DISABILITY CARE AND SUPPORT

PRODUCTIVITY COMMISSION POSITION PAPER

A CRITIQUE AND COMMENTARY – TREVOR ROBINSON

It is regularly said that the old system is broken. Few would argue otherwise. Yet state and Territory government policy documents, government and bureaucratic end of term (financial, political, etc) reports, budget allocations, and social and service programmes continue to paint a rosy picture on the quality and quantity of service delivery in the Australian disability sector. Should Australia head down the path of a centralized funding approach to servicing disability, there can be no assurance offered that a newly found candor exists within government to honestly depicting unmet need and deficient service delivery within the disability sector. With bureaucratic mindset and political willingness entrenched, unyielding and easily distracted by populist or propitious issues, it is doubtful and highly unlikely that by shifting disability responsibility, funding sources or management and/or control from one fiefdom to another would have any genuine long-term effect or influence where it counts. It is on this point I decline to endorse or accept any new system as being beneficial to the disability community.

However, rejection or negativity towards a disability insurance scheme doesn't assume a stance of resolute opposition to change. On the contrary, the speed of change within disability is rapid and, alas, reactionary. It is this last cause – reaction – that results in an inferior, retrograde effect.

Rather than adopting a mass evolution of disability funding and service delivery, Australian governments should, in good faith, first look at harmonizing (and implementing) existing disability issues. Accessible parking, guardianship, continence schemes, training, employment, education, accommodation; the list is both significant and comprehensive. By harmonizing a myriad of existing disability areas, it demonstrates the capacity of the Federal government to perform a significant opus such as the proposed disability insurance scheme.

To respond to the minutiae of the Disability Care and Support Issues Paper is impossible with resources equivalent to the Productivity Commission is impossible. Frankly, the Issue Papers theme is strongly dismissive of current transgressions and lays a singular focus on a disability insurance scheme mirrored on Medicare. So any effort towards countering this view would be shrugged off as recalcitrant and obstructionist, both views I reject totally.

RESPONSE

To better impart my position on various issues, I've used headings with summation as an effective method of response.

I have no objection of my names being published, provided my comments are used in context.

Regards

Trevor Robinson

ISSUES PAPER

The Issues Paper examines different support, funding and delivery proposals, yet neglects to critically question why these programmes have failed (or not met expectations). With the likelihood that administration and oversight of any proposed model will be performed by agencies that are currently performing the function, how can any future success be achieved by those failing to deliver today? While the quantity of disability support falls short of encompassing everyone, the quality is equally deficient.

To manufacture a new structure without examining the flaws of the existing mechanism of support provides a blank cheque for history to repeat itself.

EMPLOYMENT

Australian government jurisdictions having inexcusably low levels of public service labour force participation of people with disabilities, among some of the lowest in the OECD. Enlisting those responsible for continuing this travesty of discrimination to inquire about any issue pertaining to disability support demonstrates acceptable contempt towards an already marginalized group of Australians.

Better access to employment opportunities would reduce many people with disabilities dependence on welfare support.

REVIEW

The need to conduct a review demonstrates the failure of existing quality management strategies. Ongoing monitoring, measuring, assessment of satisfaction and evaluation of service delivery ensures appropriateness and suitability of funding, service delivery and care. As mentioned previously, unless the systemic failures are identified and corrected, any new system is guaranteed to inherit the same errors, develop the same flaws, and make the same mistakes as the current system.

The most obvious two flaws in the existing system are measurement and communication between the coal face and management levels. This disconnects between levels needs to be rectified and proven before any progress is possible.

DISABILITY

With slick marketing and lobbying, I'm concerned that some disabilities will enjoy more support at the expense of perhaps more deserving, but less promoted disabilities. This already occurs in health, where some cancers or diseases receive much more funding and support than others due to *vox populi*. A famous sufferer is not only beneficial for highlighting a specific ailment, but it also helps attract more government funding and support. Merit, it seems, has a populist streak.

Additionally, it is regrettable that as the list of disabilities grows, manageable disabilities (e.g. asthma, ADHD) are seen as comparable with those more insidious disabilities (e.g. severe to profound brain damage). A level of realism needs to be included when evaluating what disability should be supported and what shouldn't.

FUNDING

If the figures for unmet need in the disability sector are know (or assigned approximate speculation), why isn't funding appropriately increased to meet need? It seems that disability has been characterized as being very problematic and indefinable, with little genuine desire to understand or grasp the complexities involved in being having a disability or caring for a person with a disability.

AUDIT

Who will audit expenditure to ensure appropriateness, fairness and suitability? Some jurisdictions already do a poor job, so how will this be performed under the proposed scheme?

PRIORITIZING

Historically disability has been low on any Australian governments' priority. This devaluation of people with disabilities has transmitted to Australian society, with people with disabilities (and their families) marginalized and ignored. It is this low prioritization that adversely affects the disability community, not competing obligations. Billions were magically found and spent on stupendously failed projects such as the non-existent Weapons of Mass Destruction, the Household Insulation programme, the Education Revolution, the Broadband Rollout and Carbon Trading Scheme, to name a few. Yet, help for vulnerable and marginalized Australians require burdensome and overly complex justification before any dollar is spent.

NEED

True need should be based on severity (severe or profound) of disability, disability type, location of person and level of existing support mechanisms. The proximity of therapy (occupational, physio, etc) and its frequency also influences and determines level of need.

QUALITY OF DELIVERY

With government providing the bulk of services, and all of the oversight and eventual approval, how is it possible for service delivery to be person-centred and customized? Equipment under this paradigm tends to be pegged to a standard and level determined not by the person with a disability, but by a bureaucrat located away from the end-user. Service delivery tends to take the same path. Price over quality is the norm, yet than suitability over worth should be the standard.

ELIGIBILITY

Different Federal government departments mandate their own medicals to confirm 'disability'. Whether Australia goes with a new system or remains with the current jumble of jurisdictional demands and whims, the continual and ongoing need to reconfirm a permanent disability should cease. In my case, I need a different medical for each of the following benefits from each government agency:

- Australia Taxation Office (GST Exemption on car & car parts)
- Centrelink (Mobility Allowance, Health Care Card)
- ComSuper
- ACT government (Taxi Subsidy Scheme, Companion Card, Mobility Parking Permit, Driver Licence)
- Australian National University (registration as a student with a disability)
- Australian government (Continence Aids Assistance Scheme)

One element that no system should allow or permit is one based on 'competitive misery'. That is, a system that encourages hopeful beneficiaries to embellish their negativity of their disability to advantage themselves over others. This form of competition is socially destructive, and results in mistrust, depravity and deceit.

Without question, anyone with a permanent disability should take precedence over those with temporary or short-term disability (<12 months). The only exception would be those with multiple disabilities. The rationale behind this simple criterion reflects normal ebbs and flows of life. While those with a short-term disability could view their impairment as ebb, life will eventually flow. However, those with permanent impairments, their life will struggle against ceaseless ebb.

MEANS & ASSETS TESTING

To receive assistance to be part of Australian society is a fundamental right, corresponding to education, health and any other social programme. Suggesting that delivery of disability services be means or assets tested is tantamount to means or assets testing basic education of health services. Many of Australia's social services (basic education and health, tertiary education, child support, baby bonus, etc) enjoy horizontal equity i.e. government support not contingent on income.

Furthermore, people with disabilities and their families are among some of the most vulnerable, marginalized and disadvantaged groups in Australia. Australian governments have regularly offered affirmative action to reduce the disadvantage of disadvantaged groups e.g. women, Aboriginal & Torres Strait Islanders, unemployed. None of these groups have been means or asset tested, so I see no reason why people with disabilities and their families should be as well.

INDIVIDUALIZED FUNDING

Financial training, mentoring or assistance is an imperative, irrespective of existing or proposed schemes, to those receiving funding help. From software to flip-cards, people with disabilities and their families and/or carers should be encouraged to gain controlling independence on their funding arrangements. By promoting controlling autonomy, the person can gain significant improvement in their confidence and self-esteem, gaining a greater understanding of the issues affect their life.

FINANCIAL MONITORING

Take the scenario: three people with a similar disability and accompanying individually managed funding: person A, person B and person C. Person A is careful and astute with their funding, and under spends by 15%. Person B spends all their funding. Person C is a poor negotiator or barterer, and overspends by 15%.

The way to approach this very real scenario is to allow everyone to keep their funding, offering person C intense financial training and supervision, and person B a modicum of financial oversight. Funding assistance should not be seen as an endless bucket of money, and should be handled with due diligence and care.

Rural, regional and remote areas should be viewed similarly to taxation zones. Often these areas are poorly serviced by disability services, with excessive travel and higher costs incurred by people with a disability and their families. I do not count service providers within this zoning, as costs associated with delivery (as opposed to receipt) of services are less than metropolitan areas.

Monitoring of funding should be done under stringent guidelines, and performed by local government. The reason for enlisting local government is simple. The services provided by local government authorities impinge more on a person with a disability than perhaps any other level of government. Access to shopping precincts, housing and building approvals, parking, parks and recreational areas, and community services are more than likely delivered by local government than any other governmental level. By including them in financial fund monitoring, local government gets a better idea of what's available and what's not.

NEEDS EVALUATION

Like technology, any evaluation of need is passé and out-of-date almost immediately when it assessed. Disability needs evaluation is specific to time, a person lifecycle, their location, the intensity of the disability, and a myriad of external factors. How confident a person is within themselves and the community, the acceptance and support of the community, their relationships and care networks, and their past experiences, all combine to influence and affect needs evaluation.

Current trends and philosophies also affect need. In a group house situation for people with a moderate to severe intellectual disability, the approach is to community access, type and frequency of therapy, acceptance or rejection of medication for behavior management and desire for interaction between carer and resident strongly determines the needs evaluation. These elements are external to the person with a disability, and are therefore beyond their ability to influence.

I take offense with the need to discuss needs assessment and evaluation for a person with a disability. Does the question of needs assessment for an elderly person requiring a hip replacement, or cancer treatment for a smoker, or surgery for someone involved in a dangerous activity or sport, or therapy for a substance abuser ever get asked. If not, then why should needs assessment or evaluation of a person with a disability to do something so basic as help a them to perform fundamental activities ever posed? Its shame on Australian society that this approach is even considered.

COMPENSABLE INJURIES

Compensable injuries can take many years to reach settlement, and settlement is neither guaranteed nor of sufficient value to met current and future needs. Because of this uncertainty, compensable injuries should be included in any funding scheme.

If any support scheme excludes compensable injuries, it gives insurance companies greater incentive to fight compensation claims in the knowledge that the state is duty-bound as the default support provider.

CENTRALISED FUNDING APPROVAL

Centralised funding and approval processes historically tend to stymie and prevent non-standard approaches to service delivery. Trialing unusual or experimental methods tend to be discouraged and rejected by processes that have approval separate from where service delivery is taking place. Recommend any scheme or system allow and promote customized approaches to care and service delivery. Since every person is different, the way they react to a disability also widely varies. By examining service delivery from the outset in a flexible, individualized manner, better outcomes for the person with a disability can be achieved.

REVENUE

The Federal government does not need to access a new revenue stream to fund disability support. Ample finance already exists to adequately fund disability support. What is need, however, is a philosophical shift by government to prioritise people with a disability higher up the 'must do' funding ladder.

DISABILITY WORKERS

Strong parallels can be made with aged care. Here is a basic list of what is needed to attract and keep disability workers.

- Better pay – government must fund agencies employing disability workers on wages analogous to what government employees are paid;
- Better training – training must be at a Certificate III level as a minimum. Education beyond this level must be a mixture of on-the-job training, face-to-face lectures and literature review, with both essay and practical assessment. Workers should be able to specialize in a particular disability stream (e.g. physical, sensory, intellectual) beyond the Certificate III level;
- Improved representation – workers should have greater say in training, on-site management, etc;
- Greater exposure to other professionals – workers should interact with allied health professionals, funding agents, and other professions involved in disability. By being involved more, greater appreciation of roles can be achieved;
- Cultural awareness – (aligned with training) Australia is a multicultural community, and thus workers need an acute awareness of the issues pertaining to culture, language and behavior;
- Accreditation – like nursing, workers should be accredited and registered. Professional development (linked to training) should be a component of accreditation.

COST OF FUNDING SCHEME

The cost to run any scheme constitutes the first dollars paid out. This can detract from setting up a new government entity to manage and administer a scheme. An example is the Child Support Agency. This agency costs three times more to run than it garners from parents behind in their child support payments. If any proposed scheme follows this scenario, then the money raised will first be directed to the organisations operations budget before one person with a disability receives a benefit. How can this be ameliorated?
