

**Title:** Concepts of support – support frameworks for people with impairment and the emerging NDIS

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The provision of support in Australia for people with impairment is moving towards its biggest transition since deinstitutionalisation in the early 1980s. The shift to a model of support based on an individualised funding approach and consideration of a new national funding framework - the National Disability Insurance Scheme (NDIS) – are changes set to again transform provision of support for people with impairment across Australia and how support is conceptualised and distributed. The wide-scale transition to an individualised funding approach and an implementation of an NDIS are viewed as changes that will significantly improve equity, choice and flexibility of support service provision for people with impairment, and establish a more thorough basis from which a person with impairment can seek to explore their full capabilities. This significant restructuring of Australia's support framework for people with impairment will also establish a platform from which Australia can effectively begin meeting its formal Human Rights obligations as defined by the recently established United Nations Convention of Rights of Persons with a Disability (CRPD), to which Australia is a signatory, and will redefine how support is conceptualised in Australia.

The provision of resources to support people with a disability in Australia has traditionally been complex. Since European settlement in 1788, a mix of both formal and informal models of funding supported 'disability'. In the main, people with impairment were provided with support at an informal level by parents, partners or friends while remaining in the community. Social discrimination and stigma for both the person with impairment and their carers however was common, and people with impairment were forced to endure ongoing attitudinal and physical barriers on a daily basis. Individuals with complex needs or difficult behavioural problems, in addition to their impairment, were increasingly segregated from society and moved into institutional settings, where in most instances they endured isolation, hardship, exploitation and abuse.

In the early 1970s, new international models of thinking about the support and the social status of people with impairment began to filter through to Australia. These models, such as the Principles of Normalisation, Disability Rights, the Independent Living Movement and the Social Model (Nirje 1969; Barton 1989 ; Oliver 1990 ; Zola 1992; Barnes, Mercer et al. 1999), supported improved Human Rights, social inclusiveness and the improved status for people with impairment. They also promoted the removal of physical and attitudinal barriers that prevented obtainment of these ideals. In response to these emerging discourses, Australia shifted its policy responses to 'disability' away from a model of segregation and institutionalisation, towards a model of support based on deinstitutionalisation and social inclusion supported by community-based care (Parmenter, Cummins et al. 1994 ; Gleeson 1997; Parmenter 1999 ; Clear 2000).

In 1986, the Disability Services Act 1986 (Cwlth) was implemented at a national level, as the dominant piece of legislation that would oversee the establishment of community-based care for people with impairment (Victorian Government 1986). Following the implementation of the Act, the Commonwealth State/Territory Disability Agreements (CSTDAs) funding agreements were established between the Federal, State and Territory Governments to support the Disability Services Act in undertaking this role. The aim of the CSTDAs were to create administrative efficiency, establish funding parameters and define the roles and responsibilities between the Federal, State and Territory Governments given the large expansion in service delivery that would be required in establishing wide-scale community-based care and services (Yeatman 1996; Victorian Government 2005).

As with much of the Australian health system, the funding split between the Federal, State and Territory Governments instead led to complexities, inefficiencies and claims of cost-shifting between Governments. The framework of the CSTDA led to duplicity in many of the operationalisation and administrative procedures, lack of clarity around support service parameters and gaps in service delivery and support programs. Many support service programs were set up in an ad hoc manner in response to crisis driven need, with access to support programs and funding allocations for support and equipment differing dramatically from state to state. There were also difficulties with monitoring and determining accurate levels of need and usage of community-based support services at a national level (Cass, Gibson et al. 1988a; Yeatman 1996). Further, the State and Territory Governments were faced with ongoing difficulties in obtaining adequate amounts of funding to operationalise service delivery and meet the diverse parameters associated with service delivery by each state. The sector came to be characterised by shortfall and difficulties in obtaining support, services and equipment. Although achieving its aim of implementation and transition to wide-scale community-based care for people with impairment on a national level, shortfall in funding, lack of uniformity and lack of equality in relation to funding for support services at a national level, significantly hampered state-based delivery of services (Yeatman 1996; Australian Institute of Health and Welfare 2003 ).

In addition, the failure to include disability support services funded through Home and Community Care (HACC) services, the Commonwealth Rehabilitation Services (CRS) programs, state-based transport accident and WorkCover schemes or public liability claims within the structure of the CSTDAs, distorted the view of how support services for people with impairment were truly funded (or not funded) across Australia. The defined parameters of the CSTDAs and complexities of each state's individualised reporting structures meant the CSTDA struggled to provide an accurate picture of the inequities in funding and service delivery that actually existed at a national level across the disability sector. As noted by the Australian Institute of Health and Welfare (AIHW) (2003), despite a population in Australia of then only 20 million people, Federal, State and Territory Governments were responsible for more than 60 programs and services both within and outside of CSTDAs in relation to delivery of disability support (AIHW 2003). For any one state, support services for people with impairment were funded by between 4 and 8 different funding providers, inclusive of services funded under the CSTDAs, but also inclusive of transport accident schemes, WorkCover schemes and services received through Federally funded schemes. The support framework for people with impairment thus came to be characterised by siloed and jurisdictional funding approaches, difficulties in navigating service provision, inequity and unmet need.

On 1 January 2009, the National Disability Agreement (NDA) replaced the previous CSTDA funding agreements. The NDA included bilateral agreements with each state that had been established with the 3<sup>rd</sup> CSTDA, plus additional transfers to the States and Territories of further administrative responsibility of targeted support services such as respite. Further, the development of National Minimum Data Sets (NMDS) and a National Population Benchmark Framework established improved monitoring and accountability mechanisms of formal support utilisation and estimates of demand (Australian Institute of Health and Welfare 2005; Family Housing and Community Services Indigenous Affairs - FAHCSIA 2008b). NMDS data is now collected in all Australian states on a regular basis, and once collated, provides a nationally comparable aggregate of all support service usage and need funded under the NDA (although still exclusive of service delivery provided through private or statutory schemes as noted above). The mechanisms have been effective in identifying on a population basis, gaps and unmet need in support service provision within general government parameters. They have also acknowledged the significant role informal support has, and is currently providing, in the support service area.

Recent increases in funding under the Labor government have addressed many identified gaps, reduced waiting lists and have supported a number of highly effective programs such as the Younger People with Disability in Residential Aged Care (YPIRAC) Program. The YPIRAC has sought to 'move younger people with disability currently in residential aged care into appropriate supported disability accommodation, and divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation' (Social Policy Research Centre (SPRC), Ryan Gleeson et al. 2010). Further, other initiatives such as Victoria's Disability Housing Trust, were established to 'enable people with a disability, their families and a range of organisations to enter into partnership... to develop innovative and affordable housing... and choice for people with a disability' (Victorian Government 2002). The Trust was provided with an initial capital investment of \$10 million from the Victorian Government, and sought to develop housing that would provide accessible accommodation for a minimum 100 people with impairment.

Yet despite these considerable reforms, two new developments are set to radically transform the support framework for people with impairment in Australia and how support services are funded and utilised. The transition to individualised funding approaches, again based on newly emerging international discourses, and the consideration of a National Disability Insurance Scheme (NDIS), will see the biggest reforms in support provision in Australia since deinstitutionalisation. In scale, they will mirror the introduction of the original Medibank scheme in the 1970s or compulsory superannuation in the 1980s. These two reforms will be discussed in-depth now.

### **Individualised funding approaches**

The model of individualised funding emerged within international discourses on support and care approximately ten years ago. In Western European countries, these individualised funding approaches were known as 'direct payments' or 'consumer-directed care'. In the United States, the term 'self-determination' was utilised for individualised funding approaches, while in Canada, the term 'self-managed care' was utilised (Priestly 1999; Shakespeare 2006; Prideaux, Roulstone et al. 2009; Productivity Commission 2010). At present, the United Kingdom and Germany appear the most advanced in terms of transition to individualised funding arrangements (Thomas 2007).

The primary goal of individualised funding is to increase choice, equity and flexibility for people with impairment in relation to support provision. This is achieved by placing control of support options and funding directly into the hands of people with impairments as consumers, which in turn provides increased support options and choice in how required support services are then purchased. Under an individualised funding approach, the range of consumer control is increased as control of how funding is utilised is moved from the support service agency to the individuals themselves. Individuals are thus viewed as being more in control of the support that they require, more informed of parameters of support being utilised and as more able to make accurate judgements about amounts and specific forms of support that may be required.

The main element of an individualised funding approach is that the consumer holds the allocation of funding for support, rather than government or the service provider. With their allocation of funding, an individual has the freedom and choice to purchase support as they require and from where they choose (within the parameters of the allocation of funding received). Individuals may thus choose to utilise mainstream services, utilise a support agency of their own choice or choose to direct allocation towards home modifications rather than attendant care. Individualised funding approaches thus transform support provision for people with impairments by transferring control of funding away from service providers, and placing funding for support directly into the hands of the consumer. In contrast to the previous funding arrangements of community-based support where funding for support moved only between funding bodies and service providers, an individualised funding approach directs funding for support services to the individual (or their facilitators), who then have the capacity to purchase support from support service providers on the open market. Like mainstream service providers, individualised funding approaches requires disability support service providers to compete against each other in the open market to attract and secure business from individuals. Individuals are thus effectively able to shape their particular support preferences and purchase the amount of support they require from the service provider they choose.

Individualised funding approaches also seek to operate in collaboration with an individual's natural support network and enhance informal support networks. Although not linked to assessment of allocation or ability to formally purchase services, the enhancement of informal networks is acknowledged as a component of individualised funding, and where possible, an individualised funding approach will seek to draw out an individual's natural support network to be utilised in conjunction with a formal individualised funding allocation. As with the mainstream population, developing informal networks are viewed as crucial for continued social development of people with high or complex needs, and are viewed as essential in maintaining social inclusiveness and continued social development.

FACHSIA (2010:1) defines an allocation of individualised funding as 'a portable package of funds allocated for a particular person that facilitates control over how they purchase their disability support needs'. Thus when an individual first transfers onto the individualised funding scheme, there is a requirement that an assessment be completed by the relevant funding body to assess needs and requirement and establish the size of the funding allocation that will be required to maintain adequate support, wellbeing and quality of life. Assessments are generally based on functional capacity of the individual, previous usage of support services and extent of informal support available.

In all instances, individualised funding packages must be accountable and undergo reporting requirements. Most commonly, reviews of allocation take place on an annual or biannual basis, or on request when a significant change to existing support circumstances occurs, while transactions and accounts are monitored on a 1-3 monthly basis. Responsibility in how funding is utilised however exists at all levels - with the individual themselves (the consumer/ purchaser), their carers and frontline support providers, with chosen service providers and with government. It is recognised that where individual capacity to manage the administrative aspects of the individualised approach are required, that a facilitator may be required to manage aspects of the allocation, and/or that additional administrative support services, such as intermediaries, support planning advice, brokerage, case management, financial and technical management or risk management may be required.

In Victoria, the parameters of individualised funding packages provided through the Department of Human Services (DHS) must meet reporting requirements that involve auditing and review of support purchased. The Victorian Direct Payments Project utilises the following financial, administrative and accountability requirements in relation to each individualised funding package:

- individuals must sign a deed of agreement with DHS
- individuals are required to open a bank account for the sole purpose of managing transactions related to purchases of services
- DHS are required to transfer prescribed allocation of funds each month into this bank account as per funding schedule
- individuals then have responsibility to arrange the purchase and payments of their chosen services and supports
- individuals have the responsibility to comply with the accountability requirements as specified in the deed of agreement and user manual
- DHS is authorized to monitor an individuals transactions each month, and complete three-monthly financial reviews of support utilised.

Victoria has also adopted the language of 'self-directed approach', rather than 'individual funding packages', in seeking to emphasise the personal control of the approach and move the emphasis away from a focus on finances. It has sought to focus foremost on an individual's requirements and need, and then on the support and funding required to meet these requirements as defined by the individual. Victoria is also developing a resource allocation tool to assist in the assessment process and funds allocation. The tool aims to facilitate access and equity within the individual funding approaches (See Victoria- 'Support Your Way: a self-directed approach for Victorians with disability' (2009)).

#### *Effectiveness of Individualised Funding Approach*

Initial studies on individualised funding approaches have suggested positive outcomes for most individuals that have transitioned onto individualised funding approaches so far. Individuals acknowledged increased flexibility, control and improvement of lifestyles, greater flexibility to achieve life-goals, wider options related to recreation and activities, and more options related to purchasing of medical and equipment aids. The Social Policy Research Centre (2010) in their report on the effectiveness of individualised funding approaches to disability support suggested there was an increase in the life-satisfaction with the control afforded by the individualised funding approach. There was also evidence that an increase in personal health, felt achievement in life and personal safety was evident, and that individuals found the shared responsibility of individualised

funding had improved control, choice, independence, wellbeing and self-determination in their lives. Further, individualised funding was viewed as having increased the availability of qualified support workers by enabling individuals to more readily facilitate the type, quality and quantity of support they required, and drive support rosters. Individuals noted that they enjoyed being more in control of personal budgets, and that direct control of their support enabled more responsive usage of their support allocation. Provision of support was also viewed as more informal, less-centralised and more focused around a person's home in their community.

### *Risk*

Some level of risk however has been identified with individualised funding. Primarily, risk was associated with how people with restricted capacity for decision-making or communication could effectively participate in individualised funding approaches. There is concern that this group of individuals may be denied effective input, and that individualised funding approaches might privilege the young, more educated and professional people with physical impairments (Social Policy Research Centre (SPRC), Ryan Gleeson et al. 2010). There is significant concern that without adequate support, more vulnerable individuals could be excluded from participating in the decision-making aspects of individualised funding options, and that prescribed facilitators could become substitute decision makers, reducing the quality of support provided as individuals struggled to manage some of the complexities of individualised funding.

Risks of self-directed approaches as identified included:

- that the procedures for managing individualised packages of funding may be too complex and difficult for some people
- that there may be resistance to transition onto individualised funding approaches based on an adherence to traditional agency-based services despite the choice and flexibility the option of individualised funding presents
- that control over the funding for support may simply pass from an agency to a brokers without providing autonomy, choice or flexibility for a person with impairment and how support allocation is utilised
- that decreased contact with support agencies and agency staff could lead to greater incidences of isolation, vulnerability to exploitation and abuse
- that self-funded packages may obscure extent of government responsibility where support reporting elements changed, including for service innovation and development (Social Policy Research Centre (SPRC), Ryan Gleeson et al. 2010)

Further, the recent discussion paper by the Productivity Commission on Long Term Care and Support (2010) identified concerns with individualised support approaches and potential misuse of funds on non-support related activities (e.g. drinking, gambling), the extent to which any individual can be fully informed about the quality and efficacy of service provides when making a transition to a different support provider, the ability of individuals to manage any tensions with informal carers without the support of an attendant care agency and of risks associated with individualised funding arrangements where families effectively pay themselves for attendant care and utilise allocation from an individualised funding package as regular income. As observed in New Zealand, this may potentially create dependency by carers on the support system and undermine the goal of achieving independence for the individual (Productivity Commission 2010).

### *Service providers*

Service providers face significant change under individualised funding approaches. Service providers have noted that they have had difficulty implementing some of the administrative requirements into their systems where new systems have needed to be established to support accountability for people using individual packages. They have also noted an increase in costs associated with transitions onto individualise packages, such as costs associated with holding training seminars, conducting individual meetings and sending out information packs about reporting requirements, guidelines and parameters around direct employment of staff (Social Policy Research Centre (SPRC), Ryan Gleeson et al. 2010). Service providers in some instances were resistant to the transparency, and in other instances, viewed individualised funding as a threat to their overall viability. These service providers highlighted that they needed a certain critical mass of demand to survive, and were reluctant to move into the more uncertain, open market and away from the security of block funding provided by governments (Productivity Commission 2010).

### **National Disability Insurance Scheme (NDIS)**

The second major reform to support services for people with impairment, currently under consideration, is the establishment of a National Disability Insurance Scheme (NDIS). The Productivity Commission, with their Inquiry into Long Term Care and Support, are considering the cost and feasibility of introduction of an NDIS. The implementation of an NDIS would remove many of the current framework's structural problems which is viewed as 'deeply flawed... and increasingly unable to meet people's needs' (Productivity Commission 2010). The Commission's terms of reference for the Inquiry are to examine the feasibility, costs and benefits of a new national disability care and support scheme that would provide long-term essential care and support, be cost-effective over the long-term care, and that would take account of the desired goals of individuals over a lifetime. A focus on early intervention, decision-making and opportunity for participation in education, training and employment are also paramount. The Commission is notably seeking advice to consider how a national disability scheme could be designed, administered, financed and implemented through a model of no-fault insurance.

The creation of a new long-term disability care and support scheme would reflect the desire by the Australian Government to achieve its overarching policy goal of enhancing the quality of life for people with impairments, improving social justice, increasing the economic and social participation of people with impairment and their families and improving protection of people with impairment through Human Rights instruments. Any new scheme would seek to formally meet the requirements of the recently implemented United Nations Convention of Rights of Persons with Disability (CRPD) to which Australia is a signatory, which are not fully recognised in current support arrangements (Productivity Commission 2010).

The discussion includes the extent to which an NDIS would cover all catastrophic injuries, and absorb all of the current, specific state-based schemes, such as transport accident and Workcover schemes. Under such a scheme, any individual acquiring or born with a serious, permanent and catastrophic impairment, would be supported by a single scheme, regardless of how the impairment was acquired and the circumstances surrounding the impairment. Allocation of funding for support would become more standardized and centralized, and assessment for allocation would be made by a single assessment tool in all instances, improving consistency and standardization

with assessment. Currently, all levels of government provide some funding for disability services (Local, State/Territory and Federal governments). Each of these jurisdiction have many portfolios and funding streams directed partly at disability services (such as education and housing). A nationalised disability support services framework could provide a means to consolidate all services related to impairment into a single scheme. A nationalised disability support services framework could also provide a more standardised means of monitoring and allocating funding for support services required, and provide increased efficiencies in administration and assessment. As with state-based statutory authorities, such as motor vehicle insurance schemes, allocation of NDIS allocations would most likely be based on a 'reasonableness' test. The Productivity Commission view the key test of any new scheme as the extent to which it can address existing deficiencies in an equitable, efficient, cost-effective and accountable way (Productivity Commission 2010)

#### *Common Law and Compensation and the NDIS*

Further, a nationalised disability support services framework would be strengthened were opportunity to claim for compensation through a Common Law claim was maintained. Compensation plays an integral role in providing redress and rebalance, on both an individual and social level, where the acquirement of impairment was a result of significant fault or negligence. Inclusion of the right to claim for compensation through Common Law could be achieved if a system similar to that of the Victorian TAC system was expanded at a national level. The hybrid TAC system retains a Common Law claim component for serious injury where fault can be proven, and where loss-of-earnings and pain-and-suffering can be claimed through the courts. Under the TAC system, any claim for compensation and income related payments remain separate from funding for general support services, accommodation, medical and general entitlements, which remain within the standard TAC service support division. Any reduction or abandonment of the opportunity to claim for compensation through a Common Law claim would, in many respects, be introducing a differing form of injustice into the arena. Compensation or redress for a wrong would be difficult to address under a support services platform alone, particularly where income and/or livelihood was lost as a result of the acquirement of a serious impairment where there was fault. Compensation provides scope for an individual that has acquired an injury to make significant life changes required as a result of acquiring a permanent impairment, such as income needed to repurchase a more accessible home or vehicle, or continuing to meet established financial commitments from work-role provided or providing income for existing dependents.

#### **What do we mean by support?**

As is evident from these two significant changes being considered within the support service arena, the way in which support is conceptualised and utilised will alter dramatically with the wide-scale implementation of a new model and framework associated with support service provision. What we mean by support will be re-conceptualised under widescale individualised funding approaches, and the introduction of a nationally funded support service framework will dramatically standardise provision of support allocation. These transitions combined would work towards adequately meeting Human Rights requirements, and potentially work towards repositioning 'support' as a mechanism for not just increased social inclusion, but advancement of individual capability and capacity. How support for people with impairment is defined, conceptualised and utilised will alter dramatically. However, as with the advancements of Australia's first significant

transition of deinstitutionalisation, these new and emerging structures are set to once again redefine provision of support for people with impairment in Australia.

## Recommendations

Continued wide-scale transition onto individualised funding plans  
Implementation of NDIS inclusive of opportunity to claim for compensation through Common Law

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