My Feedback on a NDIS

Disability Care and Support

I fully support a no fault scheme for all people with a disability that do not receive the supports we require regardless whether we receive no funding support, or whether we do, if we require more, then we need to be able to access it with minimum fuss & very little wait time.

- **an assessment that is based on a person with disability(pwd) need-if a person has a disability & can be verified as they receive Centrelink benefit, a state run disability service or found to be eligible but not receiving a service, or accessing some other service that is advocacy, health department etc. &/or has an occupational therapist or speech therapist(ie. Allied health professional) assessment, then the pwd should receive a service/support.**
- **Pwd’s need to not constantly be assessed by different government & NGOs for whether we have a disability or whether we need a service, if we have any one of the above mentioned assessments then that should suffice.**
- **For those new to the service system there should be one National assessment tool, that regardless of where we live in Australia we are assessed similarly to others & it should be administered by Commonwealth Rehabilitation Services, like they used to during the 1980s.**
- **The assessment should be a Needs/entitlement” assessment, not the usual “deficit” assessment, whereby pwds who have the “worse story/case” get funding, with an emphasis on what “we pwds can’t do”.**
- **The questions need to be strength based & “what does a good life look like for a pwd”.**
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Pwds are constantly letting government & NGOs know that we need assistance. My concern is that pwds who have a physical disability are certainly a high priority, as we can't get out of bed or dress ourselves; we can hardly be able to participate as citizens fully in the community. However, there are a whole lot of pwds that are non verbal, & have significant intellectual &/or ABI or cognitive disabilities who are even further disadvantaged as they are voiceless & many end up in the criminal justice system, &/or nursing homes or bording houses where they are abused & exploited they shouldn't be there.

Many of us live in constant worry about what will happen to us if our partners die, or leave us, or our family member dies or has had enough.

The question should not be who is in most need, this type of question just pits pwds against other pwds.

It needs to be an entitlement based system.

A national tool of assessment needs to replace state based assessments & a tool that is entitlement/human rights based is required.

I think we need to abandon the notion that people with similar needs should have similar supports.

Such premise just further shows me that professionals don't want to work in the "grey", pwds can not be categorised in to boxes, where life needs are "black or white".

One thing I have learned as a pwd & service provider is that pwds who have a similar disability/need are often not needing the same level of supports due to a range of other variables in that person's life; they include; number & quality of family & local supports; formal & informal; attitude towards disability of pwds & family members, resources & capacities of pwds & family members, & indeed if the pwd is alone etc.

Pwds need training & support by citizens to ensure they

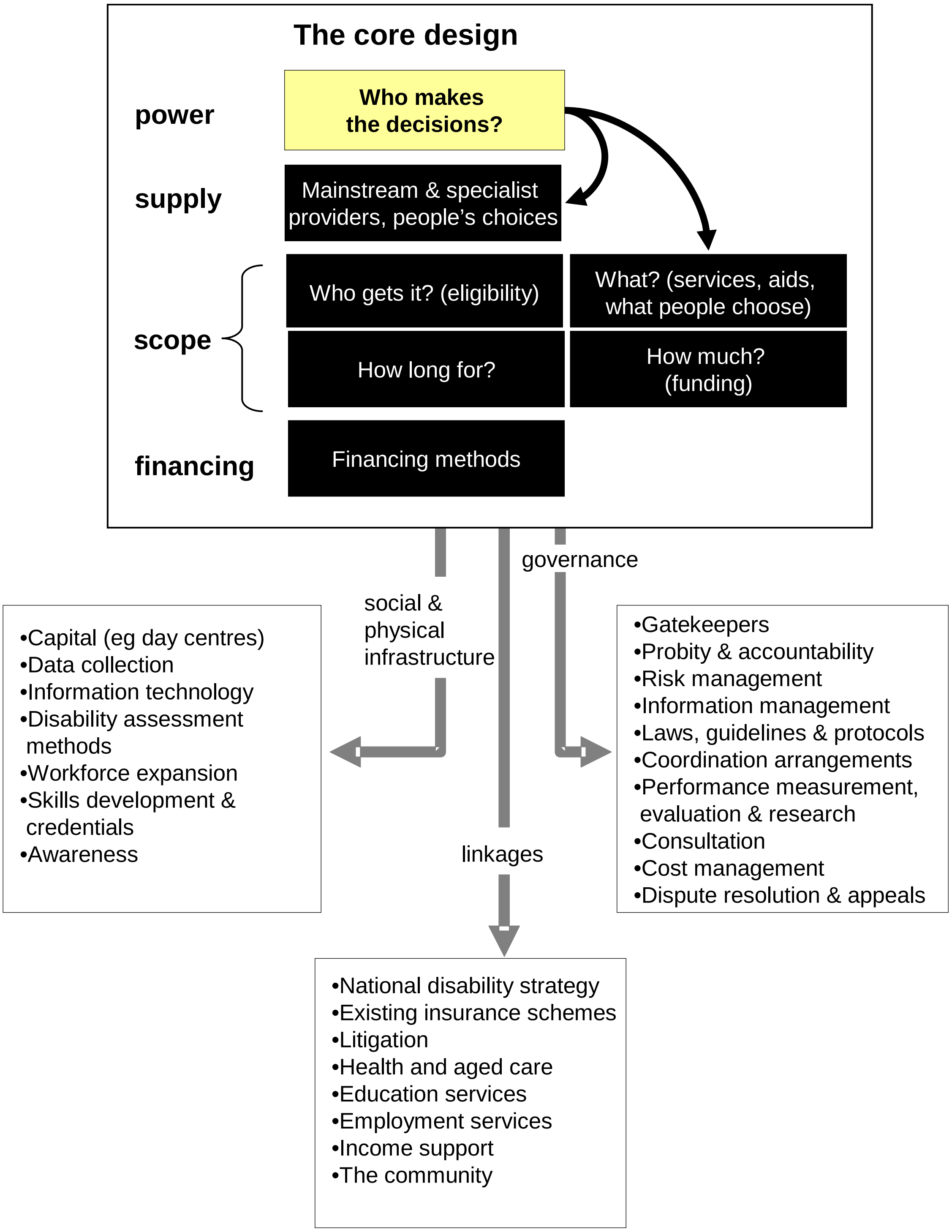
understand how individualised self directed funding can & should be set up & accessed.

Having a range of self directed/family governance set ups provided as there are a number of examples across QLD. & Australia-having people like Michael Kendrick & his supporters give workshops & develop booklets/DVDs on what & how to set up these types of self directed supports & the options available are vital for real empowerment to occur.

Victoria is well on it's way to allowing pwds to receive direct payments & have supports be delivered through a self directed service model.

As previously stated a National body such as CRS, in conjunction with pwd.

The main aspects of any system



I need & I know several that need:

*   several individualised paid support hours to assist with personal care, domestic care, transport, shopping, & access to community events & health appointments.

Also, if I need a piece of equipment or any other pwd requires equipment, such as wheelchair, hoist, electric bed, outdoor hoist for spa, car modifications, communication devices etc. pwds should not have to wait more than four weeks & should not have to beg, borrow, plead for another government body or charity to pay for the gap, after Medical Subsidy Scheme has paid or if they don't fund certain items pwds should not have to beg, borrow, or get charity or other government funding which can take some months/years & is often humiliating.

Many of us would benefit from specialist therapy services; physio. Occupational, speech & Behaviourist. In regional centres there is hardly any of the above & only for perhaps 0-6 year olds with certain types of disabilities-those pwds that have missed out on EIS could benefit hugely & possibly reduce some of the disabling elements of disabilities.

Other services required are:

Leisure/recreational support services to facilitate pwds to access,

More paid advocates/citizen advocates to assist pwds to speak up for ourselves.

Disability awareness/campaigns to educate the community as to inclusion & how it makes our community stronger & richer.

Mentors & leadership programs run by & for pwds to encourage empowerment & pwds to take up leadership roles.

Host programs-like Interchange program in Victoria, whereby volunteers in the community who are screened & trained become the host for children with disability & could be extended to adult pwds-so as the community citizens become the natural respite provider, instead of traditional respite services.

Setting up self directed funding, & increasing our numbers of paid independent advocates across Australia.

Abolishing the costly & inefficient State Disabilities government services.

Millions has been spent on Disabilities Services in QLD. & yet only 13% of pwds receive support, tthis is a crime against humanity..

Other supports needed include:

Having a range of specialists & case management services to all children diagnosed with a disability-early intervention services would prevent many of the adverse impacts of disability;

Occupational, speech, physio. Behaviourist, intensive case management-as can be seen by the AEIOU service for children with ASD, a huge success; no reason why all children with a disabilirty-cerable palsy & other disabilities can't receive the same EIS support-children with ABI, other physical disabilities too.

If we could receive the supports we need, to live, then work opportunities would be more able to be pursued as the struggle just to function each day would have been addressed. Also, we need to have Community Mentors to empower pwds & their families to dare to dream & see what is possible. Many pwds are very afraid to branch out & take risks & do different things, & many don't know how, & haven't had opportunity to explore & develop safeguards, while still taking the plunge.

Ask the pwds & family members what works well!

In Regional & Remote Australia:

There should be financial incentives for allied health professionals to work in rural remote areas as well as a higher salary for Support Workers & service providers.

Paying for staff's re location costs, reduced rent, additional free training, all could help get staff & keep them.

Provide funded Supervision/Mentors via Skipe or other IT means.

How to fund NDIS:

Through an increase in the Medi care levy or any other increase in tax, as long as it goes to a NDIS fund & not touched by governments for other purposes.

Have an appropriate levy scheme funded, & ensure it's got sufficient funds always.

I fully support the QLD Blue Skies vision, which should be embedded into a National scheme:

The Blue Skies Scenario:
A vision for an inclusive community

In 2019, the community is strong and vibrant and embraces diversity. While the work of growing community will never be complete, wherever a person with a disability lives, whatever their choice of lifestyle, their experience is one of rich inclusion and sense of belonging.

Central to a better life for people with disability is acknowledgement of their inherent rights as citizens, with an emphasis on having a secure home and enduring relationships, with service, family and community working well together to provide supports as and when required, in the community of choice. The shift is evident as early as when a child with disability enters the child care system then school. They are welcomed into the facility of the family's choice, and have full access to the standard curriculum with supports as required. There is a marked increase in the diversity, inclusiveness and uniqueness of lifestyles for people with disability.

What were the drivers for change in 2009?
In 2009, the most powerful driver for change was the shared commitment by all parties, including state and local government, to adopt a strengths based framework for enhancing sector/community partnerships. The

focus shifted sharply over a 5 year period from crisis based investment to proactive, early intervention and capacity strengthening responses to meeting needs.

The role of government changed with the Commonwealth taking on full responsibility for funding individual support needs through a nationally consistent assessment process. Meanwhile, the State Government focused on:

- service development;
- accountability; and
- building capacity in individuals and families to make better use of resources and drive their own future.

By 2012 both levels of government declared an intention to move away from infrastructure capital investment to community and social capital investment. A key role of the State Government was the establishment of a strong network of Community Navigators* (Local Area Coordinators). Community Navigators provided timely access to local information and referral to generic and specialised services if required, but their primary focus is on building a network of enduring, lifelong, freely given relationships around the person.

The strategies employed by the State Government also included awareness raising education programs, such as:

- *kids teaching kids* in every Queensland school;
- mentoring programs and skill and experience building programs for people with disability and families at key life stages;
- host family and shared care arrangements; and family collectives.

These strategies were developed in direct response to the expressed needs of community, individuals with a disability and families with close attention paid to content and choice of provider to ensure coherence. These strategies were implemented as a function of specialist non government organisations.

By the end of 2010, state and local governments were, together, actively driving strategies to build a safe, capable, responsive community that acknowledged that there is a place for all, and a role for all citizens in the building of their community. These strategies included the establishment of a network of Community Builders* (community development workers) located across every region of the state. The role of these skilled, committed people was to work closely with the Community Navigators, individuals with disability and the community to:

- educate;
- remove the structural, policy and attitudinal barriers to full inclusion; and
- to ensure all people have the means and opportunity to make contribution as members of their community.

Local councils were aligned on development application processes and started working closely with developers and community groups, insisting on all new developments (in particular, housing) being based on the principles of universal design (footnote 1). By mid 2010, a strong shift was noted in urban design with a range of spaces and places being established specifically to provide opportunities for people with disability to participate safely and generously in wider community life.

Of particular note, were the frequency and quality of partnerships between state and local government, people with disability, families and housing groups. These partnerships were critical to ensure a range of inclusive and sustainable housing alternatives (and the support where required) for people with disability, as they moved into adulthood — or in the case of acquired impairment — returned to living independently.

All levels of government were making sure their own business practices (such as procurement practice and public service accommodation/travel policies) become disability friendly.

At a service provider level, services willing to work in new ways were able to position themselves for sustainability through capacity funding (for infrastructure) and were able to offer a broad range of person-centred service responses. By 2012 organisations had adapted readily to expectations that new services would be built around need rather than program eligibility, and had developed 5 year transition plans to ensure person-centred responses for existing clients. At the same time, the range of options for funding these service responses broadened to include (but not be limited to) direct payment, individual funding, recurrent and life-stage based funding arrangements.

The role of the person with disability was clear
It was that people with disability:

- identify their own vision for a good life, their needs and preferences wherever possible;

- participate actively in the life of community to their full potential (in whatever sense community has meaning for them); and
- inform and support continuous improvement in service delivery at a local level.

The role of a faithful family and enduring friends was clear

It was that a faithful family and enduring friends:

- have a natural authority in the life of the person with disability;
- assist the person with disability to envision, plan and build a decent life;
- preserve their ordinary roles and relationships as family or enduring friends; and
- are a consistent, enduring link between the person, the community and support system.

The role of Community was clear

It was that community:

- acknowledges, embraces, promotes, establishes, maintains, and develops further and rewards the gifts, talents and contributions of all of its citizens;
- works in partnership with ‘significant others’ in the addressing of barriers that restrict valued community participation for all; and
- values the opportunity to both individually and collectively act, so as to ensure that the *Convention on the Rights of Persons with a Disabilities* is evident within the daily life circumstances of individuals with a disability within community.

The role of services was clear

By the end of 2010, the disability service system was responding, person by person, within a universal set of principles including:

- consistency of application and funding response;
- entitlement and certainty for people using services;
- building capacity, competency and interdependent community relationships *in place*;
- helping build a thriving, supportive network of family, friends and community from the outset;

- respect for the natural authority and roles of family and enduring friendships in any service response;
- design of service response (generic and/or specialised) to meet individual need; and
- a focus on the least restrictive alternative and review of outcomes.

The role of government was clear
Government across all jurisdictions had:

- worked diligently to understand and ensure that the United Nation's *Convention on the Rights for Persons with Disability* was reflected in their policy and practice;
- ensured the service delivery system is driven by social policy predicated on disability as a social construct rather than personal tragedy; policy that assumes universal entitlement to adequate support to live a decent life; and
- put in place a national disability insurance scheme, similar to the Medicare levy.

At a national level, government had achieved its target of 75% of public transport being accessible, and successfully negotiated with the states for nationally consistent aged care, disability support, and aids and equipment schemes.

The Queensland government had shown strong leadership in the National Disability Agreement (NDA) negotiations of 2012, paving the way for a new, more equitable system of need identification and allocation of funding.

In 2019, funding of disability support had two key elements:

1. the *individual funding allocation* determined through the national assessment process (based on need rather than impairment), with state and commonwealth jurisdictions working well together to coordinate housing and disability service provision.
2. the *service capacity funding* (based on demonstration of outcomes-based quality certification) and support provided by the state.

While funding is predominately driven by individual needs, due regard is given to the individuals’ gifts, talents and potential contributions to the community in which they live. The individual is assisted with information, vision building, planning and navigation through the system by the Community Navigator in their community, and opportunities for contribution identified and facilitated.

Service and community capacity building is provided by the Community Builder.

Accountability

By mid 2010, the Queensland Government had pulled back on the burdensome, compliance based quality systems and negotiated successfully with community based organisations and service users for a purely developmental system, using the more generic health and wellbeing indicators alongside the disability service standards and human rights indicators.

How did this transformation occur?

By the end of 2009, Queensland's Minister for Disability Services has submitted a 10 year plan to Cabinet that had wide support from a broad range of stakeholders, including:

- people with disability;
- family and carers;
- service providers;
- advocates;
- government;
- educationalists;
- business people; and
- other interested Queenslanders.

The 10 year plan was well supported by Cabinet and paved the way for the *Inclusion Bill* of 2010.

The broad objectives of the *Bill* were:

- enactment of UN *Convention on the Rights of Persons with Disability*;
- strong individual, family and community capacity;
- inclusive communities – spaces and places, that are physically and socially accessible;
- a government investment strategy that supports strengths based rather than deficit or crisis based responses to need;
- a service system predicated on building supports around the individual and family as its first priority;

- government policy that ensures seamless access, not only to personal support but support to access, participate and gain strong outcomes from health, education (including VET and University education) and employment; and
- acknowledgment of the inherent vulnerability of people with a disability and the need for independent systemic and individual advocacy.

A *Diversity Charter* was also developed as a result of the consultation that informed the Minister's 10 year plan, and provided the *litmus test* or basis for evaluating all new and existing policy and practice initiatives. The *Diversity Charter* was a rallying point and important symbol of change for the sector between 2009 and 2014.

A range of strategies were put in place to implement the charter which included but were not limited to:

- a review of existing Commonwealth, State and Local government policy and practice as a starting point for realignment of funding policy and programs, with the *Diversity Charter*;
- incentives (financial and flexibility) for funded services to engage with their stakeholders and make the transition required of the 10 year plan;
- establishment of local planning, resource allocation and community engagement mechanisms to ensure responsiveness at a community level;
- funding of research (sourced from specific research funding programs rather than from disability budget) to establish evidence based policy and practice; and
- a well-resourced community engagement strategy to enhance visibility and increase the community of concern.

Where to from here (2009)?

For Queenslanders to live this scenario, the quality of leadership and engagement from both government and community sectors is critical. The community sector has committed to comprehensive engagement of both the disability sector and the broader community, including government, to gain a better understanding of what an *inclusive community* means for people.

Moving from vision to reality will require, among other things:

- An acknowledgement that step-by-step change is required.

- Transparency and a willingness to scrutinise current policy, practice, and reforms underway.
- Acknowledgement of the need to ensure that available funding is distributed fairly with as many people as possible accessing services.
- Acknowledgement that existing funding is insufficient to respond to all people who require support through specialised services.
- Acknowledgement that diversity includes older people and cultural and linguistic diversity.
- Willingness to explore new ways of working.
- Willingness to allow evidence and the needs of people with disability inform policy & practice.
- Willingness to align government investment with the vision.
- Commitment to the developmental work and capacity building required by all parties, including, government, non-government service providers, individuals with disability, families/carers, and the community needed to effect the shift in culture, policy and practice to make the vision a reality.

Footnote:

1. 'Universal design' - Changes to the Building Code through the Access to Premises Standard will cover most new and extensively modified public buildings – the real gap now is with Class 1 and 2 buildings (single dwelling houses and flats).