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# The Road to NDIS:

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## Lessons from England about Assessment and Planning

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JFA Purple Orange is the social policy arm of the Julia Farr Association Inc. We are a non-government, social profit organisation that conducts research and engages in dialogue with people with lived experience of disability to develop policy and practice. Our work is anchored on the principles of Personhood and Citizenship.

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## 1.0 Executive Summary

Australia is undertaking the design and implementation of the National Disability Insurance Scheme (NDIS), to reform the way disability support is understood and funded. In England, there has been a growing public focus on individualised funding arrangements since the mid-1990s; progress has been fast, there have been many important achievements and there have also been mistakes. This paper explores what the governments of Australia might learn about the English experience, to help ensure the NDIS gets the best possible start.

In particular, this paper explores what might be learned from the English experience in relation to the design and implementation of approaches to assessment and planning; these represent the acid test of the relationship between the system and the person and the basis on which the person might access resource assistance. While the system can be expected to evolve over time and learn from its experiences - implying the initial mechanisms for assessment and planning will themselves evolve - it is important to start with the assessment and planning arrangements that best reflect the principles the NDIS seeks to live by. These principles include personal control and choice.

Based on a commentary on the experience in England, the authors identify key learning opportunities for Australia as it considers the design and implementation of the NDIS. These opportunities are:

Lesson 1 - Make the entitlements real

Lesson 2 - Only define the essential parts of the system

Lesson 3 - Enable an ongoing process of social innovation

Lesson 4 - People need to know enough to be able to plan

Lesson 5 - Set clear and public rules that are easy to understand

Lesson 6 - Enable a pragmatic process for transition

Lesson 7 - Develop a system which is sensitive to time and outcomes

Lesson 8 - Do not put undue focus on the plan

Lesson 9 - Do not let any group dominate the process

Lesson 10 - If in doubt, focus on peer support

## 2.0 Introduction

The design and implementation of the NDIS constitutes a major piece of social reform in Australia. Anchored ultimately in the values that underpin the United Nation's (UN) Convention on the Rights of Persons with Disabilities, the scheme heralds a significant increase in investment in the lives of Australians living with disability. It is a radical departure from the current situation that sees too many Australians living with disability:

1. with insufficient support
2. living in poverty
3. underemployed
4. excluded from mainstream community life

The governments of Australia are currently developing the scheme using five launch sites, scheduled to begin work from 1 July 2013. The NDIS, if implemented well, will put Australia at the cutting edge internationally of disability policy development. As Australia defines the NDIS we hope the work will:

1. keep the advancement of people's life chances, and associated human rights, at the heart of the NDIS
2. start with the best possible principles in support of these life chances
3. design the system so that it can evolve and improve over time

England's developments in individualised funding began in 1996 with 'Direct Payments' which gave some people the right to turn their social care service into its cash equivalent (Glasby & Littlechild, 2009). In 2003 a further development came in the form of 'Individual Budgets' (or 'Personal Budgets') which meant everyone had a budget, but with several different options for managing that budget (Needham, 2011). In 2007 the English Government committed to rolling out this new approach for all of social care and currently (2012) this has been achieved for about 30 per cent of the social care population (HM Government, 2007).

There have been many other international examples of the use of individualised funding, but the English experience is interesting because progress has been (relatively) fast and because the model used has been designed to reflect earlier international experiences (especially in Northern Europe, USA and Canada) (O'Brien, 2001). Social care is delivered through 150 local authorities who each carry lead-agency responsibilities similar to those of Australian states and territories. These local authorities have not just one approach; instead there has been wide variation in the way local authorities have designed and implemented the availability of individualised funding. There is still significant debate about what constitutes good practice in England but these variations in practice offer opportunities to explore what seems to be more or less helpful in designing an effective system of individualised funding.

A good idea is at its most vulnerable during implementation and often the drama lies in important details. This paper aims to shed as much light as possible on what can be learned from the English experience - there will also be some reference to other international experiences.

For this paper we have framed the analysis by considering the mechanism or pathway by which a person navigates through the system. Before examining the NDIS design issues in relation to the pathway, it is necessary to first consider the context of outcomes.

### **3.0 An Australian approach to outcomes: Citizenhood Support**

Williams (2010) defines Citizenhood as:

... an active lifestyle that has the prospect of fulfilment for the person concerned. Such a lifestyle is one where, as part of a personally defined set of lifestyle choices, the person is in and part of their local community, contributing and growing through involvement in meaningful valued activities, and participating in a network of relationships characterised by acceptance, belonging and love.

The Model of Citizenhood Support (the Model) was developed by Williams as a framework for considering how best to assist people advance into good lives. It is based on the premise that each of us wishes to live a good life and that such a life is built and maintained by attention to four key assets in a person's life. The assets are termed the Four Capitals and comprise Personal Capital, Knowledge Capital, Material Capital and Social Capital. The Model contends that people's life chances are advanced through the presence and growth of these assets (Williams 2012). Applying this model to the NDIS, the system design must be capable of understanding people's circumstances in terms of their distance from life chances, and what it might take to reasonably and necessarily bridge the gap.

Interestingly this framework, rooted in Australian values, is mirrored by similar thinking in the UK (Duffy, 2010a). Duffy has defined active citizenship as the central goal of public policy and defined the central components of active citizenship (Duffy, 2003). Murray has gone on to analyse the necessary resources that underpin that citizenship as Real Wealth and this model is very similar to the Four Capitals approach (Murray, 2010)

## **4.0 NDIS Pathway as a Series of Decisions**

### **4.1 The design challenge**

Typically there are stages that a person moves through when using human services. However, while it will be necessary to define a pathway by which the person can organise their relationship with the state, public service systems have a tendency to design systems where the administrative process is dominated by professional perspectives and the following progression:

- Gateways or referral arrangements
- Eligibility testing
- Assessment
- Planning
- Contractual agreement
- Orchestration or coordination
- Evaluation.

Depending on how they are designed and operated, there is a grave danger that professionally defined processes can take over the life of the person, frustrating their autonomy, limiting choice and control and undermining the very rights that NDIS is there to support.

Mindful of the experience in England and elsewhere, it may be more helpful to think about this pathway as a series of decision-making moments where, at each step along the way, there is a decision to be made. When a system pathway is conceived as a series of decision-making moments there is a corresponding focus on who the decision-maker is at each of these moments, and how they might arrive at effective decisions.

Presuming the focus of the proposed NDIS is on advancing the life chances of a person living with disability and is anchored upon the principles of control and choice, it follows that the person living with disability is the natural decision-maker for most of the decisions in the pathway. Such decisions include, but are not limited to:

- whether to approach the system for assistance (referral)
- which detailed information to share about the person's circumstances
- the type of lifestyle imagined
- the life opportunities/issues to focus on
- who might assist in the planning
- the elements to include in the plan
- the degree of involvement in self-management of funds
- which freely given supports to draw on
- which neighbourhood amenities to approach
- which service providers to approach
- which refinements to make once arrangements are in place.

By contrast, and again mindful of the principles of personal control and choice, the English experiences suggest government only needs to have control over relatively few decisions. This might be limited to:

- the decision about what quantum of public funds can be made available to the person
- the decision to sign off the person's plan so that funds can flow
- the decision about what the NDIS might learn about the degree to which the subsequent support arrangements helped advance the person's life chances

These decisions remain with government because they relate to matters of accountability for public funds and also, importantly, to how the system evolves so that its funds produce ever-stronger results in terms of people's life chances and their rights as per the UN Convention.

Therefore, to advance and uphold principles of control and choice, it seems critically important that the NDIS operates on the assumption that people have capacity to make their own decisions. This will bring its own challenges in relation to some people where there may be a genuine concern about their capacity to arrive at a personal determination without being subject to unhelpful influence by others with competing vested interests.

In establishing good safeguards for this, the NDIS may include a role for itself in deciding when safeguards should be implemented, especially where there are concerns to protect a particularly vulnerable person from abuse, exploitation or neglect. If so, this role for the NDIS will need to be crafted with great care, and be capable of being adjusted in the light of experience, to maintain a proper system bias towards a person's right to make their own decisions, both about how funds are used and how the arrangements are managed.

This careful crafting could include methodologies such as Supported Decision Making, so that in every case, including where there is a substituted decision maker, there is proper regard for the person's wishes. This principle was reflected in the report on guardianship by the Victorian Law Reform Commission which asserted:

“... disability alone should never cause a person to lose responsibility for making their own decisions and that all reasonable efforts should be made to assist people with impaired decision making ability to participate to the fullest extent possible in decisions about themselves” (Victorian Law Reform Commission 2012, page xxii).

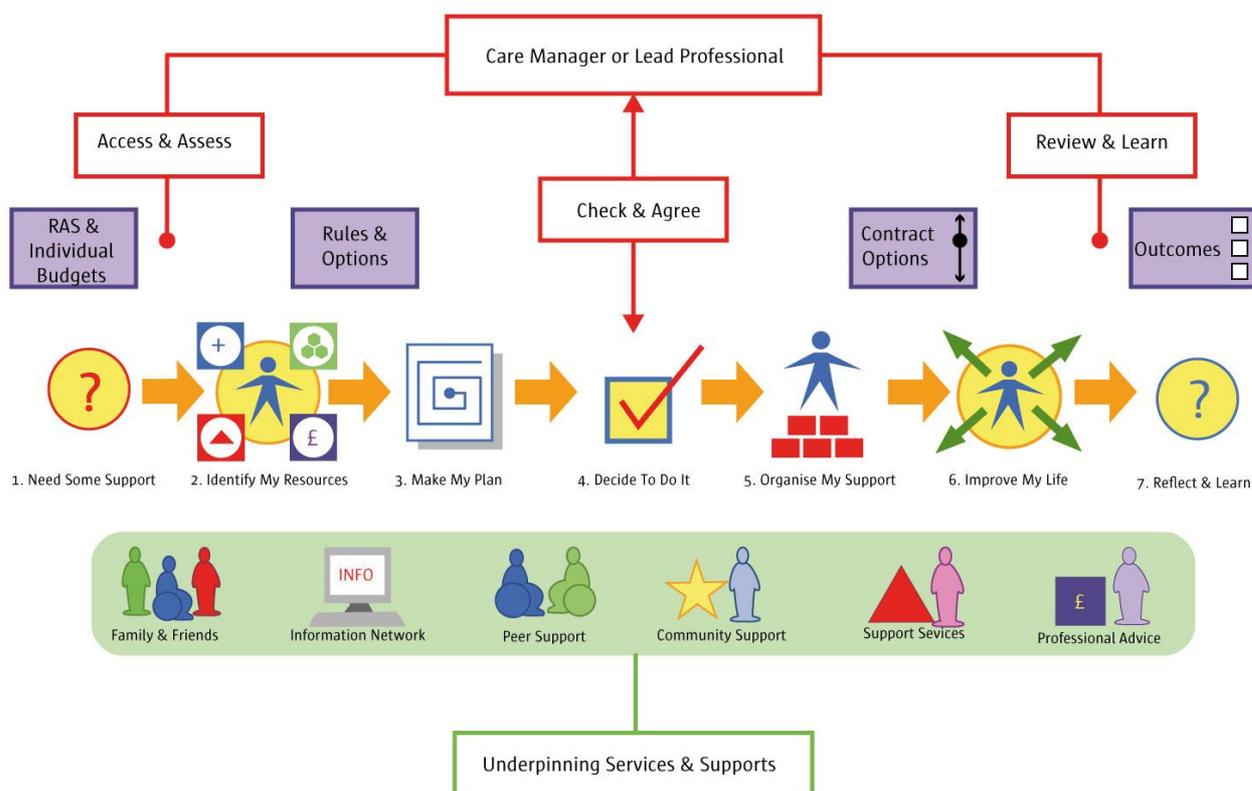
JFA Purple Orange has partnered with the South Australia Office of the Public Advocate on a pilot Supported Decision Making initiative that has made encouraging progress.<sup>1</sup>

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<sup>1</sup> [http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//11\\_Supported%20Decision%20Making](http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//11_Supported%20Decision%20Making)

## 4.2 The English experience: Self-Directed Support

This perspective is evidenced in England, where one of the key innovations came in the form of a new model originally developed in Scotland by Duffy (Duffy, 2004) for organising the pathway called self-directed support. This model (Figure 1) suggested there were seven critical steps in the process but that the state only had to be involved at three points.



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**Figure 1: Model of Self-Directed Support**

In keeping with a pathway characterised by moments of decision making, the process of self-directed support for citizens should largely be a process they control themselves. The citizen is entitled to:

- clear information about entitlements
- clear processes by which decisions are made and, if necessary, challenged

Reflecting on the English experience, the use of the word *entitlement* seems critically important because it helps redress the imbalance of power between people and professionals in traditional funding systems. When a system fails to clarify entitlements and processes then it does not empower citizens. Instead it pulls citizens into a dependency relationship and requires professionals to take on increasing levels of unnecessary and wasteful work 'on behalf of the citizen'.

In particular the term *entitlement* clarifies the necessary resource (however it is defined) is vested in the individual and therefore that person has control and choice over the funding.

Although some people will need support or representation for managing their budget it remains critical to any decent system of individualised funding that the funding is treated as a personal *entitlement*. Without this element any system of individualised funding risks frustrating basic human rights.

However, the use of the word *entitlement* is not intended to convey a culture of handouts where a measured degree of disability automatically translates to a specific amount of funds. Some jurisdictions in England have attempted to accomplish this through the operation of complex resource allocation formulae; this approach can get in the way of an authentic connection with a person's individual circumstances. The focus is not merely on receipt of the funds, but on its potency for advancing the person's life chances. The idea of the scheme is that eligible people are *entitled* to reasonable and necessary assistance to advance their life chances and have control over the resource.

As the NDIS develops, it is possible it will quickly accumulate helpful data about the relationship between people's circumstances and the approximate level of resourcing that typically constitutes reasonable and necessary support to have a fair go at life. Therefore, we believe it makes sense to give the person an early indicative signal about the approximate funds that might be available, as this will help the person with their planning. It is rare for anyone to do any planning – be it a house purchase, a family vacation or the weekly grocery shopping – without having an approximate idea of the budget available. The key word here is *approximate*, because the final amount of resource can only be fully resolved once the person's circumstances are properly understood.

#### **4.2.1 The role of the state**

In places in England like Barnsley and Hartlepool, you'll find local systems that are highly competent at (Newbrunner et al. 2011):

##### **1. Providing information and clarifying entitlements**

Early contact focuses on ensuring people quickly know what they are likely to be entitled to and in tackling any basic problems of prevention, safety and competence. Ideally the system provides clear information and can then leave the citizen to craft their own plans and arrangements (Duffy, 2010b).

##### **2. Agreeing assessment and support**

The second critical decision required is the agreement to actually provide the agreed individual budget. In the UK the existence of this second step has been the critical stage for assessing and validating the size of the budget (Glendinning et al. 2008). Arguably, if there was a very reliable process for agreeing upon the size of budget at the first step then even this second step would not be necessary. However, as it stands, best practice is to use this second step to amend the budget in light of the proposed plan and to ensure the proposed budget-holder (who may or may not be the recipient) seems competent to manage the budget effectively.

### **3. Reviewing and safeguarding**

Again, in the UK, the legal framework under which these arrangements have been developed assumes a 'duty of care' from the state to the citizen and this usually leads to some ongoing contact and conversation about how life is going. In the best places this conversation is focused on ensuring people are healthy, safe and well and are living the life they want.

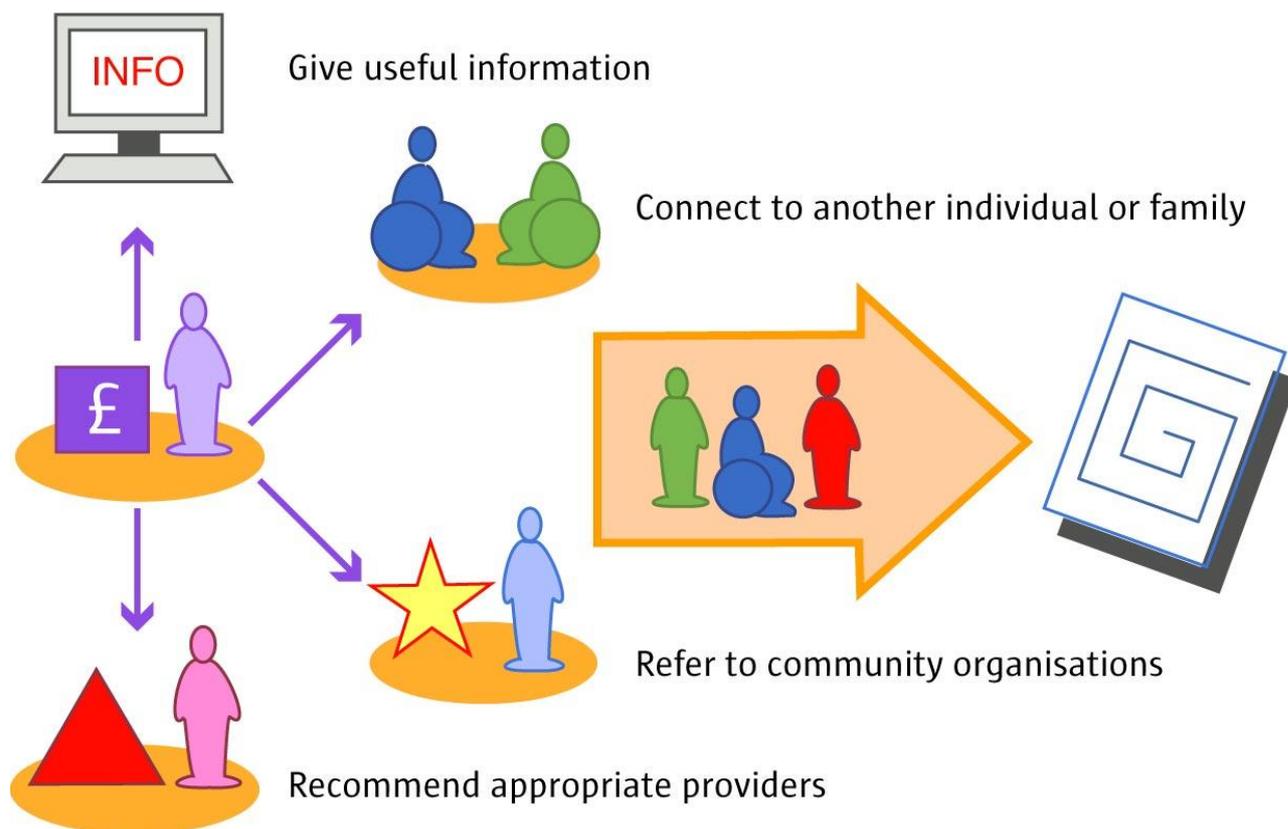
#### **4.2.2 Community brokerage - supporting decisions**

If the system is conceptualised as a series of decision-making moments, then it follows that we must then identify the location of decision making support. Within the development of the English model there was an intentional decision to develop an inclusive and pluralistic approach to supporting people with decisions at every stage. This was a decision to avoid the hazards associated with focusing on one system of brokerage or support and to instead open up a range of options (O'Brien, 1997).

This model was further developed by Duffy and Fulton as community brokerage. Community brokerage means treating the whole community as a potential source of support for people managing their budgets. The system requirement is to evaluate how effectively the wider community is working to support effective decisions and provide strategic support (which may or may not be financial) only where required. This approach means encouraging:

1. people to do more for themselves where this is possible
2. connecting people to peers, families and other experts by experience
3. encouraging existing community organisations to provide support
4. enabling existing service providers to provide support
5. providing expert professional support, ideally building on the best of current practice

Duffy and Fulton argue this is the right kind of architecture for personalisation because it is both more empowering and more inclusive. It does not treat people living with disability as a peculiar object for professional interventions; people living with disability are full citizens and should be treated as such (Duffy & Fulton, 2010). This model is illustrated in Figure 2:



**Figure 2: Model of Community Brokerage**

### 4.2.3 Creating a space for innovation

Where self-directed support has been effectively implemented it has led to positive life changes and has opened up multiple spaces for social innovations. The challenge is not to be drawn into defining the state's role in a way that is all encompassing, taking responsibility for solving problems which the state, and even the best of professionals within, is incompetent to solve on its own. Where the state manages to avoid this happening, there are a number of very positive social innovations that have begun to develop in the spaces left by self-directed support:

1. **Self-help and user-controlled supports** - groups are emerging who can provide mutual support at a lower cost and higher quality than professional services. Many people are providing each other with support and advice (Duffy, 2012a).
2. **Family leadership** - families, especially if they are provided with early information and support, are developing creative support options and offering each other support (Murray, 2011).
3. **Community-led initiatives** - schools, community groups and other local groups have begun to act as the hub for social change and shared learning (Cowen, 2010).
4. **New kinds of brokers and advocates** - there is no need to invent a new band of independent brokers; however individuals, social workers and community advocacy organisations are developing increasingly thoughtful ways of helping people plan and

organise support (Fulton and Woodley, 2011).

5. **Personalised support providers** - services are beginning to develop new and more flexible ways of managing people's funds or staff for them, cutting down work and reducing overheads (Fitzpatrick, 2010).
6. **Micro-enterprises** - some people are using their budgets to help create new business ventures.
7. **New forms of professional practice** - for some social workers this way of working has helped liberate them from an overly standardised bureaucratic process and enabled them to innovate and focus their energies more intelligently.

None of these is possible if the state tries to commission or provide too much on behalf of citizens and communities. Instead the priority must be to ensure resources are shifted directly to people or to a very local level. In the UK, commissioning systems have failed to generate innovation, however personalised and localised funding does seem to generate more creativity.

#### 4.2.4 Poor practice in England

The initial developments in England tended to be very positive, partly because the early motivation of citizens and professionals was focused on advancing people's life chances and improving practice (Poll & Duffy, 2008). There is increasing evidence that this early wave of reform has not spread to other areas and is not always being sustained when the local leadership changes (Hatton & Waters, 2011). There seems to be a risk of increased professionalisation and inefficiency. The lack of a legal framework to support the reforms (unlike with the NDIS) now appears to be a critical weakness (Duffy, 2012b).

In particular some local authorities:

- fail to tell people what they are entitled to and then end up having to plan 'for people'
- interfere inappropriately with people's plans, sending plans to panels and refusing without good reason to agree to plans
- restrict how people can use their own money (which is what an individual budget should be), creating insecurity about the funding and the rules associated with it
- limit the range of options available for people to manage their budget, get help to plan or get support
- confuse genuine personal outcomes with provisional objectives defined in plans

The impact of these mistakes is to undermine the ethical basis of the reforms and to leave people in the same disempowered, dependent and damaged relationships that existed previously.

## 4.3 Learning for Australia

Australia is in a great position to learn from England. It can design its own decision making system mindful of the key priorities:

### Lesson 1 - Make the entitlements real

Establish the assurance of access to reasonable and necessary funding assistance, over which the person has autonomy or authorship, to advance life chances; this entitlement will reinforce the status and rights of people living with disability. Critically this entitlement must be one over which the person has real choice and control – otherwise it is not an entitlement but just a gift.

### Lesson 2 - Only define the essential parts of the system

Minimise any unnecessary interference from the state by focusing efforts on the key decision points where the state's role is actually essential, arguably these are:

- defining the person's budget
- ensuring competence of budget recipient
- ensuring overall competence of system over time in advancing people's life chances

There certainly could be many other ways of doing this that improve on the English model of self-directed support. However, it seems implausible that it would be an improvement for the state to have more involvement and control than is set out in that model.

### Lesson 3 - Enable an ongoing process of social innovation

An empowering, permissive and flexible system is required to enable people living with disability to exercise their human rights. However this is not the only advantage of such a system. If the system design is right then Australia should see progressive and evolutionary change led by people living with disability and their families.

One of the gravest dangers of systemic change is the tendency for the system to try to solve too many problems, and in the process, rob citizens of the opportunity to find better solutions and improve these solutions over time.

## 5.0 Assessment

### 5.1 The design challenge

It can be argued that the purpose of assessment within the NDIS is to gather sufficient information to determine the nature of a person's circumstances in relation to life chances and, based on the costs of assisting people in similar circumstances, begin to estimate the

likely amount of required public investment to provide the reasonable and necessary assistance to advance those life chances.

By delivering a signal about the approximate degree of assistance the scheme might give someone, assessment represents a critical moment in the pathway and its methodology should reflect the key values of the system in which it sits. Therefore, if the NDIS aims to uphold a value base anchored upon personal control and choice and the advancement of life chances in line with the UN Convention, then these value characteristics should be reflected in the assessment approach - so there is an early understanding of a person's distance from ordinary life chances.

At the heart of the NDIS is the assumption that it is the role of the state to ensure people living with disability are entitled to a fair and reasonable level of resources - a budget - which they can use to overcome the additional barriers to life chances they face because of their disability.

How to do this raises two important questions:

- What do we mean by fair and reasonable?
- How do we decide what is fair and reasonable?

It is our view that the best answer to both these questions is to be found in the thinking that underlies the NDIS - fulfilling human rights and advancing the life chances of all people living with disability.

### **5.1.1 The nature of 'reasonable and necessary', and who decides**

At its simplest it seems to us that a budget is fair if it is enough to enable someone to access the life chances that can lead to citizenship. The budget does not need to be 'more than enough' - but it must be sufficient. A budget is reasonable if an objective observer would agree that, in that person's circumstances, that budget is sufficient.

Ultimately the process of decision-making starts with a dialogue between citizen and professional acting for the state; but it will become subject to democratic and judicial processes. Reasonableness is always open to dispute - but a competent system of law and government seeks to bring order and to make vital decision where necessary. In other words, any decent, rights-based system should be comprehensible to all citizens. A system of entitlements which is obscure and incomprehensible is not a system of entitlements.

## **5.2 The English experience - Individual Budgets**

Prior to the development of individual budgets in 2003 the process for defining a budget, even when that budget was to be handed to the person as a 'direct payment,' always followed the same general pattern:

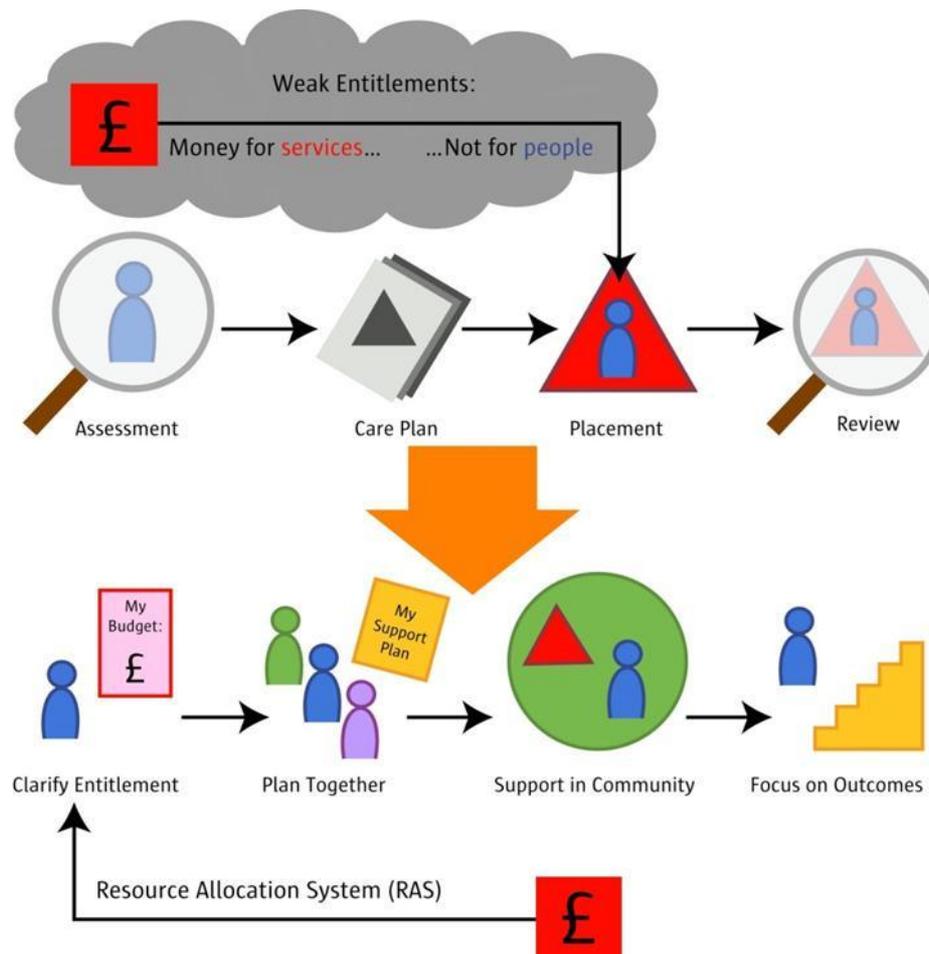
- 1. Assessment** – there was a period of professional assessment often involving significant information gathering, form filling and etcetera.

2. **Care plan** – then the professional would develop a care plan which described the proposed ‘solution’ for the person’s needs (only rarely would the person play any significant role in shaping this plan).
3. **Costing and placing** - sometimes plans were costed explicitly (as when someone chose to receive direct payments) but much more often there was no explicit costing; instead people would be slotted into a pre-existing service that already received state funding.

This professionally dominated process of assessment, care planning and placement had many negative features. Effectively it left the person ignorant of their rights and unable to shape their own support and, hence, unable to shape their own life.

It was for this reason that Duffy developed an alternative model of how to make an assessment. He proposed the process be changed so people could be given an initial ‘indicative’ budget which could be used by the person as the basis for developing their own plan.

This new approach to defining individual budgets is set out in Figure 2 (Duffy, JIC 2). Note the figure uses the pound sterling symbol to indicate financial resources.



**Figure 3: Comparison between Traditional and Duffy Approach to Resource Allocation**

Although this approach can seem challenging at first, it is much less difficult than it might appear, and reflects four facts:

### **1. Practical experience**

Early experiments in Scotland demonstrated that individuals, families and paid professionals all seemed to benefit from having this new information - it improved the quality of their planning and creativity (Scottish Executive, 2000). All 150 English local authorities have subsequently used some form of Resource Allocation System (RAS) to make such judgments. This has been achieved despite increasing cuts in public funding for social care in England.

### **2. Human rights**

The human rights of people living with disability cannot be realised if a right to support cannot be defined in a clear entitlement. Without such clarity a system could be in abuse of Article 3 of the UN Declaration of Human Rights: Everyone has the right to life, liberty and security of person. It will be impossible for people living with disability to be free if their support is defined for them and they are not free to use it flexibly. Otherwise the person would always feel dependent upon some obscure process of assessment and the subsequent 'gift' of a service (Duffy, 1996).

### **3. International policy developments**

Early models of individual funding tended to work with a norm-free approach for a while but then struggled to advance. Many European countries started with a 'blank sheet of paper' approach to planning and found that costs escalated (Carr & Robbins, 2007). States in the USA and Canada that moved towards a clearer specification of the rules by which budgets were set seemed to move much faster at making real progress and working within existing resources (Moseley et al. 2003).

### **4. Status quo**

The current system is already making resource allocation decisions, day in day out. Capturing the characteristics of these evaluations, giving them greater transparency and putting them under greater scrutiny would seem likely to improve both fairness and efficiency.

In the authors' experience, the traditional approach, as shown in the top half of Figure 3, tends to contribute to an ongoing inflationary effect on service costs, because of the emphasis on functional deficit and the incentives this creates for people competing for scarce resources. By contrast, the alternative approach in the bottom half of Figure 3 tends not to create the same inflationary pressure, and in some instances can reduce future costs; this is because people construct more effective support arrangements tailored to their personal circumstances and with a focus on building capacity and participation.

## 5.3 Resource Allocation Systems

The development of a RAS in England, and its future fate, remains one of the most fraught and disputed elements of the whole system. There are now a number of competing consultancy and information technology companies competing to provide 'the ideal' RAS (Duffy & Etherington, 2012).

In addition, that the UK economy is now in a severe economic crisis and central government has targeted local government for cuts (31 per cent by 2015) means these systems are now coming under severe pressure and some seem to be becoming subject to manipulation and challenge (Whittaker, 2011).

In order to draw out some critical lessons for Australia it is worth approaching this issue objectively. First, it may help to abandon use of the term Resource Allocation System (which may imply some perfect system which does not exist) and instead use a more general term not attached to any one proposed solution. So let us talk instead about the rules for defining budgets. Approaching the problem in this way may be more helpful.

### 1. All systems have rules

The old social care system in England, with its cumbersome assessment process, professional care planning and slotting of people into already funded services was a rules based system. It was incompetent at delivering personalised solutions people could control - but it worked to clear principles and solutions.

### 2. Obscuring information is risky

The UK's old system had two significant weaknesses. First, it made it near impossible to empower citizens to plan and make decisions themselves. Without any budget such major life decisions seem impossible. Second, it tended to lead to more extreme and inequitable resource allocations. Without reference to any budget, decisions tend to follow one of three routes:

- People are slotted into a very limited range of services
- People can't be slotted and so push for something much more expensive
- People won't be slotted and often get nothing.

In other words, an institutional and service-focused system allocates resources to a rule, but the system tends to be skewed towards unjust allocations.

### 3. Good systems can be very simple

A system does not need to be complex, and it can use a mixture of explicit rules and human judgment. Human judgment is inevitable in all systems as human beings are necessary for the development, interpretation and implementation of those rules and, ultimately, the rules will be tested by civil society and the democratic process as individuals and groups test and challenge the new system.

Some areas in England (for example, Barnsley, East Renfrewshire, Hartlepool) have tried to keep the systems simple, clear and comprehensible to professionals and citizens alike (Duffy, 2011). The critical element of the English system is that any indicative budget must be validated at the later point when it is agreed upon - this considerably reduces the need to try and ensure the setting of the indicative budget is 'accurate' (Duffy & Etherington, 2012).

When asked recently which system they would prefer to adopt, the social work staff of East Renfrewshire Council voted for a simple system with explicit amounts of money for different levels of need, but one that allowed for discretion and human judgement.

The strength of these simple systems is that they encourage more understanding, human conversations and a common-sense approach. It is based on a reliable iterative process and can be subject to reasonable degree of public accountability.

#### **4. Complexity is often used to take back control**

Unfortunately there seems to have been an acceleration of complexity in many local areas, fed by a combination of budgetary anxiety, mistrust of local people - but most importantly a loss of trust in the professional staff themselves. Tellingly, much of the drive towards complexity seems to be rooted in a managerial anxiety that staff will undermine it. Unfortunately this mistrust tends to provoke the very thing it fears - for professionals then seek to 'game' the system on behalf of their 'clients' (Series, 2011).

#### **5. Loss of common-sense**

A further problem in England has been a complete loss of common-sense when it comes to implementing the system. There is a major distinction to be made between local areas that began their journey to self-directed support by choice, and those who were impelled there by central government policy, following the *Putting People First* policy in 2007.

A significant number of these less-willing authorities chose to impose self-directed support upon themselves in a way that was far from pragmatic, often creating unnecessary costs and complications. For instance, very few authorities seem to have taken the following pragmatic approaches to developing individual budgets:

- Letting existing services break down budgets themselves, working with the people they already know to fix a fair budget (Hoolahan, 2012)
- Turning budgets that were already individualised, such as direct payments, into Individual Budgets (Duffy, 2006)
- Letting local community groups define budgets (an approach being developed by Rachel Mason, [www.247grid.com/index.html](http://www.247grid.com/index.html)).

A more practical approach is found when rules are treated as a means to achieve the overall goal - not as the end itself.

## 6. Thinking about time

Another weaknesses of English implementation has been little sensitivity to how funding is timed. The timing of funding and the length of any entitlement is a critical issue, but one that has not received enough attention. For instance, it is important to distinguish:

- when people need some immediate, practical and predictable preventative support
- when people would benefit from a grant - with no presumption of ongoing entitlement
- when people need some more contingency funding, and incentives to manage it sensibly
- when people need more regular review, because need is likely to change, or when people need much less regular review, because needs will not change quickly
- whether the review process should be ended and instead people should be able to renew their entitlement at appropriate intervals

Time is a key variable and the state should have an eye to the long-term needs of its citizens - not just the financial year. It is expensive and inefficient to impose rigid or frequent reviews on people who do not need them, just as it would be risky not to amend budgets when appropriate.

## 5.4 Learning for Australia

In thinking about assessments and individual budgets it's helpful to keep a sense of perspective: the current system is already making such allocations and there are systems for making such judgments. There is nothing about having rules which are problematic - rules are already inherent in the system itself.

For Australia it will be important to remember:

### **Lesson 4 - People need to know enough to be able to plan**

If people do not get enough budgetary information in order to plan without professional involvement then you can guarantee lower levels of citizen engagement, creativity and independence.

### **Lesson 5 - Set clear and public rules that are easy to understand**

If people don't know how the system works and what is normative and reasonable then you can guarantee cynicism, dispute and increased reliance on the judicial and political systems. NDIS is happening because Australians demanded a stronger system that gives the assurance of support to people who need it - this will be undermined by obscure or unduly complex systems.

## **Lesson 6 - Enable a pragmatic process for transition**

Whatever system is developed it is important the new rules do not become overly static, rigid or prescriptive. It is important to develop a sensible and phased approach during which many different approaches could be used in order to achieve the goal.

## **Lesson 7 - Develop a system which is sensitive to time and to outcomes**

The test of the competency of any new set of rules about resource allocation is whether they deliver enough money for people to advance their life chances in pursuit of citizenship. However it is important to ensure this system can validate its allocations by reference to outcomes (and this can be done by sampling - it does not require undue interference in each individual's life). The system also needs to enable different kinds of arrangements over time.

# **6.0 Planning**

## **6.1 The design challenge**

Citizens have a right to control their own life, to make their own plans, make their own mistakes and achieve their own outcomes. This is not a professional process and none of us standardly require help and support to plan, to organise our own support or live our lives. Human beings are already hardwired for freedom - as long as we have some friends, family, and are not living in circumstances that undermine our basic capacities.

If one of the NDIS goals is to advance people's life chances and uphold people's rights in line with the UN Convention, then the NDIS may understandably develop a bias for signing off plans that advance people's life chances (with an intuitive 'golden thread' link to the person's current circumstances of reduced life chances) and which do not maintain or deepen that person's disadvantage.

Therefore, the NDIS has a key role in the signing off of the plan but not necessarily in the process leading to its construction. While the NDIS may be able to offer decision-making support to people when developing their plans, such support can also come from many sources, perhaps most importantly from sources the person trusts.

In this sense, the process of planning (including access to trusted others who can assist the person arrive at their decisions) is more important than any particular planning template. Indeed, the adoption of a particular planning template may result in the accredited facilitators focusing more on the proper completion of the template properly connecting with the person and their story.

For this reason it is extremely important the NDIS does not stray into dictating matters outside its proper scope. There is certainly no international evidence that a particular mandated system of independent brokerage or of person-centred planning will add significant value to a system of individualised funding. In fact it is very likely that such interventions would put the Australian system at risk.

Planning tools can be useful, for any of us, but the authors of these tools are very clear they should not be used for standardised planning. In fact it seems highly likely that person-centred planning has been unduly commodified and over-sold.

Person-centred planning was developed as a tool to help individuals and families connect to communities and build better lives (Mount, 1987). The resources are freely available, alongside many other mainstream approaches to planning and thinking about the future. They develop and change at their own pace and as new innovators emerge to rethink, challenge and create. They are not suitable tools to build into administrative processes (O'Brien et al. 1998).

As Jack Pearpoint, one of the leading authors of person-centred planning, writes (O'Brien & Blessing, 2011): "When it is just one more requirement that staff have to meet, it has to do with system requirements, rather than noticing, focusing on, and developing a person's capacities."

Interestingly many of the authors of self-directed support have also been intimately involved in the development of person-centred planning in the UK. However there are a variety of views as to the best way of supporting people living with disability to arrive at their decisions, including whether person-centred planning (or any other system) should play a significant role.

In consideration of approaches to planning within the NDIS, it is again useful to consider what might be learned from the various implementations in England.

## **6.2 The English experience - 'Support Plans'**

The term Support Plan, which has become very prevalent in the UK, was first used by Duffy in 1999 while working with the North Lanarkshire Council (Thompson et al. 2008). The term was invented to overcome a problem inherent in the UK social care system - that no package of support could be approved unless there was a 'care plan' for it which must be written by the social worker.

The solution to this problem was to argue that if a family produced their own support plan then the act of signing off the support plan could then be a reasonable proxy for the care planning process. In other words support planning was conceived simply to get around an existing problem - there was no necessary intrinsic value to the plan - it was just a way of differently navigating the step of 'social worker mandated care plan' so that people could author their intentions.

This idea was taken forward with the development of self-directed support from 2003 onwards and the concept of a support plan - authored by the person - has become central to English practice. However this fact conceals important ambiguities and a number of fallacies seem prevalent:

### **Fallacy 1 - People need support plans in order to be competent**

There is no evidence that support planning makes people more competent. At best support plans are an early and limited way in which the professional can determine the existing competence of the budget-holder: i.e. this seems to show that you know what you are doing. In and of itself, it does not create new capacities and competencies (Toner, 2011).

### **Fallacy 2 - Support plans increase creativity**

Thoughtful planning may increase creativity, but it is probably much less important than being directly in control of your budget and being confident that you can use it flexibly. It is living - not planning - that fuels human creativity. Even worse we find increasingly that professionals are now judging plans by their 'creativity' and then failing to agree to plans that do not pass an arbitrary threshold of creative worth. Given that self-directed support has increased creativity compared to the old system it is ironic that the professionals who ran the old system have now become the guardians of 'creativity' (Anon, 2012).

### **Fallacy 3 - Support plans are contracts**

One of the biggest systemic failings in England is to treat the support plan as part of the contract and to thereby hold the individual to account for fulfilling their plan. This is an extreme case of 'back seat driving'. Plans are projections into the future, but as needs, opportunities and problems change, so must our plans. People must be free to make immediate decisions about these matters without needing approval.

## **6.3 Living without brokers**

Another area where the English experience is interesting, by international standards, is that the model of self-directed support, as originally developed, made no role for any specialist planners, organisers or coordinators - professionals who sometimes go by the name broker.

This was not an accident. Duffy had led one of the early brokerage projects in England and had researched the USA's systems which were then making heavy use of brokerage. His enthusiasm for these systems waned in the light of certain facts:

- The ongoing lack of empirical evidence to support it as a mandatory part of the model
- The tendency for such systems to undermine faith in individual and family competence and to increase dependency on professionals
- The tendency for such systems to add further professional complexity to an already over-filled field.

Of course some system of underpinning and support is essential - but this needs to be plural. There is no evidence to suggest one system is best and common-sense dictates that

enforcing one solution for everyone will lead to wasteful monopolies, complacency and a failure to innovate.

## **6.4 Learning for Australia**

The gravest danger for Australia would be to repeat the well-meaning mistakes of colleagues in the USA. The desire to help people to do more, to live better lives or to get connected is admirable - but when you try to make these things happen through bureaucratic systems you often end up making poor assumptions about what really helps , consequently limiting future opportunities for innovation and creativity.

The three central lessons of the English experience are:

### **Lesson 8 - Do not put undue focus on the plan**

Plans are, at best, just one possible piece of evidence of competence and should not be made a central requirement of the NDIS.

### **Lesson 9 - Do not let any group dominate the process**

Systems of helping, planning and support are systems that should be subject to this ongoing social innovation - central specification is not required.

### **Lesson 10 - If in doubt, focus on peer support**

The most reliable, valued and sustainable form of support comes from people living with disability and families helping each other - do whatever you can to support and stimulate this without commodifying it or turning it into another professional intervention.

## **7.0 Conclusion – What is the outcome?**

Within the space of this short paper it has not been possible to explore more than a fraction of the system-design issues at stake in the development of a NDIS. However we want to end with some thoughts about the purpose of all this work.

From beginning to end we have assumed the purpose of the NDIS is to advance people's life chances in line with their human rights and with the goal in mind of citizenship. This is not just a matter of transferring the necessary resources to the control of the individual it is also about treating people living with disability and their families as citizens at every stage of the process.

To us, this seems to require the NDIS to establish two things:

1. A clear public account of what it means to be a citizen. It is only if we know what we mean by, and expect from, citizens that we can have any sensible conversation or research process to determine whether the NDIS is successful in its first goal: ensuring people get what they need to advance their life chances in support of citizenship.

2. Work hand in hand with people living with disability and their families to make sure the process feels respectful, effective and enabling at every stage. The NDIS process must be co-designed with people living with disability; but even more importantly for the future it must be accountable to them.

The challenge will be to achieve these two overarching objectives while maintaining sufficient discipline so as not to over-design the system. Space for variation and innovation at every level would seem important and much more consistent with the real goal of the NDIS – assisting fair access to life chances so Australians living with disability are active citizens socially and economically.

It is difficult to expect the NDIS to be perfect from day one, and there is significant complexity in the transition from existing arrangements. However, it seems reasonable to expect *every* design issue to be resolved in ways that facilitate the scheme's intended outcomes, which are to uphold and advance people's rights to good life chances, anchored on the principles of control and choice and authentic participation in community life and the economy. Any proposed scheme elements that fail to demonstrably achieve this (including elements contained in relevant legislation and regulation) should be avoided, else there is a greatly increased risk the scheme will not achieve the hoped-for social reform and instead double the size of the existing system and its failings.

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