Submission from Steve Dowson
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May 2011

Background to this submission

I am a UK-based social care consultant who has specialised for the last twenty years in the development of individualised funding (self-directed support) systems. I am particularly interested in the way that the design of these systems impacts on the interests of each of the main stakeholders, and I have explored these issues through work in Canada, the USA, Australia, and the UK. In view of this expertise I was asked to contribute to the development of submissions by PWD Australia and In Control Australia to the Commission last year.

I was also privileged to deliver a keynote presentation to the National Disability & Carer Congress in Melbourne on May 2nd and 3rd this year. While I made it clear in the presentation that I strongly supported the overall proposals for a NDIS, I did also identify concerns about some areas of detail. Afterwards, Bruce Bonyhady suggested that, even at this late stage in the Commission's work, it would be worth making a submission to identify my main concerns. These are now set out below, as succinctly as possible.

Association between assessment and support planning

The discussions in the Productivity Commission report are not entirely clear and consistent about the appropriate relationship between assessment, as an activity focused on establishing the appropriate level of funding; and support planning, the activity centred on making plans to use that funding. I very much hope it will be made clear in the final proposals that the NDIS needs be designed in a way which keeps these two activities completely separate. The rationing of scarce public funds is the proper and necessary responsibility of government or its mandated agent (here, the NDIA). It is not, however, the business of government to dictate how people should live their lives (except where there is very clear justification based on the protection of the individual or others). Moreover, an effective person-centred approach to support planning typically needs to be driven by a strong sense of the person's goals in life, with the funding or support set within the context of those goals. If the assessment procedure is linked to support planning, the focus of assessment on what is 'reasonable and necessary' is likely to undermine the broader and more ambitious aims of support planning.

This suggests that, at the very least, the two activities should not be carried out as a continuous process. Logically, moreover, they need to be performed or assisted by people located at different places in the disability support system. Although the assessment process may be delegated to a professional with appropriate specialist expertise, that professional will nevertheless be acting as the agent of the NDIA, and accountable to the NDIA. It is important that this relationship remains explicit, so that it is clear to the person being assessed that the decision on funding remains (as it should) with the NDIA.

In contrast, if people need assistance with support planning, they should have access to help that is free from conflict of interest, i.e. help that is not linked to the NDIA and its duty to ration expenditure, nor to service agencies which may have an interest in selling their own services. It is important to recognise that conflicts of interest are not only concerned with line-management accountability, but also with the ‘mindset’ associated with a role and its appropriateness to the task. Thus, for example, a mindset focused on the standardised collection of data, or on the clinical aspects of impairment, is unlikely to be supportive of an holistic, person-centred planning process.

The international self-determination movement by and for citizens with disability seeks to end the implicit presumption that, because people need publicly-funded supports, they must forfeit the right to have control of their own lives. The separation of assessment and support planning is the technical means by which this can be achieved in the design of the new disability support system.

Lessons from the UK Direct Payments provision

In its discussion (Section 6.7) about the implementation of Direct Payments (DPs) in the UK, the Commission appears to reach the conclusion that relatively few people want the option of self-directed supports. This conclusion seems to have had substantial inluence on the proposals for the NDIS. I suspect, however, that there has been some misunderstanding about the origins and scope of DPs in England, and their relationship to self-directed supports.

Direct Payments, which were introduced in England through legislation in 1996, had their origins in the Independent Living Movement that had begun two decades earlier in California. This movement was led by people with physical impairments who were politically active, assertive, and intellectually very able. They identified the services of personal assistants (‘personal attendants’) as the crucial requirement to achieve independence, and saw the employment of these assistants as the most effective way to gain control. They were not so much interested in re-shaping the disability support system as escaping from it, and hence their main demand on government was to release the funds that had been locked into service provision.

Direct Payments provision in the UK, as a minor addendum to the main case managed system, was entirely shaped by these demands. Custom and practice have evolved on the assumption that DP recipients will use the money to employ personal assistants, and the level of funding is usually based on an assessment of hours of support required multiplied by a standard hourly payment rate. There has been little encouragement to use the funds to access mainstream opportunities or to contract with service providers, and the level of funding allows little scope to do so. Monitoring of the use of DPs typically requires recipients to keep detailed accounts. Although local schemes have gradually emerged to provide assistance with such tasks as recruitment and payroll, the quality and cost of these services is very variable. There has been no recognition in policy on DPs that individuals might want help in deciding how to use the funding, and few sources of help have emerged.

DPs in this form have met the essential demands of the people with disability who campaigned for their introduction, and for others who want to employ their own assistants and are willing to take on the responsibilities. On the other hand, it is hardly surprising that DPs have not proved a popular option. This does not mean that individuals with disability and their families do not want the high level of freedom and control that DPs provide. A sufficient explanation[1] is that people have seen the

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[1] In reality a number of other factors have influenced the take-up of Direct Payments, for example the level and quality of information given to people deciding whether to choose a DP, and these have produced the variations in take-up across the country which the Commission noted.

constraints on the way that the DP could be used, and the responsibilities and chores that would come with it, and decided the benefits weren’t worth the effort.

The jargon of ‘self-direct supports’ and ‘self-directed funding’ signals a set of ideas entirely separate from the Independent Living Movement. These ideas began with a group of parents of people with intellectual disabilities in British Columbia in the 1970s. The ideas lost momentum before being resurrected in the Self-Determination movement which spread across the USA in the 1990s. The aim of these initiatives is not to extract money from the system, but to redesign the system in a way that allows the individual to control their own funding allocation. This in turn enables individuals to use their funds more creatively and efficiently, and makes them the true customer of their support services.

The Independent Living Movement, intent on maximizing control over money and supports, sought to extract funds and use them to employ personal assistants. But the self-determination movement, in effect, argued that the physical location of the funding is irrelevant. It is the design of the system, and where it places power, that determines control. Direct Payments, or ‘cashing out’, should not be necessary to achieve self-directed funding or self-directed supports.

The false dichotomy between arranged support packages and self-directed funding

It seems that the Commission has been led to the conclusion, like the originators of the Independent Living Movement, that self-directed funding means Direct Payments; and that those who opt to ‘cash out’ are also opting to move outside the system of specialised support providers. In other words, the proposed NDIS presents its future beneficiaries with a fundamental choice between two options:

> *On the one hand*, the individual may choose a system in which professionals take the lead in the sequential processes of assessing need, planning support, and organising services. It is to be hoped, of course, that these professionals will adjust their mindset as appropriate to each of the processes in turn, and strenuously uphold the rights and choices of the individual. Then again, it is easy to see how the professionals might start to become overbearing, allowing their concern to ration funds to influence the way in which they assist people to develop plans, and encouraging the service provider to see the NDIA, not the individual, as the real customer. In truth, this part of the system as proposed is very similar to the care management system introduced in England in the early 1990s, now being replaced by Personal Budgets – precisely because it proved impersonal, inefficient, and disempowering.
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> *On the other hand*, the individual may choose to cash out. They will then be able to enjoy the advantages of self-directed funding. However, rather like the English recipients of Direct Payments, they will be left to ‘go it alone’. And like their English counterparts, they may well decide that it’s not worth the trouble. If that proves to be the pattern, ‘cashing out’ will remain on the periphery of the disability support system, and largely ignored. The provider market, in particular, will be overwhelmingly shaped by its single dominant customer, the NDIA.

This problematic future can be avoided by ‘levelling out’ the two options – strengthening the control afforded to people who opt for a service package, and increasing the assistance available for planning and secondary supports. This would replace the dichotomous choice with a variety of arrangements, all of them offering real control over funding and support, and all with help available to deal with both the opportunities and the responsibilities. More specifically, that means –

A. Ensuring that the design of the system allocates the key tasks to the appropriate player, with safeguards to ensure that the tasks and responsibilities do not migrate or become inappropriately conflated. As discussed above, this crucially includes the separation of assessment of funding allocation from support planning, but also applies to other areas – for example to ensure that service providers do not decide what they should deliver to the individual.

B. Ensuring that there are trustworthy, reliable, and competent services available to help people plan how to use their funds from the NDIS and (separately, and where needed) to help with ‘secondary supports’ such as support coordination, recruitment, and accounting. These secondary supports are most likely to be needed by people who choose to employ their own assistants, but could be needed to underpin other arrangements (for example to coordinate a complex package of supports).

The secondary support services may include holding money on behalf of the individual. This type of fiscal intermediary arrangement need not undermine the control of the funds by the individual. In this way, all sorts of arrangements can be put in place to suit the individual while still preserving the essential qualities of self-directed funding and supports. However, some additional requirements must be met if this system is to be kept true to the principles of self-determination and personalisation:

1) *The system needs to be designed, with provision of funding, to include high quality sources, independent of the NDIS and of service providers, of assistance with support planning and brokerage tasks.* While, as argued above, it is right that the funding agency should draw back from involvement in support planning, it is unreasonable to expect individuals to acquire the ability (or, for that matter, the desire) to undertake planning entirely without skilled help. As the Commission has indicated, this help may come from Disability Support Organisations, but – as a vital and integral part of a good system – it needs to be properly defined, located, and funded.

2) *Some founding principles need to be agreed and enforced through regulation to hold the boundary between legitimate variety and corruptions of the system.* It is possible to mount a persuasive argument that the people assisted by the scheme should, in the spirit of self-determination, be left totally free to obtain help – whether with brokerage, service delivery, or fiscal intermediary services – wherever they choose. However, this would also mean abandoning the very principles that have been established to protect the choices and rights of the same individuals. It is also naïve to assume that no regulation is required when, in almost every other area of public and commercial life, regulation is accepted as necessary and desirable.

3) *There should be strong regulations governing the activities of service providers operating as fiscal intermediaries.* Strictly speaking, this is only an instance of the general need for regulation as set out above. However, it calls for special attention because the use of provider organisations to hold

funds on behalf of an individual may seems a safe and convenient arrangement, especially when there is a shortage of alternative agencies. Disability support systems in a number of jurisdictions, including Victoria, make substantial use of individual support packages based on this arrangement. While there may be circumstances when it is justifiable (for example as a transitional arrangement between block funding and true individualised funding), it plainly weakens the status of the individual as the customer. Providers may respond to the funding authority as the true customer, sometimes to the point where they act as the agent of the authority in monitoring and constraining the actions of the individual. This is a reversal of the relationship that is required to support self-determination. So, if this type of arrangement is to be used, the quality of fiscal services provided by support agencies needs to be rigorously monitored.