A RESPONSE TO THE PRODUCTIVITY COMMISSION REPORT

Disability Care and Support (February 2011)

Context

The Australian Government has developed a National Disability Strategy to improve the quality of life and increase the economic and social participation for people with a disability. Concurrently, in February 2011, the Productivity Commission (Australian Government) released a draft report for further public consultation and input, 'Disability Care and Support.'

This report was prepared as part of the Productivity Commission's inquiry into a National Disability Long-term Care and Support Scheme. The scope of this inquiry requires assessing the costs, cost-effectiveness, benefits and feasibility of an approach which:

- Provides long-term essential care and support for *eligible people with a severe or profound disability* (emphasis added), on an entitlement basis and taking account the desired outcomes for each person over a lifetime.
- Is intended to cover people with a disability not acquired as part of the natural process of ageing.
- Calculates and manages the costs of long-term care and support for people with severe and profound disability.
- Replaces the existing system funding for the eligible population.
- Ensures a range of supports options is available, including individualised approaches.
- Includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs for a person's lifetime.
- Assists the person with a disability to make decisions about their support.
- Provides support for people to participate in employment where possible.

In undertaking the inquiry, the Commission was required to examine a range of options and approaches including international examples for the provision of long-term care and support for people with severe or profound disability; consider specific design issues of any proposed social insurance model on a no-fault basis, reflecting the shared risk of disability across the population; consider governance and administrative arrangements, together with costs and financing for any proposed scheme; and consider implementation issues of any proposed scheme. The following report has been prepared in response to the Productivity Commission's invitation for written submissions by 30 April 2011.

Introductory Remarks

This response has been prepared by a team of academics who teach and research in the School of Human Services and Social Work, Griffith University (Logan). Our specialist areas are in the fields of rehabilitation, disability services, vocational counselling, community mental health, rural and remote health, and Indigenous health**.** Our knowledge and expertise are drawn not only from our academic teaching and research, but also from our extensive professional experiences in these fields together with our own personal life experiences.

In preparing this response, we commend the extensive level of consultation already undertaken by the Commission and appreciate the opportunity to contribute to this nationally significant social, health and disability policy debate. It is the most significant such debate since the review of the *Handicapped Persons Assistance Act (1974)* during 1983-85 which resulted in the *Disability Services Act (1986)* which, in turn, resulted in the transition from institutionalised, segregated, custodial care for people with disabilities to a more community-based infrastructure for service delivery to people with disabilities and their families.

This was one of those rare transformative 'moments' in Australian disability history, resulting in the undoubted improvement in the lives of very many people with disabilities and their families. People enjoyed raised expectations about what was possible for their lives—in education, work, relationships and also in those intangibles of joy and wellbeing. However, as with any great transforming changes (*cf* the radical restructuring of the Australian economy during the 1980s and 1990s), there were many casualties and many terrible unforeseen, unintended consequences. The Productivity Commission has recognised this in its first 'key point':

> *The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.*

The challenge facing us all today—and it is not just the Productivity Commission's responsibility alone—is to help build a new system in which there are no losers in the disability stakes . . . just winners.

Policy Assumptions and Realities

The Commission confronts considerable tension in its meeting the twin aims of:

- establishing a financially sustainable insurance scheme to support the needs of people with disabilities, while at the same time
- facilitating their capacity to participate as fully as possible in their community through education, work, and social and wellbeing activities.

It is important then, to acknowledge that many people with disabilities have in the past or now pay income tax or direct taxes as do their informal carers. People with disabilities also contribute significantly to the employment market through direct and indirect employment of others in the human services, disability and other sectors. In any case, *all* Australians, including those with disabilities, pay indirect taxes through consumption of goods and services. The Commission's Report tends to underplay this reality. This needs to be explicitly acknowledged to redress any implied assumptions or misapprehensions that might arise from the Report that people with disabilities are not taxpayers and thus do not contribute to the national economy.

There are many balls to juggle in designing and implementing the proposed national insurance disability scheme including issues of ethics, avoiding the traps of creating excessive bureaucracy and duplicating functions, and inadvertently embedding inefficiencies that create barriers and fail to take advantage of local resources.

Big reforms require both patience and clear priorities such as:

- A clear identification of the problem that needs to be solved: the Commission has achieved this.
- A 'road-map' with realistic timeframes for achievements.
- A strong argument based on values, not just facts and technical details: this Report includes some discussion about disability, the United Nations Convention on the Rights of People with Disabilities, rationales and objectives. However, a clearer and more incisive statement of values and principles driving this proposed reform would be helpful.

- Champions: this proposed reform has strong champions, advocates and barrackers behind it. However, more still needs to be done to make this a mainstream media and national issue, rather than an issue that merely captures the imagination and support of those people 'inside the tent'.
- The capacity and strength to confront powerful vested interests: opponents (whether potential or actual) of this proposed reform package are not clearly identified. This is a significant risk. We need to anticipate, transparently and in accountable ways, those vested interests who may try to unravel or defeat the proposed reforms. Apathy and indifference are the hardest enemies to defeat.
- Attention to detail is especially important to prevent policies from being derailed by implementation oversights. In this particular reform, clarity is needed about the management of the tension between the commercial realities of ensuring a sustainable disability insurance industry and the life-long, daily support and service needs of people with severe or profound disabilities.[1]

Consumer focus

The Commission's commitment to building a strong evidence base to establish the best and most effective national disability care and support scheme is commendable (Table 10.1 on page 10.27). However, while the Commission appears to be clear about the benefits of qualitative research and other social research approaches, it also appears to be privileging quantitative randomised control trials which can throw up a raft of ethical concerns and muddy the waters. It is important to ensure that the consumer's voice and understanding of outcomes are not lost in this process.

- **The needs of Indigenous people**

The Report grapples with complex issues with sensitivity and insight. The issues confronted by Indigenous people with disabilities and particularly those who live in rural or remote communities present uniquely challenging issues. While the Commonwealth Government's 'Closing the Gap' initiative attends to the primary and preventative health concerns of these communities, much needs to be done in those communities in the provision of secondary and tertiary rehabilitation, disability and wellbeing services.

It is important that the NDIS picks up the current national strategic policy ambitions for a local, regional focus in providing adequate access, quality of services and care of *all* people with disabilities. In particular, the proposed NDIS must keep within its sights the need to support those people in remote and rural Indigenous communities with existing disabilities or who acquire them in the future. As acknowledged in the Commission's Report, it is essential that local solutions are identified and in operation are flexible and innovative ways; this will go some way to respecting cultural and local needs and traditions.

- **Remote and rural communities**

We have struggled with the problem of how to provide support and or services for people with complex need in rural remote areas for many years. Issues of isolation, unreported spousal and carer abuse, 'border' issues *apropos* the location of services, workforce shortages and so on, all compound the complexity of responding to the needs of people with disabilities in remote (and 'very remote' such as North and Central Australia) and rural communities. This is especially so given that the numbers of people with disabilities can be quite low and widely dispersed.

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[1] This discussion of the logistics of implementing 'big reform' has been influenced by Tim Dixon's essay in *Quarterly Essay*, Issue 41, 2011.

The low incidence of particular impairments means it is difficult to equitably balance the tension between the efficient allocation of resources on the one hand, and having the required infrastructure or expertise in every community on the other. Perhaps the Commission might consider approaches developed within community-based rehabilitation (CBR) philosophy to service delivery being used extensively in developing countries such as Mexico, Bangladesh, and South East Asia. (The WHO has a section on CBR on their website). Practical experience has shown that the recruitment and rallying of local communities depends on the motivation, energy and local connections in local communities of recruiting agencies. Local connections are vital. Relocation of people with disabilities out of their home communities does not assist with the maintenance of informal and community supports, reduces quality of life and causes adverse psychosocial effects and is generally devastating for people. Rather, Innovative local strategies developed in consultation with people with disabilities, their carers and communities should be promoted including provisions for recruitment and training. It is possible in most situations, and has been achieved many times in the past. If a person chooses to stay in his/her community, all efforts must be made to enable this decision.

Outcomes focus:

- **Wellbeing**

Early appropriate intervention from a qualified human services professional, such as a social worker or a rehabilitation counsellor, can reduce secondary risks associated with disability such as social exclusion, vocational exclusion, secondary mental health issues, as well as secondary impacts on families and other life domains. All of these risks are related to long-term preventable health issues.

To ensure quality processes and to maximise outcomes, the emphasis should be on securing the services of qualified relevant professionals to assess individual early intervention needs and their potential benefits.

- **Employment and social participation**

Employment and social participation opportunities benefit not only people with disabilities, but also their families, their communities, the workforce and society. The draft report indicates that disability employment services would remain outside the National Disability Insurance Agency that would refer to them for service provision.

Future costs associated with the NIDS scheme would be offset by the increased participation and productivity of people with disabilities only if the scheme is effective in ensuring increased access in the first place to communities, education and training, and workplaces. Spending dollars early has been demonstrated to be very effective for increasing return to work outcomes in occupational rehabilitation, thus saving long-term dollars.

The Royal Australasian College of Physicians and the Australasian Faculty of Occupational and Environmental Medicine have issued a position statement to promote the positive effects of work on health and well being. This has been supported across Australia and New Zealand: in March 2011, 79 organisations, including Comcare and Safe Work Australia, signed a consensus statement about the health benefits of work (Street, 2011). The position statement

> presents compelling international and Australasian evidence that work is generally good for health and wellbeing, and that long term work absence, work disability and unemployment generally have a negative impact on health and wellbeing. (AFOEM, 2011, p.1).

It also acknowledges the importance of vocational rehabilitation, counselling and disability employment services for people with disabilities to achieve their vocational and career outcomes. The Commission's report acknowledges that the benefits of early intervention include:

- reduced long-term costs, secondary disablement and family relationships strain, and
- increased independence, community participation, health, rehabilitation and employment outcomes.

Research in disability services indicates that the bulk of the costs of workplace injury and disability are not included in direct cost measures. Indirect costs incorporate increased insurance premiums, lost productivity, labour costs for replacement workers, and claims administration expenses, as well as personal costs impacting on stakeholders. In 2004, NOSHC updated its method for calculating indirect costs with input from independent consultants (Australian Safety & Compensation Council, 2009). Applying the new approved methodology to the 2005-06 reference year, the total cost estimate to the Australian economy was revised to $57.5 billion, equivalent to 5.9% of the Australian Gross Domestic Product (GDP) in 2005-06 compared to 5% in 2000-01. This increase was partly attributed to an increase in wages above the increase in GDP during this time (Australian Safety & Compensation Council, 2009). Despite having taken more factors into account in these new estimates, these costs still excluded those that are not directly attributable to work related injury or illness such as the cost of prevention activities and loss of company image (Australian Safety & Compensation Council, 2009).

More Australasian research to establish the cost benefits of early intervention promoting employment and social participation for people with disabilities would provide useful additional information to Commission about the costs of non-participation.

Implementation Challenges

- **Workforce Development and Education & Training issues**

Improvements in disability care and support must address issues of workforce casualisation and transience associated with limited professional career pathways in the disability care and service industry, and the medicalisation of services.

The Commission's Report seems to assume that an immediate upsurge of disability service organisations across Australia will take place to provide the services required for the successful implementation of the proposed NDIS. However, history has shown us repeatedly (*cf* the Institutional Reform movement of the 1980s and 1990s), that this simply does not happen.

Of course not all people with disabilities need the support or intervention of medical or allied health professionals. Notwithstanding this caveat, we need to recognise that there is already a significant shortage of appropriately qualified education and research professionals in the areas of rehabilitation counselling and disability studies. With the establishment of the proposed NDIS, demand will increase for trained case managers, social workers and rehabilitation counsellors and other professional groups.

However, the Productivity Commission's report is silent on the role of, and need for, more rehabilitation counsellors, social workers, human services professionals, disability care workers, disability support specialists and advocates. Professions listed in the Report, for example, include physiotherapy, occupational therapy and 'counselling'. The silence on social work is remiss. Not only is this profession recognised by Medicare for specialist mental health skills, but it is often the most accessed service in times of crisis: a 2010 Australian Association of Social Workers study revealed that, in the wake of the 2009 Victorian Bushfires, more people made use of social work services than any other professional services. Similarly, the Commission's Report overlooks the significant contribution of rehabilitation counsellors who specialise in vocational rehabilitation for people with disabilities. Social workers and rehabilitation counsellors have specialised case management skills, university qualifications, accrediting professional associations, and codes of ethics. Psychosocial supports are equally important to achieving the goals of the disability care and support reforms.

We need to move away from grouping these professions under a generic 'counselling' brand and also from only listing paramedical and larger professions in national reports, and be more explicit in identifying the specific roles and responsibilities of specific professions.

The Productivity Commission attempts to minimise the ambiguity of terms such as 'disability worker', but we suggest that not only the *size* of the professional group should be considered in listing them, but also their *relevance* to disability support services. Whilst high support employment service provision will sit outside of the NDIS, employment opportunities for people with disabilities have been recognised as important and therefore employment specialists for people with disabilities, i.e., rehabilitation counsellors, should be noted (Matthews, Buys, Randall, Biggs & Hazelwood, 2010). Such acknowledgement impacts directly on recognition for a small profession that has much to offer but has difficulty attracting students to programs because it is a small and therefore a less visible profession . . . which, in turn, will impact on the necessary growth of this profession workforce if the aims of NDIS are to be fully realised.

Long term planning and additional resources need to be directed towards recruitment, training and educating the future workforce through the vocational and higher education sectors. It is inappropriate to 'cross fertilize' and use staff from Centrelink or Medicare to fulfil these functions. Instead, we need to work concurrently towards stronger partnerships across the disability insurance industry (*apropos* their new workforce of assessors and managers), the current disability services sector, and the VET/ higher education sector. Strategies to draw staff into the sector should also include more emphasis on careers which include opportunities for higher education in relevant areas such as disability studies, social work, rehabilitation counselling and related human services areas. This would require promoting opportunities, especially for the less well known professions and discipline areas such as rehabilitation counselling and disability studies. It would also include career paths for people already working in the industry via industry graduate certificates, which recognise relevant experience and provide access to masters programs that provide qualifications in disability studies and rehabilitation counselling.

We acknowledge that the emphasis of Chapter 13 is on non-professional staff, but suggest that non-professional staff should have opportunities for professional development and career advancement within the disability sector to reduce attrition of staff. High staff turnover rates in the industry could be addressed by increasing opportunities to make a career of working in the sector, which should include increased access to professional development at all levels, including university programs focused on practitioners working with people with disabilities. That way university students currently working short-term in the disability field could be working towards a more professional role within the field rather than having to leave the field for career advancement.

Overall, disability care and support reforms need to recognise professions and non-professional staff at all levels and should aim to maximise knowledge and skill retention and minimise attrition of experienced staff from the industry. This can be achieved via a balanced focus on skill mix, professional development opportunities, career advancement, competency research and appropriate recognition for all members of the workforce.

- **Insurance arrangements for injury and funding models for acquired injury**

Australian residents

It is appropriate that only Australian resident citizens be eligible for the services of the proposed NDIS scheme. However, the scheme ought to secure reciprocal arrangements with other countries to cover the support needs of non-Australian residents. Many non-residents have lived and worked in Australia for years, acquired an injury, and been unable to return to their home country for a raft of reasons. This has resulted in many costly legal battles. This is particularly pertinent to considerations of care towards any proposed immigrant workforce who may become disabled during the course of their employment within Australia.

Work related accidents and motor vehicle insurance

It is reasonable that NDIS does not include people covered by insurance for work related injury or motor accident insurance. However, insurance for workplace accidents, for example, Workcover Queensland is inadequate to meet the medium and long term support needs of those people with serious injuries such as tetraplegia who require long term support.

Much of the insurance from these schemes goes towards initial medical/rehabilitation, community resettlement costs and short term income maintenance. Income from these insurances usually excludes these people from subsidies for equipment and other items even though their temporary replacement income may not be particularly high. A mechanism needs to be developed whereby people in receipt of insurances such as Workcover can move to the NDIS scheme when their funds are exhausted. Failure to do this risks creating an underclass of certain people with disabilities.

Transitions to the Aged Care Sector

Less than 10% of Australia's older population accesses institutional models of aged care services. Current services for supporting elderly people in their own homes are usually inadequate and vary—usually confusingly— from region to region.

Institutional and community services geared toward older people are not equipped to support older people with disabilities who have different and often more complex needs. The now somewhat arbitrary 'old age' bench mark of sixty-five years needs to be reconsidered: most Australians do not plan to enter an aged care facility at age 65 (or even younger as is planned for Indigenous Australians). However, this will be the only option for many people with disabilities with high or increasing care needs who move to the aged care sector at age 65 years.

Conversely, many people with disabilities have survived on minimum income and higher health and technology costs by the age of 65 years and are comparatively disadvantaged. Expecting co-contributions from people with disabilities before and after the age of 65 years does not address structural disadvantage and contributes to greater poverty. Poverty is associated with poorer health outcomes and greater costs to the community (Marmot, 2005). Perhaps funding from the state and federal aged care budgets that would normally support people with disabilities after the age of 65 years could be redirected to NDIS to support people in their own homes and communities. This could also contribute to continuity across the lifespan and enhance quality of life.

Assessment, care planning, assessors, case managers and intermediaries.

The Commission's Report elides the difference between the assessment of functional limitations and care planning processes by merging the two processes under the single heading of 'assessment'. These are two entirely different processes with two different purposes:

- Assessment of impairment and disability establishes the limitations of a condition.
- Care planning, particularly person centred planning, is a skilled process, including information, education and goal planning techniques, that enables people with a disabilities and their informal carers to establish the 'best fit' of supports for their unique needs and

context that mediates the effects of disability (the interaction between impairment and the environment) (WHO, 2002).

In addition, caution needs to be exercised in the application (and applicability) of assessment methods. The exclusive use of certain assessment tools is in conflict with consumer-driven or -led support such as care planning and direct payments. All assessment tools are limited in their use and the scope of what they are expected to assess because they cannot account for contextual factors. Assessment tools have a place, particularly in physical functioning, but are not suitable for determining *all* aspects of support, or relationships and social connectedness. Furthermore, most instruments are not usually valid and reliable for use across cultures and are informed by western biomedical perspectives, rather than say disability perspectives and culturally appropriate methods of assessment and intervention. This is particularly the case when considering Indigenous Australians because of the act of researching on, and the acceptability of certain research methods by Indigenous peoples (Humphrey, 2001; NHMRC. 3003). Similarly, assessment methods designed for a particular population are not therefore generalisable to younger people with a range of disabilities. This is why measurement tools should never be used in isolation from other assessments such as the collection of qualitative data and methods that can more accurately depict context and the individual circumstances of the person in their unique environment, for example, psychosocial assessments conducted by social workers and care planning tools. This further underlines the need for trained professionals who are able to exercise professional judgement and individualise needs in the interpretation of any assessment tool.

This is also the issue of duplication. It is inappropriate for certain assessments to be repeated simply as a checking or gate-keeping exercise. Doctors' reports are able to be provided, as are the reports of all qualified professionals in the allied health professionals including social workers. Existing collaborative relationships are important in assessment processes as shared trust, expertise and knowledge enhance the assessment process. Only when particular data requirements do not exist, should additional assessments be conducted. An analysis of the NDIS' reporting requirements might be useful in determining their assessment needs.

The Commission's Report emphasises the commitment to the independence of assessment. Nevertheless, there remains the risk that assessors will be biased towards institutional goals—particularly the financial goals and obligations of the NDIS—rather than to consumer goals. This is an issue that has dominated the insurance industry for many years (*cf* the insurance industry's response in the 2011 natural disasters across Australia).

The Report is silent on who the assessors would be, what qualification and training they would receive, particularly in relation the needs of people with a wide range of disabilities, or from where this pool of workers would be drawn. They do not currently exist in the Commonwealth system. There is a suggestion that Medicare and Centrelink are appropriate sites for a speedy introduction: does this mean that employees in these agencies are earmarked to conduct assessments? The existing skills and experience of staff in these agencies do not align with the development of individualised packages and care plans, case management and intermediary roles for people with disabilities. Rather, their roles are biased towards the demands of bureaucracy ie. processing, monitoring and eligibility determinations.

It is also essential that these separate assessment and care planning processes are conducted within a person's own living circumstances and communities. A true picture of need and functioning cannot be made in isolation from the person's living environment. It cannot be conducted in an office and certainly not via the telephone. Identification and training of persons to undertake such assessments will take time. This is of particular importance for people living in Indigenous, rural and remote communities. An understanding of local resources that can be rallied is important. There are no standard norms for a person's needs (nor a 'right way' of doing things) including adjustment, coping and life satisfaction that includes context, culture and needs that are unique to the individual. Detailed and continued planning is essential to success. The person must be central to those planning activities and the selection of providers must be based on more than price. Choosing and changing providers is more complex than the oversimplified restaurant analogy suggests.

The commentary that the Board, made up solely of those with financial expertise, would make decisions on which assessment tools would be used needs to be reconsidered. This would be beyond the domain of financial expertise, and also raises perception regarding management issues, with the inevitable implication that financial outcomes, rather than consumer outcomes, will be sought. The NDIS Board ought to also have representatives with social policy and social inclusion expertise, in addition to business and financial capacity, as well as an advisory board representing a range of disabilities, cross cultural, and Indigenous perspectives.

Training

Assessment and case management are both skilled activities. Again differentiating between assessment and care planning, case management

> is a complex and dynamic process, requiring critical and reflective practice, flexibility, and creative thinking from the human services professional . . .Managed care and care coordination . . . emphasise service co-ordination and the meeting of organisational objectives such as reduction of costs and re-hospitalisations, whereas case management while paying due attention to outcomes does not assume client and organisational goals align . . (Dorsett & Fronek, 2009, p.248).

Case management thus requires a defined skill set that includes a mix of knowledge, skills and values such as high level communication skills, goal setting, networking, co-ordination, relationship building, assessment and referral to name a few. Case management in this field will also require in-depth understanding of the particular disability and how it impacts on people and their families.

The report refers to the Cash and Counselling model in the US: an important feature of this model is the inclusion of booking keeping and other counselling services. This should, however, be provided separately to packages and cash payments along with training and ongoing support for individuals and their families regarding all aspects of self-direction. This requires specialised training, provision of information and support that would include such aspects such as book keeping, human resource matters (industrial awards, recruitment and retention) workplace health and safety, rostering etc. The importance of this has been noted in the UK (Arksey & Baxter, 2011). The required skills are similar to those needed to run a successful small business. A mentorship program in addition to training and support similar to that available for small businesses would maximise success and effective use of resources in self-direction. Many people will require the provision of computers and training in order to support self-direction.

Training and the development of competencies is essential for formal carers especially when they are new to carer work. Young people in the industry are often students who move onto better paid jobs after graduation. Basic first aid and other training such as manual handling, hoisting, dressing, showering, communication etc is important. Particular emphasis must be placed on communication and its role in the management of challenging behaviours and maintaining appropriate boundaries. Much carer training is best conducted in the person’s home directed by the person with the disability and in some cases other family members. The training needs of formal carers ought to be identified by the industry and consumers, not exclusively by the NDIS.

Training must include philosophies and values appropriate to working with disabilities. Some consumer led organisations prefer to do their own training especially about developmental disabilities. However, specific training content is essential such as manual handling, health maintenance regimes, managing ventilators, emergency procedures, problem solving, managing ethical boundaries, managing challenging behaviours, use of specialized equipment, to support people to manage their daily tasks independently. Access to continuing professional education and development is important for recruitment, retention and skill development

All training involving Indigenous people and their communities would ideally take place in their communities, and appropriately involve consultation with elders and the education of appropriate people within the community. Aboriginal and Torres Strait Islander people should have the same opportunities for self-direction as any people with disabilities, but they may need increased support to do so given the structural training and educational barriers they face.

Additional training for immigrant workers (and their employers) is important given the potential for cross cultural misunderstandings, causing costly and avoidable issues. These can include different understandings of disability, understandings of the carer role, and expectations of family involvement to name a few. Understanding one's rights and responsibilities is also important aspect of training immigrant workers and cultural support.

Co-payments of contributions

The Commission's Report notes that people with disabilities and their families experience severe social, financial and personal disadvantage over their lifetime. Many families experience subsistence living and are unable to contribute $500 per year towards their care or any other nominal amount without experiencing additional hardship as a result. There is also an implied assumption that contributions will reduce unreasonable claims. There is no evidence to support this notion.

Centrelink, Medicare and informal carers

Disability Support Pensions (DSPs) are granted for two year periods, not for life, and the process of qualifying for a DSP is rigorous. Living on a DSP is not usually a person's preferred option, but people with disabilities are faced with a range of structural barriers to employment and leaving poverty. The NDIS scheme should aim to assist in reducing those structural barriers by improving access to care, housing, education and employment through the provision of user-led support (BSL, 2001; Smythe, 2011).

The proposed sharing of information between NDIS and Centrelink sails close to the wind of infringing privacy laws and serves no clear, consumer-centred purpose. The provision of income support has no bearing on the provision of disability support packages, or *vice versa.*

Access to work will not necessarily mean a reduction in support services; in fact, it may increase the variety and intensity of the support services. Some people will require physical support in their work place and this must be ensured. Employment should not be linked to paying for a service as the scheme is not subject to income and assets testing. The long term benefits of full community participation including vocation have already been noted and discussed earlier in this response.

If Carer Payments, Carer Supplements, Carer Allowance, Mobility Allowance and Child Disability Assistance Payments are to be subsumed into a self-directed packages it will be vital that support offered for vocational and community engagement as well as support of informal carers is not lost. Currently none of the above payments are sufficient to meet their original policy objectives of redressing the financial hardships and additional expenses incurred through the caring role. The mobility allowance is a token sum that minimally assists with transport costs associated with work or study (Herscovitch & Stanton, 2008).

Use of restraints

The use of coercion is problematic. There are serious clinical and ethical concerns regarding the use of constraints outlined in the Commission's Report. Such matters should be mandated to refer to the appropriate body such as the Office of the Adult Guardian on each occasion. This is delicate territory.

Skilled care is required in these situations and should only ever be used in emergency safety situations. Training and strategies to reduce the use of restraints should be supported. Additional training for carers should be provided about the principles and practice of ‘least restrictive environments’. At a clinical level, more skills and supports are often required by the professionals caring for a person rather than the forcible restraint of the person with a disability.

Assessment of capacity is a contested, problematic area, notwithstanding the establishment of guardianship tribunals and other mechanisms in Australia to assist decision making for those with impaired capacity. Capacity is a legal concept that can vary from minute to minute, day to day. In a medical sense, it is most properly assessed by neuropsychological assessment but there are insufficient resources to do this properly in Australia. People with cognitive, intellectual or psychological impairment can make reasonable decisions for themselves. Support should be provided to assist people or their representatives to do this. Decision making should involve person-centred planning and family professional development rather than that of capacity which is also culturally problematic (Fronek et al, 2009).

Conclusion

It does not always follow that a rationally designed system founded on the principles of logic, measurable and quantifiable performance indicators, a fair apportionment of funds, and even good intentions will deliver the best quality of life features for people with disabilities and their families.

What is needed is a system that rewards innovation, encourages creative responses to unusual situations, and does not reify compliance for compliance’s sake rather than asserting the leadership and autonomy associated with professional expertise.

Consequently, any national disability insurance scheme must resist the temptation to place system design before individual outcomes. Inevitably (and awkwardly), this requires a willingness to suspend policy cynicism, and make that leap of trust in the preparedness of people to make their own right decisions.

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