



The Foundation for Social Inclusion Inc

“an inclusive society where all people are valued, where everyone has a sense of belonging and all have the opportunity to contribute”

Submission to the Productivity Commission Commenting on Draft Report for a proposed National Disability Insurance Scheme

Thursday 21st April 2011

“Inclusion is about peace, acceptance, tolerance, commitment, compassion, helping, empathy, growth, development, community, sharing, belonging and concern for others”

Member Comment (1)

Given a proposed 'Transport Accident Commission,' (T.A.C. Victoria) model, comment is made here by a parent member who also works professionally in the disability sector who has twelve years experience in liaison with the TAC on a very regular basis:

- **The bureaucracy of the TAC does not support the notion** that the agency 'knows' the needs of a claimant. I have seen a TAC representative three times in the past twelve years in WA.
- **Staff turnover** has been significant and it has been very difficult to have my son's needs met with any consistency or reliability.
- In my opinion **the TAC officer has acted as a gatekeeper** to opportunities. It has been the responsibility of the family to seek what the TAC will cover; become au fait with the process and then advocate strongly for support. A very tiring ongoing activity.
- **The TAC operates on a medical rehab model** – not an inclusive social model. It has twice been suggested to me that TAC would prefer my son to live in a nursing home (in which case better funding would be available) or live with me (similarly more funding and consequently more support hours). I have on both occasions, emphatically refused to discuss this option.
- **TAC are happier for me to work unpaid** for 30/40 hrs per week: they will not cover family for services.
- **At this time however, I have a supportive TAC officer.**
- **My son has 'attendant care'** to take him to medical and therapy appointments **but not** to take him shopping, or to any recreational activity.
- **TAC language** used and insisted upon is extremely limiting.
- **Long delays in reimbursement** result in gap periods between personal outlays in monies to cover support, medications, therapies, medical attention where these services require payment on the day. It has taken 120 days for reimbursement. I fear that small agencies, often flexible, responsive and creative, will not survive the financial burdens placed on them under the proposed NDIS scheme with a result likely being the larger organisations will become dominant to the demise of the smaller which will have adverse affect on overall capacity to provide quality service to consumers. Such an outcome will also likely afford undue control to a few.
- **The marketing of this scheme is urging of high family expectation** in terms of an injection of vast quantities of money into the sector. There is huge probability for disappointment at the end of the day. Families will experience even more pressure and stress to become savvy, articulate advocates as they enter into a funding system which is highly adversarial.

- **Now is the time for improvement:** I acknowledge that we are fortunate to have been recipients of TAC's support over the years however if there is opportunity to improve the model, then I feel strongly that now is the time to do so.

Member Comment (2)

- **Canberra based control versus local control:** The current system is fractured, under-funded and in several pockets ineffective. We survive in a system of competing need which looks at a deficit model, (the more difficult and devastating a person's circumstances, the more likely that the person will be funded). Strengths based, person centred support; control lying with individuals and families, is how people would best be served. If W.A. had just a percentage of the \$6.3 billion of new money proposed, with such allocated to individuals and families it would likely be that current systems here in WA would be best positioned to support people to best practice standards, through holistic, person centred, tailored services and supports.
- **Canberra centred control will challenge individual/ family expectations and current experiences:** From a W.A. perspective, there is no evidence to show that a scheme operating from a new huge bureaucracy centred in the eastern states can deliver the sort of outcomes people are being led to expect from this proposed scheme at individual, family and community level.
- **Factoring quality communication and relationships into the 'frameworks':** A universal assessment of the needs of people with disabilities (A Common Assessment Framework) is felt to be a regressive indicator and begs the question "where are the connections and relationships with people?" Such a bureaucracy will work in the context of forms, boxes to be ticked, and referrals further compounding vulnerability and challenging years of work in W.A. around person centred approach to service delivery and control.
- **Safeguards to ensure a stable environment:** An abundance of money flowing into a system already struggling to provide contemporary support to individuals and families without appropriate pre-investment by way of community development and skilled staff resources is doomed to a chaotic environment and transient workforce.
- **All the good small agencies could go:** Small agencies providing quality support could be disadvantaged in the process and fold in the future.
- **Potential for huge disappointment:** Many people who are seeing (and being encouraged to see) the NDIS as the answer to their needs will be disappointed. Over 2.6 million people are identified as having a disability requiring assistance through the NDIS scheme. Only 360 000 people are expected to benefit from the scheme (in terms of an allocation of funding). This is a small number of people in the overall scheme of things, so the definition of "disability" will be of paramount importance to the outcome for many people.
- **The devil will be in the detail:** it is key critical that some real figures, real stories and outcomes are evidenced before any new system (scheme) is rolled out."

Member Comment (3)

- **It is important that funding is flexible** enough to support community building and the nurturing of unpaid supports.
- **Investment in family learning and development** will be vital to ensure people with disabilities have strong advocacy within their own personal networks.
- **Investment in capacity building** for people with disabilities who choose to self advocate and their families will be key critical to supporting safe, secure and fulfilling lives.
- **Funding direct** to families, individuals, Microboards or facilitated networks will be vital to ensure real community living and maximise the value of unpaid supports.
- **"Red Tape"** A concern with a federal centred bureaucracy is the expectation of arduous volumes of "red tape" and the obstacles it will present particularly in creative initiatives.
- **Assessment methodology and assessor accountability:** What is the commitment to the person with a disability in the process?

Member Comment (4)

- **Dr. Erik Leipoldt states very well a strong and philosophical perspective,** with a depth sadly missing from the whole investigative and consultation process for the proposed scheme. While accepting all perspectives in the spirit of democratic process and acknowledging several would be genuinely motivated, it is difficult to shake off concerns around the whole political manoeuvring in the process, including the exclusion (wittingly or unwittingly) of proper and in depth participation and representation of people with disabilities and their families in the process which, one would expect, should appropriately have taken place in the first instance.
- **Absence of Virtue Ethics:** The NDIS through its marketing campaign, presents to the writer as a product owned and driven by a politically motivated bureaucracy (in so saying this is not a generalisation and it is quite acknowledged and respected that there are many good people within the system who work within the realm of 'virtue ethics' however not particularly evidenced throughout this national conversation).
- **Quality based on values & rights:** The potential for the proposed scheme to achieve a tangible quality outcome for everyone. on the face of the draft report, is severely limited. The reticence to facilitate the philosophical conversations around the principles of 'social role valorisation', a rights alignment and compliance with the UNCRPD and how we can as a society best invest in an attitudinal change around the value of and dignity in human life and how we can achieve truly inclusive practice throughout our nation at all levels and through all population groups. The whole process has been rushed to the point of blur (which is very concerning).

- **The distanced aspect of a federal centred scheme** where people will undoubtedly become reference numbers is a big worry and in probability has capacity to constitute a major obstacle, undoing years of work in access to services and support particularly in W.A. where we have a viable and largely successful Local Area Coordination system putting a local community face on, and relationship with, the system. This system has, since early ninety's, provided an integral link/ access to an otherwise complicated system for people with disabilities and their families. Any suggestion of removal or even changing what has become a comfortable, personalised and known "face"/relationship will result in extreme disturbance for families whose challenges are already significant and known to be so.
- **Integrity:** While we all have positions (favourable and otherwise based on experiences from time to time) on our formal services, there is yet a unison of voice in families, that there is confidence in a communication line which is accessible, open to opinions and scrutiny and we are indeed well placed in Western Australia to comment in this vein insofar as W.A. has been and is a forerunner in service design. There is great potential for the proposed national scheme to lose integrity and confidence very quickly through the absence of rights and values base.
- **"Money Can't Buy Me Love"**! Sure the system overall is fractured, however great volumes of money flowing through it will not fix it: in fact if the fundamental needs of people with disabilities ... same needs as everyone else ... are not addressed first and foremost; if we don't commit to and invest heart and vision in building inclusive communities where all people are valued, welcome, and feel a sense of belonging, then all the money in the world will not add quality to lives. As has been raised in so many and varied conversations, "while the formal system has an important place, it cannot provide a good life".
- **'The United Nations Convention on the Rights of Persons with Disabilities'** has largely gone unreferenced in this process. If the Productivity Commission and in due course the Government of the day which receives the report, is accepting and serious about our nation's commitment to and compliance with the treaty, it would behove us to utilise it as a set of guiding principles, values and tools, underpinning every aspect of a new system, indeed also all current systems and practices therein. Should it be used as an ongoing guiding reference, we can have confidence all deliberations can be addressed with due process driven by and with a strong values and rights base.
Indeed the system can through its practice fulfil treaty compliance requirements and feed into required UN reporting.
- **Lack of participation and representation of people with disabilities and their families (particularly people with intellectual disabilities):** The process thus far in the NDIS deliberations has in my view been condescending and tokenist with participation and representation of consumers limited to sector organisations, some people who are wheelchair users and a few connected families: there has been no visible representation or participation of people with intellectual disabilities.

- **“Marketing” element of the process:** It is felt rather unfortunate that we are en masse being driven or seduced by a marketing campaign which in itself appears to be driven by as yet to be defined interest/s. Media savvy forum presentations with acclamations such as “this is the best thing that’s ever happened in the disability sector” by a sector organisation begs caution on the part of consumers. Sadly the ‘marketing campaign’ to which we are currently subjected strikes a devaluing cord.
- **This is a national conversation which has largely not included consumers** who happen to be in a most vulnerable population group. It has not penetrated to a depth in any meaningful way the underlying philosophical and ethical questions which should have been addressed in the first instance. The system has placed an incredibly short, unrealistic and unachievable timeline for comment/submission (for most people primarily consumers and their families/networks).
Hasty process, it is felt is unhealthy as it is disturbing and deadlines for comment/submission should in good faith at the very least be rolled out to allow for and ensure facilitated in depth conversations with the very people the proposed scheme aspires to serve.
- **People in all corners of our nation** have the right to speak and to be assisted to communicate their positions on this proposed scheme. Should they not have the opportunity to contribute, the outcome will not be valid and it can never be said that this was an authentic, relevant and potent process.

Member Comment (5)

- **Direct and flexible funding** is important in our current system and not always achievable: it will become vital into the future and particularly in a new system.
- **Funding criteria should be flexible** enough to include money for community building; family and individual capacity building particularly in the area of advocacy.
- **Unpaid supports:** The system tends to view ‘unpaid supports’ in the same way as paid, with an assumption that “people *will* turn up to do an evening shift as planned”. However that is not always the reality Sometimes they will, but other times people just want to go out and to share experiences together, and that can cost money albeit not as expensive as paid supports.
- **There is a naive perception that unpaid/freely given supports are free....** they aren’t cost free. Many situations and creative initiatives are at a significant financial and time cost to the family. Getting personal communities to the point where they are running smoothly takes a very long time with huge commitment and personal cost.

- **Investment in inclusive lives through flexible funding approach:** If we are truly committed to inclusive and fulfilling lives for people with disabilities, there needs to be appropriate investment in supporting them to have ordinary social experiences and build on social capacity. This would be best facilitated through a flexible approach to funding to assist families accommodate unpaid support persons; social capacity building through ordinary social experiences and self advocacy.

Member Comment (6)

- **Support services on an entitlement basis:** as opposed to a charitable or "welfare" base. It should be seen as an inalterable right rather than a process subject to the whims of political favour.
- **Distanced Control:** If disability service is controlled and audited from Canberra, it is highly likely to be inflexible and favour big service agencies who can cope with the bureaucracy.
- **Quantity at expense of quality:** Already millions are spent on disability but the general summation of families and service users are that the services are poor in quality as distinct from insufficient. Why would we expect future increases to be spent well? At the moment we are experiencing a huge fervour in the disability sector, in particular with agencies, at the prospect of increased funds flowing through the system.
- **Local control:** it is vital to have control preferably at the individual or family level, or if not then at the local neighbourhood/council level.
- **The core issue is inclusion, acceptance and participation.** Without these elements, more money can just mean further alienation and abandonment in high cost segregation.
- **The UN Convention on the Rights of Persons with Disabilities,** should be the starting point -- perhaps in a pre-amble.
- **Lay person interpretation:** A very important point is the need for a lay presentation of information. Information currently is much too complex for many people.

Member Comment (7)

- **Investment in community and family capacity building** through exposing people to positive examples of people being fully included in their communities will support inclusive lives and go to change societal attitudes.
- **Good Examples** for instance, seeing a woman with profound disability living in her own home with paid and unpaid support in Canada, shaped my goal for my son back in W.A. There is something significant here about people having a range of choices or being exposed to good examples to understand how different their lives can be.

Member Comment (8)

- **The deliberations for reform as manifested in the NDIS Report** excluded the voice of disability in the decision making processes. As these reforms are about the rights and welfare of people with disabilities they should have occupied a major presence around the table. Surely an issue of Human and Civil Rights.
- **Timeline** for the preparation and delivery of the Productivity Commission's Report was an approximate twelve months with an inadequate two month timeline for response from those organizations and individuals in the disability field.
- **Forums** hosted by NDIS in this two month period represented a rush to action, an urgency to garner support via a swell of numbers as opposed to encouraging/welcoming discussion and debate on specific content in the Report. A clear case of Quantity v Quality.
- **Language** used in the Report is the vernacular of economists yet should represent and promote a human rights based social model of disability.
- **Economic Effectiveness v Strengthening Civil Society:** Economic return/viability appears to be the logic driving the NDIS psychology, serving the economy as opposed to the people. Money is a resource and not a panacea, the way in which it is spent is only as good as the wisdom of those who authorize its use. A corporatized structure will not yield investment in developing the capacities of people.
- **Advancing Human Rights:** The United Nations Convention on the Rights of Persons with Disabilities was ratified by Australia in 2008 and therefore binding upon all Australian governments and their agencies to recognize, respect, protect and fulfil the rights it contains.

The human rights and fundamental freedoms of persons with disabilities as inherent in the Convention documentation are neither promoted nor accommodated in the NDIS Draft Report in terms of: Inclusive Policy Frameworks; Building Community Capacity; Creating Policy Dialogue.

F.S.I. 'Round Table' Member Comment

Some potential positives, eg individual funding, attention to Aboriginal people with disabilities and flexible transition to aged care are undermined by the report's:

- **strong market-based 'values'**, which are a disabling force;
- **inadequate statement of the nature of disability** contrary to the principles of the UNCRPD;

- **misstatement of the problem** it wants to address: does not include articulation of, nor focus on, needs;
- **vulnerability**, it would appear is understood as arising from insufficient information, choice and referral;
- **it is based on market-economics** grounds, not on need;
- **'Catastrophic disability'** as a tragedy term;
- **National Disability Research Institute** is based on market-based values, which will strongly influence that view of disability service provision in Australia. This is not primarily in the best interests of people with disability but in that of the disability services sector as a market and industry. The Research Institute will be a competing force with research in centres of disability research expertise which is diverse, rich and more broadly focused than that of the proposed research institute. Instead research should continue to be done by this existing field of expertise.
- **The proposed data base** makes it appear as if there is a vacuum in existing research ethics. For example it appears that 'participation' in data collection is compulsory, by virtue of being an NDIS recipient. Data includes information about one's 'natural supports' and could be used for 'fraud' detection;
- **inadequate safeguards** to inevitable ill-effects of a new big, national bureaucracy, eg relying on ineffective benchmarking; minimum standards and ignoring disability advocacy as a primary safeguard;
- **needs assessment as a technology** by 'independent' assessors where need is best known through knowing a person;
- **no real disability user participation** in the conduct/running/evaluation of services funded by NDIS, in NDIS itself, except through the obligatory advisory council attached to its real hub of power: its 'commercial board';
- **ignoring the nature of presently inadequate services** as also based on inadequate guiding values and principles. Much money could be saved by a focus on real needs and quality in service, including through weeding out those programs not meeting needs, unnecessary bureaucracy and management levels. This could yield immediate results now, not 2014, 2018;
- **inadequate evidence of the extra amount of money needed**, in part because of no examination of inefficiencies in existing 'system'.
- **unclear how an NDIS would preserve the good things** in various States, but do not meet needs, where 'outcomes' may not fit its cost-effectiveness criteria. Example: individual funding does not have to wait for an NDIS, it takes political will and is already happening in some States. I would not like to see what's happening in WA cave in to the lowest national common denominator;

- **using a market-based framework of efficiency and effectiveness** as its main reference point in this inquiry, the report makes it appear as if there is a vacuum in disability research and study of human services. The report states an NDIS intention towards maximising "integrative service options" but adds that cost-effectiveness is the ultimate assessment criterion for determining its funding. In other words, neither principles, nor rights are the touchstone: it is cost effectiveness that will allow continued funding of segregative/congregative services, a stark example of what kind of 'costs' count most;
- **NDIS has been promoted as driving the National Disability Strategy.** The Strategy's central goal is social inclusion. The above problems in a proposed NDIS mean that it will not drive that goal, but primarily that of cost-effectiveness and regulation.
- **It is difficult to dispel the political market-economic reality** we live in. At the same time this reality disables us more than it enables. The proposed change is big, but superficial at a structural level only. It is not the fundamental change we need to safeguard and advance the lives of people with disabilities in a way they can live good lives. The underlying disabling base should nevertheless be highlighted by the disability movement and needs-based alternatives presented, involving high quality in service and capacity building that individual funding for example could bring. Future generations will not thank us for anything less.

***For and on behalf of the members of F.S.I. and F.S.I. 'Round Table'
Jane Browne Eacott***