



**Submission made by
Julia Farr Association**

Productivity Commission Draft Report – Disability Care and Support

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1.0 INTRODUCTION

We welcome this opportunity to make a second submission to the Productivity Commission regarding future arrangements for disability care and support. We refer the Productivity Commission to our first submission (submission 494, dated 24 August 2010) for our broader contextual analysis. This second submission is in response to the draft report released by the Productivity Commission on 28 February 2011, and includes material we presented at the Productivity Commission public hearing in Adelaide on 18 April 2011.

In preparing this submission we have drawn on a range of resources and expertise within our organisation. These experiences variously include research, advocacy, experience at all levels of service provision (from frontline to Chief Executive), government policy and procurement, employment, youth work, work with children and families, mental health services, acute health services, support for older people, and accident insurance.

In addition, we used our conference format known as *The Loop* where we take a themed conversation to a number of regional venues so that country South Australians living with disability and other local stakeholders have the opportunity to participate. For this submission, we spoke with over 100 people across venues in Adelaide, Whyalla, Mount Gambier, and the Riverland.

This submission is organised into three parts:

1. Our summary of the draft report strengths, together with areas that may be further strengthened;
2. Our response to the specific queries raised by the Commissioners with us at the public hearing on 18 April 2011;
3. Our response to the information requests posed by the Productivity Commission in the draft report.

2.0 THE DRAFT REPORT

2.1 Strengths

The Julia Farr Association believes the draft report contains many good elements and the Productivity Commission is to be commended for its careful attention to the brief. These include:

- The proposed arrangements are inclusive of all people currently living with significant disability;
- That it has a highly personalised focus, mindful of the person's strengths and capacity, with attention to a future where people are contributors to their community and economy;
- There is a strong expectation that mainstream services will be properly welcoming and inclusive;
- The absence of a co-contribution mechanism makes sense, on the assumption that the method of revenue generation means that higher income earners make higher contributions through taxation or levy;

- The coverage of all reasonable and necessary support;
- The recognition of the importance of funding innovations. NOTE - we query if this will be on an individual or population basis. We believe there are two imperatives:
 - To make sure that individual planning assistance does indeed support people to imagine an ordinary valued life and how this might be achieved, as this line of enquiry sets the scene for innovative thinking, as distinct from conventional thinking leading to conventional service choices that may be sub-optimal,
 - To set aside funds for general innovations, recognising that innovative thinking can come from anywhere, not just government or service agencies;
- The three options for distributing a personalised budget and the use of block contracts only in exceptional circumstances.
- It is important that plans get signed off quickly. It is good that people can add their own resources, and can transfer up to 10% to the subsequent year;
- The consideration of employment of family members is thoughtful, and the pilot is a good idea;
- Accountability and risk management mechanisms (which will need to be simple and accessible);
- The mechanism for reviewing the work of the new scheme, both externally and internally;
- The information database on-line to assist people to make choices;
- Early intervention (investment) funding in addition to individualised budget;
- Legislated ring fenced funding via consolidated revenue.

2.2 Matters of concern

We raise the following issues in the context of our belief that the draft report is an encouraging document. We have selected the following items either because they brought forth concerns from participants at *The Loop*, or because we felt they may be particularly vulnerable to misinterpretation or problems of implementation.

2.2.1 NDIS and NIIS

The risk of a separate NIIS means that unless the two agencies are strongly collaborating on best practice, two different classes of citizens living with disability could emerge, as happened in New Zealand following the introduction of ACC. We recommend consideration of either:

- Single common scheme, or
- Two separate schemes with explicit expectations of collaboration and alignment on best practice, with governance in each case including people living with disability, and

with the option to merge at a suitable point in order to reduce overall costs and strengthen direct value to scheme recipients.

2.2.2 NDIS, support for older persons, and co-contributions

The age threshold of 65 seems an arbitrary point for people to have to start making co-contributions, as it does not mark a common point of capacity change for people, other than being the notional age of retirement (which will likely be increasingly ignored as the average age of Australians change). We can guess at the Productivity Commission's rationale for this, given the separate funding mechanism for aged care where there is an expectation of co-contributions according to personal means. However given that the outcomes for disability support and aged care support are arguably similar, we believe that having separate schemes creates the risk that there will be different practice standards.

Therefore we believe it is possible, indeed preferable, to run a unified scheme. As with the proposed NIS, we recommend consideration of either:

- Single common scheme, or
- Two separate schemes with explicit expectations of collaboration and alignment on best practice, with governance in each case including people living with disability, and with the option to merge at a suitable point in order to reduce overall costs and strengthen direct value to scheme recipients.

2.2.3 Words translating into actions

We would appreciate greater clarity on how "reasonable and necessary supports" is determined in practice. No matter how strong the contextual principles, it is possible that people may not be served well by the new system if "reasonable and necessary supports" is implemented in a way that ironically results in a reduced horizon.

For example, a person living with severe disability requiring a particular level of support to access mainstream employment may not get that level of support if it is seen as beyond what might be interpreted 'reasonable'. Indeed, the terms of reference for the Productivity Commission's inquiry has a similar horizon-limiting moment in relation to employment, where it is stated, "Provides support for people to participate in employment where possible". The words "where possible" set an expectation that at least some people will therefore not have the chance to authentically participate in employment. Add to this a ceiling in relation to 'reasonable' and there is the real possibility that a significant number of people will miss out.

Though a person with more severe disability might need a higher level of resourced support to enter the workforce (and that seems fair), this is not about assuming people should be entitled to a 'Rolls Royce' service.

Sometimes, the difference between 'reasonable' and 'not reasonable', between 'possible' and 'not possible' comes down to a lack of imagination.

We therefore urge the Productivity Commission to be as explicit as possible when using phrases that might otherwise be open to unhelpful interpretation.

2.2.4 One-off payment at the start

We are unclear as to the purpose of the upfront one-off payment. We note that it would possibly be waived where families have already made a significant contribution of their own

time in support of the person. However, given that the scheme is expected to be funded from consolidated revenue, scheme participants are likely to have already contributed to the costs of the scheme through their taxes. The payment therefore seems unnecessary.

2.2.5 Costs of certain therapies

The draft report asserts that some therapies and intervention, because they are unproven, will not be funded in the scheme, leaving the recipient to fund the full cost themselves.

This presents another problem of interpretation. We understand the concern that a recipient might be persuaded to use, or even be over-serviced by, an approach that might not be considered a typical mainstream option for their circumstances. However, just because a particular approach has not been clinically proven, this does not mean the approach might not have benefits, and having a list of proscribed therapies may result in some people being denied access to genuinely helpful assistance.

We also think that significant resources will be consumed in maintaining and updating the list of prescribed and proscribed interventions.

We further note that in some jurisdictions overseas, the limits on expenditure of a personalised budget are refreshingly simple, barring anything that is illegal, gambling, or that might reasonably be regarded as contributing to disability or disadvantage.

Therefore we recommend that the final report not seek to exclude certain 'unproven' therapies and interventions. People should have the choice, and it is reasonable to expect that most people will make sensible choices to suit their personal circumstances.

2.2.6 Community capacity to be inclusive

We value the draft report's emphasis on mainstream inclusion. We believe the final report can give an even stronger signal about such matters so that mainstream service providers such as taxi companies and housing developers are held properly accountable for ensuring that their products and services are accessible to all. This is to help avoid some parts of our community somehow being deemed exempt from inclusive practices based on the misguided notion that the costs of inclusion outweigh the benefits. For example, the issue of how to maintain control of access taxi voucher costs would be lessened if all our public transport systems were properly accessible and inclusive.

2.2.7 Assessment

The process of assessment, and the assumptions underpinning it, will be critical to the success of the new national scheme. We note the draft report asserts the need for a toolkit of assessment tools together with an assessor trained in their use.

At the same time, we are aware of several developments in Australia aiming to create a comprehensive assessment tool.

As the scheme's success could stand or fall based on its approach to assessment, we encourage the Productivity Commission to carefully consider the degree of assessment necessary to determine a price-point quantum of funding. We believe this can be achieved through a simple, accessible tool, as is used in certain other jurisdictions.

We acknowledge that short-form, co-participation assessments may not yet have a large body of research on their effect, **but** nor is there the equivalent for larger, more technical

assessments. They may have elements of validity and reliability in terms of measuring a particular thing, but this does not mean that those assessment tools have a goodness-of-fit with the work of the NDIS. They have a tendency to be over-engineered, intrusive, and are expensive to run because they require specific levels of training for assessors, sometimes accompanied by a licence fee.

We recommend to the Productivity Commission that unless there is a compelling body of evidence that shows the short-form assessment tools are definitely *less* effective than detailed tools, then use those short-form tools as they are easier to run, and can provide good quality census-style data without having to operate an overly complex database.

Note that these short-form assessment tools are for the purpose of allocating a personalised budget. They do not attempt to replace a more detailed enquiry into a person's personal circumstances, where that is indicated. Therefore, there is still a place for the use of more detailed, technical assessments, but these should be prescribed as part of the planning process and the intended recipient should be able to participate in the decision about their use.

We further draw the Productivity Commission's attention to the potential of supplementary planning systems that can help manage risk safely. Without disrupting the contextual personal vision the person might have for the life, supplementary planning systems (including additional 'assessment') can work well for people with perceived high risks. An example of one such approach can be found in Oldham Borough Council, UK.

We make these comments because we are keen to avoid the situation where a person's capacity and value are interpreted in the context of a technical assessment tool that focuses on a person's deficits rather than a person's strengths.

2.2.8 Planning

We encourage the Productivity Commission to be particularly assertive in its final report in relation to the way people are supported to plan for their lives. Without sufficient values-based guidance, it is possible that some recipients might be led to certain decisions about supports – for examples larger congregate care – that might then contribute to continued marginalisation. This is a critical issue in Australia, and it is important that the proposed National Disability Insurance Scheme is not set up in a way that results in people orientating to congregational services such as group homes, because ultimately they are counter-productive.

Careful attention needs to be given to the mechanism for assisting people to describe their support needs and convert this to a set of choices made and plans crafted. Many people living with disability have had their horizons shrunk by those around them, albeit with the best of intentions. It is critical that people are supported to grow into a view of what is possible, within the context of the United Nations Convention on the Rights of Persons with Disabilities.

2.2.9 Responsive services

We further note the importance of considering how best to stimulate the emergence of best practice, including new agencies, to assist people to plan and orchestrate their supports. This includes the provision of strong information and guidance for support agencies wishing to make the transition to this new marketplace.

We note that new service provision can and will emerge as a result of demand as reflected in individual planning, and we can refer the Commissioners to specific examples if required.

We also note that transition funding may be helpful to service agencies where there are significant costs involved in restructuring away from block contract arrangements previously preferred by public funders.

2.2.10 Governance

We note the proposed governance arrangements involving a national board comprising typical business related expertise, and a separate national advisory mechanism to bring forward the views of stakeholders including people living with disability and the families involved in their lives.

We believe the governance arrangements must include people with a lived experience of disability on the board of the National Disability Insurance Agency. If the entire scheme is anchored on the place of Australians living with disability in our communities, on participation, on personal authorship in their own lives, then to have a board of governors, the formal leaders for the system, that does not comprise people living with disability, would be contradictory.

2.2.11 Quality

We acknowledge the Productivity Commission's interest in quality. Once again the devil will be in the detail, and it is very easy to design quality management systems that might appeal to the technocrat and that might secure compliance from all service providers but which fail to authentically connect with the lived experience of quality.

We have observed this previously, for example where a service agency achieved multiyear national accreditation via a range of quality benchmarks in human services, while delivering a service that at times was neglectful, oppressive and abusive to its recipients.

We therefore recommend that the national scheme's quality assurance mechanisms be designed in collaboration with people with lived experience of disability, and be anchored on the anticipated positive impacts in people's lives. On the basis that it is better to measure the right thing poorly than the wrong thing really well, we recommend that the quality mechanisms focus on outcomes, and work back from there.

We note that some quality assurance mechanisms focus instead on *outputs* measures (such as consumption of units of assistance) or *processes* measures (such as complaints mechanisms, policies for workplace health and safety) or even *inputs* measures (such as required levels of qualification for hands-on support workers). None of these measures necessarily have a direct link with the outcomes and are not always even successful at safeguarding people using those services.

2.2.12 Timeframe

We note the timeframe in the draft report, which envisages the full maturation of the National Disability Insurance Scheme by 2018. We recommend a shorter timeframe for the full introduction of a National Disability Insurance Scheme, particularly given the current relatively low levels of funding support for South Australians living with disability.

3.0 OUR RESPONSE TO SPECIFIC QUERIES FROM COMMISSIONERS

During our submission to the public hearing in Adelaide on 18 April 2011, the Commissioners invited us to give further consideration to a number of matters. We have attempted this, mindful that the timeframe has been very short, including the very long weekend over Easter.

Therefore, the material below is not necessarily an exhaustive contribution on the matters raised, and we would welcome the opportunity to continue the conversation with the Productivity Commission on these matters beyond the closing date for submissions.

3.1 Outcomes

Service outcomes should be measured in terms of impact on the life of the intended beneficiary. However this is a complex undertaking because life itself is complex. While there are many aspects to life that we may collectively appreciate, such as clean drinking water, there are a myriad of other life elements that will be valued differently by different people. This can make the business of outcome measurement appear very difficult. Unfortunately conventional human services have tended to measure outcomes in terms of people's experiences of those services themselves (i.e. service as context) as opposed to the contribution of those services in delivering a positive impact in the person's life (ie life as context).

As mentioned elsewhere in this submission this results in the development of service measures that often have very little to do with people's lives.

By way of illustration, we refer the Commissioners to the industrial psychology literature, for example the work of Herzberg in the area of job satisfaction. In this theoretical framework, job satisfaction is understood in terms of those elements that truly uplift the person, for example role clarity, opportunities for growth, opportunity to contribute, feeling appreciated, feeling trusted etc. In this theoretical framework other job elements relating to matters such as pay, workstation, vacation time, health and safety arrangements etc are described collectively as *job hygiene* factors. These factors can help avoid job dissatisfaction but do not by themselves deliver job satisfaction.

This can serve as an analogy for human service outcomes. Service elements such as complaints mechanisms, health and safety arrangements, polite communications, efficient documentation etc may help to avoid the person feeling dissatisfied with their service agency. However such elements will not necessarily assist the intended recipient directly into a better quality of life and therefore satisfied. Instead this is much more likely to come from an agency's attention to the intended beneficiaries personal circumstances, personal vision, together with a keen appreciation of what an ordinary valued life means in terms of personal authority and active citizenship. Services delivered in this context are much more likely to deliver authentic benefits (positive outcomes) in the person's life.

We recommend that the Productivity Commission consider outcome measurement arrangements that measure much more than hygiene considerations such as absence of harm, management of complaints etc. Put a different way, the scheme needs to authentically measure the presence of satisfaction, not just the absence (or management) of dissatisfaction.

The timeframe for completing this submission is short, and so we cannot offer further detail. However we would be very happy to continue a conversation with the Productivity Commission about emerging methodologies for measuring authentic outcomes. One such methodology is the Q50, for which we can provide further details if required.

3.2 Safety versus safeguards

Hippocrates and his oath, the first portion translates into ‘first, do no harm’, has created an approach to duty of care that is overly focused on the avoidance of risk. As a result, human services tend to be especially cautious when working with people who appear to have additional vulnerabilities. In particular, the person’s vulnerabilities (or problems) are seen as the context and therefore need to be ‘managed’. This can result in safety measures designed to suppress the likelihood of the problem emerging. Unfortunately such suppression can result, at best, in conservative practices and, at worst, in restrictive practices, that systematically prevent the person from engaging in ordinary valued life experiences.

In this way our society has built service arrangements that have separated people from ordinary life opportunities and which have trained those persons, their families, and the wider community, to have lower expectations of what is possible in those persons’ lives, and indeed even where those lives are lived.

With such a dearth of life experience it is no surprise that people and their families may then wish to make choices to enter, or remain in, congregate care settings. Put another way, many people living with disability have had their horizons shrunk by those around them, albeit perhaps with the best of intentions. People living with severe disability have been particularly vulnerable to restrictive service settings that create a climate where ironically there is as much chance of harm as there is of safety, and which in turn generates behaviours of concern. This then provokes even more cautious service settings, which in turn creates more restriction on the person's life, more separation from the community, and potentially more oppression. And so the cycle continues.

There is a better option, which is an approach to duty of care that focuses on risk safeguards, where an ordinary valued life is seen as the context and where the person’s particular vulnerabilities are seen as considerations along the way. (One such example is the Deohaeko Community’s work at the Rougemount Housing Cooperative in Toronto, Canada).

Successful safeguarding begins with this context. This means that, in the advent of the National Disability Insurance Scheme, careful attention needs to be given to how people are supported to imagine an ordinary life for themselves and their family members, how to describe their support needs in this context, and how to convert this into a set of authentic choices and personalised support arrangements. It is critical that people are supported to grow into a view of what is possible in their life and within the context of the United Nations Convention on the Rights of Persons with Disabilities.

The Julia Farr Association has spent the last 18 months examining issues regarding safeguards and restrictive practices. This has included working with expert practitioners, policy leaders, advocates and other commentators, to identify the systemic considerations necessary for effective safeguarding. We are currently working on the draft publication and, on request from the Productivity Commission we can share the draft material in confidence.

3.3 Employment

If we are to assume that all people living with disability have inherent value as human beings, we believe this means that every person living with disability therefore has the capacity to contribute in some way to the life of their community and economy.

Over the years staff currently associated with the Julia Farr Association have seen many examples of people living with severe disability moving into mainstream employment. The earlier work of Frank Rusch in the United States showed what was possible in supported employment (open employment). It is now much easier to find support agencies who are successfully supporting people living with severe disability into open employment, for example Onondaga Community Living in Syracuse, New York State, and Katahdin Friends Inc in Millinocket, Maine. We also note the success of approaches such as micro enterprises that lead people into self-employment in mainstream community settings. We can provide examples on request. Such approaches demonstrate people living with severe disability and associated challenges can be supported to make valued contributions to the local community and to participate in the economy on a similar basis to other people. We believe that the proposed National Disability Insurance Scheme should uphold and advance such possibilities.

4.0 OUR RESPONSE TO QUESTIONS CONTAINED WITHIN THE DRAFT REPORT

Below, we offer a response to each of the information requests raised by the Productivity Commission at the end of its draft report.

4.1 Funding approaches

We encourage the Productivity Commission to consider a single consolidated system that attends to the support needs of people living with disability, older persons, and people living with mental health issues. We put this view because people in each of these demographics essentially have similar issues, for example:

- Support to develop or maintain a positive view of personal capacity and personal vision;
- Support with physical daily living tasks;
- Support with decision-making;
- Support to develop or maintain connection into community life;
- Support with environmental aids and adaptations;
- Support to develop or maintain social capital;
- Support with health.

Given such commonality to people's circumstances, it appears counterintuitive to have separate schemes, especially given the costs involved in managing the interfaces between different schemes.

4.2 Extent of inclusion of other funds such as carer payment, carer supplement, carer allowance, mobility allowance, and the child disability assistance payments

We support the inclusion of these funds. It provides a single pathway so saves effort by the intended recipient and by the system. Also, it will remove unhelpful boundary constraints on how people may use their personalised budget. We recommend the NDIS scope include such payments. We don't believe this presents any significant risks in terms of how funds are used. Instead, we believe it will bring additional flexibility and help ensure that public funds are applied with a maximum effect to a person's particular circumstances.

4.3 Assessment tools

We refer the Commissioners to our comments in 2.2.7 above.

Mindful of the list of desirable traits outlined in section 5.4 in the draft report, we recommend the addition of the following:

- Simple;
- Accessible;
- Co-participation by people living with disability;
- Not over-engineered or overly intrusive.

We again refer the Commissioners to the short-form assessment tools currently in use in certain jurisdictions, where the consideration of 10 questions or less appears sufficient to determine the price point level of funding support available to a person. Far from having a rose-tinted perspective on such tools, we are happy to acknowledge that they may be far from perfect. However we have yet to find evidence to suggest that they perform less well than the more complicated and intrusive alternatives, but they are simpler to operate.

Rather than being wedded to a particular assessment tool, we share the Productivity Commission's interest in identifying the best possible approach for determining the level of an individual person's entitlement for funding support. Given the constraints of the current deadline for formal submissions, we would be very happy to provide further assistance beyond the deadline to the Commissioners on this important matter.

4.4 Monitoring instruments

We refer the Commissioners to our comments in 2.2.11 above.

We believe that there are two particular considerations.

First, the selected monitoring instruments need to be focused on the attainment of outcomes associated with an ordinary valued life.

Second, where there are significant considerations of risk, the selected monitoring instruments need to focus on the presence of safeguards that uphold a person's inherent value and help advance that person to an ordinary valued life. This is distinct from safety measures that attempt to remove risk from a person's life (or manage a characteristic of the person's disability as a contextual problem) and, in so doing, restrict the person's access to ordinary life opportunities and experiences.

4.5 Funding prevention and early intervention measures specifically targeting indigenous communities

On this matter we make two points:

1. We support the sentiment of early intervention but believe that the word *intervention* is not a word conducive to the empowerment of the intended recipient, as it places control squarely with the professional worker or service that is doing the intervening. Instead we recommend

the word *investment* be used, as it conveys much more effectively the notion of direct capacity building in the target person, family and community;

2. For an early investment strategy to be successful it must be designed in partnership with its intended beneficiaries. A strategy that has been co-designed with people of aboriginal heritage will be much more likely to have a positive impact.

4.6 Funding arrangement for catastrophic injuries resulting from water, air and railway modes of transport

For catastrophic injuries resulting from water, air and railway modes of transport, that result in permanent disability, we can see no reason why people in these situations could not receive their funding support via the proposed National Disability Insurance Scheme. The principal issue is how people living with disability might be supported into ordinary valued lives, not how their disabling circumstances were acquired.

Accordingly, we can see no reason why the incidence and prevalence of such accidents and consequences cannot be factored into the mathematical model for determining overall funding levels in the NDIS.

4.7 Reporting trends in legal fees and charges paid by plaintiffs in personal injury cases

As with any other professional service available to people living with disability in a personalised funding mechanism, information about lawyer fees should be readily available and transparent, along with their success rates in delivering benefits to their clients.

We support a mechanism for nationally consistent disclosure of such fee structures. However, we note that there is a risk that this might result in higher average pricing across the industry. One way to reduce the risk of this happening would be to gather and publish performance data alongside the pricing data. This will help people to gain a fuller picture of a lawyer's services. After all, the client may be prepared to pay a higher price for the service if it secures greater net benefits for the person compared to a lawyer charging a lower fee for poorer outcomes.

5.0 CONCLUSION

We are very pleased to have had the opportunity to make this submission as this is the most important disability policy debate in a generation.

Due to time constraints, we have not included a set of reference sources relating to some of the examples we have given. We can supply these on request.

We value the Productivity Commission's work to date on this matter, and we would be very happy to offer further input and assistance if that would be helpful to the Commissioners.

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