

The Role of Self Assessment in the National Disability Insurance Scheme

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The Productivity Commission's Draft Inquiry Report into Disability Care and Support focuses on personalisation of supports and services and promotes a model which emphasises choice and control for people with disability. We commend this approach and believe it will lead to better outcomes and better lives for people with disability because they will gain control of their supports and services.

We are, however, disappointed in the unwillingness of the commission to consider self-assessment as the method of assessment for the NDIS.

We believe that the National Disability Insurance Scheme (NDIS) must be based on the United Nations Convention on the Rights of People with Disability (UNCRPD). In the area of assessment and planning there must be the same recognition and consideration given as in the UNCRPD Preamble:

- (n) Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,
- (o) Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,

The principles of the UNCRPD (as per Article 3) should guide the NDIS. Self-assessment will meet the obligation of the first principle "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;" in particular.

The method of assessment and tools used must engage with the social model of disability and aim towards ensuring access to supports for people with disability who face barriers to full inclusion and participation (as per Article 19 UNCRPD). People with disability have a right to exert control in "decision-making processes concerning issues relating to persons with disabilities" (Article 4.3). Use of self assessment would more strongly satisfy the requirements imposed by UNCRPD, ensuring that the needs and aspirations of people with disability are fully met.

We strongly believe that without self-assessment as the first part of any person centred and individualised system, then that system will not be as empowering as it could be as it would be starting from a point of dependency on professionals.

We also believe that if the assessment tool is

- ⤴ well built,
- ⤴ has a clear purpose,
- ⤴ is consistent across jurisdictions,
- ⤴ is transparent about what is being assessed and how, and
- ⤴ there is support available for those who need support using the tool

then it will be an empowering, self-affirming tool for the individual, be cost effective for the NDIS, and have the same facility for feedback and refinement as an assessment tool managed by a fleet of trained assessors.

We believe there needs to be a distinction between assessment (which is about eligibility and how much support a person needs) and planning (which is about identifying the supports and services that can meet the person's needs).

We believe people with disability, and where appropriate their families, know in most cases what their daily lives entail and how their disability affects their daily life. They are the experts. They may not know what support is out there that can assist them or how to get that support, but that is an issue for the planning process.

We believe that it is imperative that, as with the move to self-directed supports, there is support for people with disability to build their capacity, skills and ability to self-assess their need for support. Some people will be ready and able to self-assess while others will not have the confidence and will need to see others successfully go through the process.

We believe there must be the safeguard of requesting a second assessment, or assessment by another assessor if a person finds they have under-assessed themselves through self-assessment or do not feel confident using self-assessment initially.

We believe it is vital to the integrity of the process that all people with disabilities have ready access to independent advocacy support if they wish, prior to and throughout any assessment and planning process. This is different from and in addition to any brokerage agency support they may have.

The purpose of Assessment

The purpose of an assessment under the National Disability Insurance Scheme (NDIS) “will be about identifying the supports that would allow a person to fulfil a range of functions, such as participate in their community.” (draft report 5.2)

One of the biggest problems with current assessment approaches and even the way the purpose of assessment is described in the Productivity Commission Draft Report, is that assessment is predicated on the supports and services currently available – fitting people into the boxes that are known. Assessments also set up expectations (or a lack thereof!) for the systems people with disability encounter, and in turn the expectations they have for their own lives. If you expect poor or restricted outcomes from the beginning, and that is what you are assessed for then the end results - in terms of supports provided, inclusion achieved and satisfaction ratings – are not going to be a true reflection of need in the community. Throughout the NDIS there is a need to lift the expectations of people with disability as well as the community generally.

Culture shift required

There is a cultural shift required to move the system and the people in it (people with disability, families, carers and professionals) to more creative, flexible, inclusive ways of providing and getting support to meet needs. This cultural shift will not happen if it is starting half way through the process. It must start at the very beginning which is at assessment. Assessment can box people into a certain range of supports or free people up to think about how they live their life. The shift must be to having self-assessment as the method of assessment with a choice to get support to complete the assessment if required, which is then followed by person centred planning. This would mean assessment looking at how much and what support someone needs, followed by planning which identifies where the support comes from and what form it takes.

A key component of this culture shift is the attitudes toward decision-making capability of people with disability. In the United Kingdom the *Mental Capacity Act 2005* states clearly that there cannot be an assumption made about a person's ability and capacity to make

decisions. There is an expectation that capacity will be assumed as a basic human right. When proven otherwise, policy stipulates the need to support the person to have choice and control. This shift in assumptions includes assumptions about risk in decision making. There are clear policy guidelines that work from the premise of balancing different types of risks. Not just Occupational Health and Safety or liability, but also the risk to the person with disability of social exclusion or the risk of abuse and neglect if they are not allowed to make decisions about their life (Department of Health 2007; Fulton et al 2008). Self-assessment as the default method of assessment makes that cultural shift of assuming capacity to make decisions and supporting people where they may require it.

Many of the issues identified as barriers or flaws with self-assessment as the method for assessment of support for people with disability are often related to the lack of a cultural shift among professionals and within policy and legislative frameworks. So for example professionals who hold on to their expertise and are wary of using self-assessment for fear it will not be as accurate as their assessments, have not made the shift to seeing that most people know more about their own lives than a professional. Or the accuracy of self-assessment can be hampered by risk adverse policies which limit the way it can be used and what it is used to assess. The culture of our current system in Australia allows for self-assessment to be undertaken by organisations to measure the quality of services under Disability Service Standards (FAHCSIA). Policy makers put a greater trust in organisations to report and assess themselves. They also provide organisations with a range of supports to complement the assessment. This trust is not shown to individuals.

Self assessment is not just good practice but critical to good change management.

Resource Allocation Systems and Self-assessment

The Productivity Commission draft report states that examples of self-assessment in social care settings “are limited, especially for resource allocation purposes” (draft report 5.19). Yet there is a growing body of evidence from the United Kingdom where self-assessment has been the main form of assessment used in the Resource Allocation System (RAS) that is utilised in the In Control model of Personal Budgets. Local Authorities in the United Kingdom that use this system have learnt many things about the process of self-assessment for resource allocation which the Productivity Commission should follow up. These areas that have implemented a RAS and self-directed support comment on how important it is to get the questions right, and that the tool recognises the importance of the gifts and resources individuals and families bring with them. They also talk about how developing the self-assessment questions is essentially an action learning process where it is tested and refined with feedback from users (Etherington et al 2009; Pitts et al 2009; Tyson 2009).

Most of the Local Authorities in evaluating the implementation of personal budgets compared the difference between the traditional cost of providing services, the amount indicated by the RAS and the final cost of delivering the support plan. These comparisons showed that there was evidence to suggest that this approach resulted in reduced spending when compared with a more traditional way of allocating resources. There was also a clear relationship between identified need through the RAS and the amount spent (Edwards and Waters 2009; Etherington et al 2009; Pitts et al 2009).

An example of a RAS self-assessment questionnaire from Bristol can be found at this link. <http://www.bristol.gov.uk/ccm/content/Health-Social-Care/assessment-and-paying/files/sds-questionnaire.en>

Role of the professional

Traditional systems rely on the 'expert' professional to tell a person how much support they can get as well as play the role of gatekeeper and assessor. This can then limit what the professional can do in terms of working with the person to explore the best outcomes. A lot of writing has been done which explores how 'duty of care' and the maintenance of regulatory frameworks have led to professionals retaining this position of power over people with disability (Williams 2007, p8).

The Productivity Commission draft report points to evidence from the United Kingdom that says "that case managers were not confident that self-assessment alone would adequately capture individual's needs" (draft report 5.19). This reasoning puts the role of the case manager in the position of the expert and justifies their power over people.

The original report, *Evaluation of the Individual Budgets Pilot Program (2008)*, that the Productivity Commission quoted above was an evaluation of early stages of the Individual Budgets program. Other parts of the report which discuss self-assessment show that there was an understanding of the need to apply discretion and respond to individual needs when providing support for self-assessment as described below:

Our default position is that people can do this for themselves. However, we are very much aware, particularly in older people's services, there may need to be care manager involvement especially as increasingly families don't live near the older person.... Some older people prefer supported self-assessment. In mental health, people can self-assess but this can cause anxiety around paperwork and so the care co-ordinator follows it up to make sure they're okay with it. (Glendinning et al 2008, p148)

The report also showed that self-assessment was considered by the pilot sites that used it "as an indication that people's views were taken seriously and as having the potential to generate positive discussions about needs and outcomes" (Glendinning et al 2008, p147)

There is also other evidence which shows that social workers who were at first cautious about self-assessment and concerned it was not adequate, have found that when they began working in the newer system they could spend more time on issues of importance to service users and do things such as assist people to plan more creatively rather than just being a gatekeeper (Williams and Tyson 2010; Tyson et al 2010). During a time of change it is not uncommon for those who hold the power and have done so in an entrenched way, to be reluctant to change to new systems that shift power away from themselves. However this is a quote from a social worker in the United Kingdom who has transitioned from one system to another:

The introduction of Self-Directed Support in 2008 challenged me in various ways. I thought there would no longer be the duty of care by local authorities. I thought the system would be open to abuse; I also felt that I would be dis-empowered as a social worker and that the new way of delivering services might promote conflicts between social workers and service users. Today, having completed a few cases, I feel differently about Self-Directed Support and my role. I have realised that I am still relevant in the scheme and that service users have become involved in their own affairs and that the conflicts I had perceived are non-existent. (Williams and Tyson 2010)

And another:

I feel that I am doing holistic social work: making a difference. I feel that service users have more say, that they are empowered, being independent and being valued. Some people say that social workers are no longer required, however we feel that it is now that social workers are required because we now empower clients; before it was mechanical in the way that a comprehensive assessment was completed and a care plan drawn up. (Williams and Tyson 2010)

A Report on In Control's Third Phase 2008-2009 (2010) evaluates the implementation of Personal Budgets in five local authorities in the United Kingdom. Since the second phase evaluation in 2007 the In Control project has provided resources and supports to front-line professionals about their role in assisting people to complete self-assessments, do planning, make choices and take control of their lives. This latest evaluation included asking social work staff about whether they felt there was improvements for the people they supported and in their own role. The report clearly shows that the majority of professional social work staff thought Personal Budgets, which includes self-assessment (with support if needed) as an integral part of the Resource Allocation System, either improved or maintained people's lives and their own work role and satisfaction (Tyson et al 2010, p68 & p143).

Given this evidence we do not believe the fears of some professionals to be a valid reason to not use self-assessment.

Accuracy

The Productivity Commission Draft Report has concerns about the accuracy of self-assessment based on an evaluation in the United Kingdom of older people (2010, 5.19). However this evaluation does also say that self-assessment tools that worked well were those with a well developed reference standard (Griffith et al 2005, p3).

The Productivity Commission points to our failing system in its Draft Report and we contend that much of that failure is due to the current system of assessment by independent assessors where there is considerable inaccuracy, inconsistency and inequity. Whether the assessment tool is administered via self-assessment or an assessor this goes to show that what is important is the clarity of criteria for assessment, and a common understanding of the reference standard. This is clearly seen in research from the United States which showed that there was as much under and over assessing through self-assessment by people with disability wanting to access disability funding, as there was when they were assessed by professionals. This research found that:

"Indeed, our results are consistent with the hypothesis that disability applicants are aware of the criteria and decision rules that SSA (*Social Security Administration*) uses in making awards and act as if they were applying these same criteria and rules when reporting their own disability status." (Benitez-Silva et al 2004)

In the case of the NDIS there is, as yet, no clear criteria or reference standard for the support that will be funded. It is important to note again that the self-assessment questionnaire of the RAS was tested and refined over time by actual use and comparison with traditional assessment tools. (Tyson et al 2010).

Independent assessors or self-assessment

There seems to be an expectation that the request by people with disability and disability groups for self-assessment means there would be no support for people who require this to complete the assessment; or further assessment around specialist need such as equipment; or support if required for planning. This is not the case as there is an awareness of the diversity of skill, ability and experience among people with disability. What is called for is self-assessment as the default position, with support provided if necessary and followed by further person-centred planning.

The biggest fear of professional assessment by independent assessors is that people will be boxed based on the expertise of the assessor, not the person's own identified needs. This is one of the biggest problems with the Job Capacity Assessment (JCA) experience in Australia. Independent assessors for the JCA come from a range of backgrounds with their own subjective and professional experience which may or may not match with the disability, the social circumstances or other individual factors that impinge on assessment (Nevile 2010). Unfortunately the solution proffered by Dr Nevile in her report (2010) removes assessment even further away from the involvement of the person with a disability. This model must not be replicated within the NDIS but used as an example of how not to approach assessment.

The Productivity Commission Draft Report rightly points out that assessment should be a collaborative process, but there is not significant justification to say that the process should not start with self-assessment. In fact starting with self-assessment ensures the context and expertise of the person with disability is front and centre, particularly where professional involvement is also required.

Providing the right support for self-assessment

People with disability are a diverse group of people with a range of abilities. They are also a group which has experienced dependency on others for much of their current history. One of the potential issues with self-assessment is 'many disabled people have been historically dis-empowered by dependency-creating welfare services and may lack the confidence or knowledge to make informed choices about the support they need' (Priestley 2004, 260). Often the system response to this issue is to remove the choice element so as not to burden people with disability with the effort of gaining knowledge or making a risky choice.

The system for assessment needs to allow for a level of contribution by the person that is responsive to their interests and capacities. This will vary from person to person and over time. It means that self assessment should be the default, and inclusive of capacity building support mechanisms as appropriate. It is vital that the assessment process does not serve to disadvantage those people who have difficulty (even with appropriate support) in understanding the system, expressing their wishes or determining the kind of supports that may be beneficial to them. The availability of capacity building support mechanisms to undertake the assessment process may assist this group of people with disabilities.

Providing safeguards when requested, and being able to redo a self-assessment, does not deter from the fact that we need a process that empowers people with disabilities to be the decision-makers in their own lives, and supports for this to happen.

With self-assessment as the default position there must also be support and capacity

building opportunities for people with disability. Those who currently have expertise in assessment should be working in partnership with people with disability and Disability Support Organisations to share skills and assist people in how to self-assess. Peer support organisations could also be utilised. Many of the issues and limits to the effectiveness of self-assessment can be overcome if people with disability work in partnership with professionals and disability organisations (Renshaw 2008).

Providing support for people with disability to be involved in decision making about their lives will fulfil the obligation of the UNCRPD.

Conclusion

Although there is minimal evidence currently in Australia on self-assessment as the method for assessing support needs, we do not think there is enough negative evidence to warrant dismissing it out of hand. In fact we believe that the quality of evidence for self-assessment being effective is more reliant on the actual tool that is developed and the shared and clear understanding of the criteria and underlying assumptions of what is being assessed.

Self-assessment should be the first step and default position of assessment for support under the NDIS. This does not mean that some people with disability will not need support to undertake self-assessment. Like many of the changes we hope for from the NDIS, this requires a shift in the culture of disability support and a commitment to the implementation of the UNCRPD in actions and not just policy statements or relying on professionals to do the right thing.

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