plus the little understood but imminent impacts of climate change means that this is a crucial time to vigorously work towards fundamental change.

A mere change in becoming more flush with money or apply technologies such as individual funding in a more widespread fashion, based on the same medical/market models that drive inadequate, sometimes harmful services, is no change worth having.

A change of values is never an instant thing. It takes time to change personal beliefs about how 'the world' works. The real paradigm shift is not a 'thing', an outcome if you like. To me it would be a paradigm shift if this NDCSS project could be a starting point for re-examining the status quo. What values are those we need to meet fundamental human needs? How can we devise a funding scheme that facilitates this to happen?

To have agreement at that level and to see processes of engagement with difficult issues and with the people who live with them every day in genuine involvement, would be a paradigm shift we can agree on today. As they say, it's the journey that is important, as it shapes the destination.

We should not succumb to the quest for the quick magic bullet, but engage on a positive journey towards something that is better grounded in the lived experience of disability. An NDCSS or any other organisation, or 'them', cannot do this. It can only be done in a genuinely participative way with people with disabilities and their allies all aboard.

16) Openness

Having said that being all on board does not mean there is no robust debate and engagement on issues vital to the interests of people with disabilities in the journey towards an NDCSS. Open and honest exploration also requires transparency of all interests involved in this inquiry. The interests of governments, services, people with disabilities, carers and the tax payer must be on the table. In doing so the needs of people with disabilities must be central and conflicts, overlaps and congruencies of interests must be mapped and moulded in a coherent approach.

Open and transparent communication is essential in building trust in the positive relationships that are required between people with disabilities, carers and support agencies in order to meet fundamental needs. An NDCSS must model such qualities if it is to be effective in facilitating such dynamics.

17) Utopia

In offering concepts such as care in this submission, suggesting an open and transparent process, and including critique of economics as an inadequate worldview in meeting the fundamental human needs of people with disabilities, may invite a response that such proposals are simply an example of not 'living in the real world.'

It could be thought naïve to suggest we apply care in a world where care is suspect and often perverted; to suggest transparency and openness in processes where cynicism about government spin and expediency is high; and where it is thought that if you do not at least present arguments for an NDCSS in economic language, then you won’t have a hope of getting it through.

But respondents to the government's Shut Out report called for a paradigm shift, a *fundamental* change. Serious anomalies within the business-as-usual ‘real world’ make it important now that we have one.

What I propose is no Utopia, which means 'no place.' What I propose is grounded in the everyday lived experience of vulnerable and interdependent people with disabilities, based on fundamental human needs that we all share. The real world is what we make it. If we are trying to devise a scheme that works for people with disabilities then it must be coherent with their needs and interests.

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