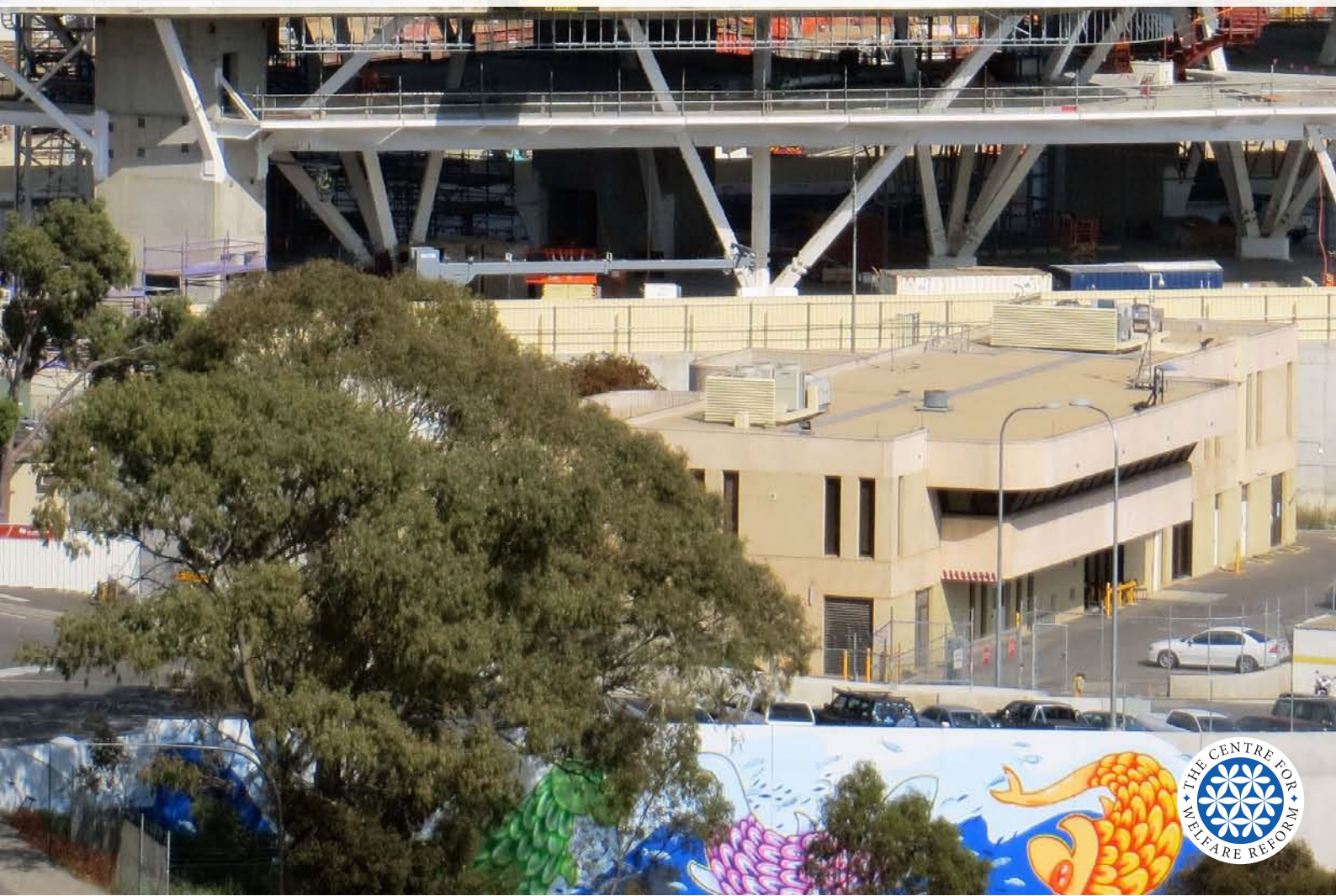




# Designing NDIS

AN INTERNATIONAL PERSPECTIVE ON INDIVIDUAL  
FUNDING SYSTEMS

by **Simon Duffy**





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Published by **The Centre for Welfare Reform**





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# SUMMARY



Australia's commitment to create the National Disability Insurance Scheme (NDIS) marks an exciting and positive step forward in the achievement of meaningful rights for people with disabilities.

However, designing this system so that it is effective is challenging and some of the current design assumptions seem highly flawed.

This paper argues that the designers of NDIS must focus on:

- Creating a sustainable system that supports active citizenship
- Generating clear and meaningful entitlements
- Rationing resources intelligently and directly
- Ensure citizens have the right responsibilities and incentives
- Assume and enable citizens to run their own lives
- Allow the maximum flexibility in how resources are used
- Increase local control within a national framework of rights
- Avoid triggering inflationary demands from services
- Minimise the cost of the system's infrastructure
- Ensure that the system can continue to innovate and evolve

The current commitment to avoid means-testing and to build on the human rights of people with disabilities is good. Following the logic of these commitments would take the current designers to a different model, one more in tune with the rightful demands of people with disabilities.

Australia needs an NDIS which is designed in the spirit of the twenty-first century - a system that is light, enabling and innovative.



# INTRODUCTION

**The National Disability Insurance Scheme (NDIS) could be one of the most important international developments in the advancement of the human rights of people with disabilities in recent years.**

**Potentially the NDIS recognises:**

- People with disabilities are entitled to a fair and reasonable level of support
- People should control their own lives and their own funding
- These are universal rights that should be underpinned by an effective national system of social insurance

It is still early days for NDIS. From early aspirations the Federal government and some States are moving quickly to implement a model that has been designed and developed from within the existing bureaucracy.

My arrival in South Australia happened to coincide with some of the first public descriptions of how the NDIS system has been designed. I am very aware that there is still much to do and the current model may change. I am really grateful that so many people involved with NDIS were happy to talk to me about their thinking and spend time exploring what lessons can be drawn from the ups and downs of the English experience.

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**Currently the early designs for NDIS seem to have the following features:**

1. A Federally controlled agency will deliver a care management service.
2. There is no overall budget for the agency to work within.
3. There is no significant strategic role for States, except perhaps as service providers.
4. Budgets will be assigned by paid facilitators who will develop a plan with the person with disabilities.
5. Funds will be released in accordance with that plan, either to citizens or services.
6. The plan is the central control mechanism and people must work to the plan. Their success at achieving any agreed outcomes will be monitored.
7. All of this will be delivered through a new national computer system and into which everybody must be linked.
8. This centralised system will be defined by detailed legislation.

There are still many debates to had and there is a consultation on this model and an election looming. Much can be achieved; much can be lost.

I have spent 22 years trying to design decent and affordable systems of individualised funding in the UK. I've also been lucky enough to have had the opportunity to explore other international models. I am really hoping that the Australian system will go on to be the world leading system that Australians with disabilities deserve.

However, if the early designs that I have seen were implemented then I think that

Australia is in danger of building the world's worst system of individualised funding. I do not make these remarks lightly, nor for rhetorical affect.

**In summary I believe:**

1. The current design does not reflect international or Australian learning about best practice in individualised funding systems.
2. The resistance to acknowledging human rights and real entitlements will undermine both the quality and sustainability of the model.
3. The resistance to accepting the reality of rationing will have the perverse consequence of promoting the worst kinds of indirect rationing.
4. In principle, the concept of insurance could be very helpful, but it is not currently being used effectively to guide the design of the NDIS.
5. The current design is in conflict with human rights and lacks any basic trust in the competency of Australians with disabilities to make their own decisions.
6. The proposed model does not do enough to harness the efficiencies that come from shifting responsibility to citizens and making resources flexible.
7. The model is hyper-centralised and risks eroding the responsibilities of States, communities, services and families.
8. The current model is designed in a way which will create significant inflationary pressure and will damage social capital at every level.
9. The proposed design involves an unnecessarily expensive and centralised bureaucratic infrastructure.
10. The current design is not innovative, but bureaucratic, and it leaves no room for social innovation at any level.

# 1. Sustainability

Internationally, individuals, organisations and governments have been designing systems of individual funding for at least 50 years. There have been many steps forward, many steps back and much has been learned along the way. However, as it stands, the proposed design for NDIS seems to share many of the features of the worst systems, and just a few of the features of the best systems.

The current design does not seem to be rooted in any meaningful reflection on the lessons that can be drawn from international experience.

**It could be that I am wrong and that the current design of the NDIS will perform brilliantly. But if it does it should be measured by the disability community, and by society as a whole, by two interlocking criteria:**

1. Does it deliver entitlements that enable people with disabilities to live as full citizens?
2. Does the system create socially sustainable and affordable solutions over the long-term?

The design challenge is to meet both these criteria. And, as we will see, they are intimately linked. If you only focus on providing fair and decent entitlements then you will quickly create a system that is unaffordable and potentially damaging to your social and community capital. However, if you only focus on sustainability you will quickly end up with a system which is mean-spirited and fails to support citizenship and community development.

**However, the good news is that there are strong reasons to believe that, with the right kind of design, you can meet both criteria:**

1. Decent systems of entitlements will increase productivity, relationships and community capacity.
2. Responsible systems will encourage good stewardship and positive incentives at every level.

My argument is that NDIS - as it is currently designed - fails to meet both these criteria. This is not a problem inherent to the NDIS - but it is a problem inherent to the early designs for the NDIS.

## 2. Entitlements

The term ‘entitlement’ is not always loved by policy-makers; it generates anxiety both about the fiscal impact of entitlements (affordability) and the kind of relationships they may create (dependency). However much of this anxiety is misplaced. First, because it is not entitlements themselves that creates the problems they fear. Second, because many of the problems they fear are actually rooted in their failure to really understand the true nature of an entitlement.

To begin with it is important to recognise that entitlements are essential to any system of individual funding. Unless the person has the right to support and funding there is no good reason to give them support and funding.

The easiest way of testing the point is to ask ourselves the question:

*Are we giving people help and money, even though they are not entitled to it?*

I find it hard to believe that any government can justify transferring resources to people who it does not believe are entitled to those resources. So we have to accept that the NDIS is a system for recognising and responding appropriately to entitlements that already exist - at least as a reason for action. However, it turns out that there's much more to the notion of an entitlement than simply being the reason for action.

The simplest way to see this is to notice that, even if someone is genuinely entitled to something, we can still respond to that entitlement in a way that is demeaning and insufficient. The fact that an entitlement exists does not guarantee that it will be fully recognised.

Maimonides, the Jewish philosopher and theologian, made this point when distinguishing the different degrees of charity, he said:

*There are eight levels in charity, each level surpassing the other. The highest level, beyond which there is none, is a person who supports a Jew who has fallen into poverty [by] giving him a present or a loan, entering into partnership with him, or finding him work so that his hand shall be fortified so that he will not have to ask others [for alms]....*

*...A lower level [second lowest] than this is giving him less than what is appropriate, but with a pleasant countenance. A lower level [the lowest] than that is giving him with sadness.*

It is not just the fact of recognising the existence of entitlement that matters. It is also a questions of how much we give and how we give. In particular Maimonides was concerned to ensure that the very act of giving itself was performed in a way that treated the recipient with the maximum degree of respect possible.

If we follow Maimonides and examine the details of how entitlements are actually realised by any society through its social institutions (like the NDIS) then we find that there are at least seven critical issues to address:

1. **Democratic** - Is the entitlement supported by the people and underpinned by the democratic process?
2. **Legal** - Is the entitlement defined in law and open to testing and clarification in the courts or in other open administrative systems?
3. **Clear** - Does everybody know that the right exists and that it is relevant to them and what precise entitlement it provides?
4. **Accountable** - Is it clear which individuals and organisations are accountable for meeting the entitlement or for ensuring that it has been met?
5. **Effective** - Does the existence of the entitlement provide what is necessary, neither too much nor too little?
6. **Reasonable** - Is the entitlement affordable and sustainable so that rights can be realised in practice?
7. **Consistent** - Is the entitlement organised in a way that is consistent with our other rights and freedoms?

People with disabilities have real human rights and the entitlements generated by those rights. However whether a society has figured out how to competently realise those rights - turning them from paper rights into real rights - is the big question. What made NDIS so exciting to the international community was that it seemed like this was going to be at the heart of your thinking.

However, as it stands, the designers of the NDIS seems unsure of whether they aim to meet people's human rights and to achieve the realisation of entitlements. There is a real nervousness about using the language of entitlements. The proposed design, while it will certainly transfer resources, does not seem to be rooted in a respect for human rights or for equal citizenship.

The failure to recognise the existence of entitlements does not just undermine respect for human rights. It also undermines the affordability and sustainability of the system.



# 3. Rationing

One theme that arose out of many of my conversations in Australia was an antagonism towards rationing and a hope that the NDIS would be good because it would be uncapped. Many people seem to believe that the current rationing system is so negative that a system with no rationing would be better. However, rationing is not the problem. Rationing will emerge in any system over time; but the wrong kind of rationing will cause significant problems for Australians with disabilities.

I can understand that many people are pleased that the new system promises to provide many more resources than the old system. Internationally it has long been observed that Australia provides somewhat less funding for people with disabilities than other similar countries. [Although it is worth noting that the per capita costs of your services are high. This suggests that you must be careful in calculating the size of your own 'under-funding' and that Australia has had a tendency to provide expensive and institutional services rather than appropriate and personalised support.]

However the promise of new funding should not distract Australia from the fundamental fact that all public services ration resources and that a good system of rationing is entirely consistent with a decent system of entitlements. In fact it is possible to go further and argue that all entitlements must be rationed and capped. I have set out my argument for this in more detail in *Travelling Hopefully* which is the report I wrote for the South Australian Government.

An uncapped entitlement is logically confused. All entitlements must be matched by real duties, and all duties must be reasonable - must not demand more than it is sensible to ask of the duty-holder.

I suspect that one of the reasons that policy-makers are nervous about entitlements is that they think entitlements are uncapped or they believe that the recognition of entitlements will unleash uncontrollable demands on taxpayers. But the reality is that positive social rights - entitlements - demand reasonable public duties - otherwise they are empty and aspirational - not real rights.

The importance of being realistic about the need for rationing is not just logical it is also practical. In practice, if you avoid rationing directly - rationing cash - you end up rationing indirectly - desperately trying to impose multiple different control mechanisms in order to limit the liabilities on the tax payer.

## Indirect rationing can come in many forms:

- ◆ Creating eligibility thresholds, which exclude people with lower needs
- ◆ Imposing funding caps, which limit support to people with higher needs
- ◆ Limiting how money can be used, restricting it to more 'traditional' services
- ◆ Clawing back resources that have been saved up by citizens or organisations
- ◆ Controlling the expenditure process so that costs must precede funding

- ◆ Controlling people through formally agreed plans
- ◆ Reducing resources for people with better incomes or savings
- ◆ Reducing resources for people with strong families
- ◆ Reducing resources for people making better use of their community
- ◆ Reducing resources for people who use mainstream services

All of these forms of proxy-rationing or indirect rationing end up creating problems, often vicious problems. I will explore some of these problems below because I think the NDIS is already in danger of following some of these indirect routes to financial control.

**But first I want to make a more basic point:**

**It is better to ration cash directly rather than to try and design indirect methods that you hope will control costs.**

It can of course be argued against this that we cannot tell what is needed yet: we need to fund what people need first, not ration resources. My prediction, based on every system of individualised funding that I have ever seen, is that rationing will arrive sooner than you think and often in forms that you will not like. It is better to address the issue clearly from the very beginning.

## 4. Social insurance

I have also heard it argued that Australia's model for the NDIS will be effective because it is based upon an insurance model of dynamic investment aimed at reducing need rather than creating entitlements. Here I think an attractive and positive approach to social policy - flexibly investing in citizens to increase capacity and reduce need - is being muddled up with fears about entitlement.

It is certainly right that the best way of meeting someone's needs may be to spend more up-front on things like:

- ◆ therapy and rehabilitation
- ◆ equipment
- ◆ adaptation
- ◆ community development

But the idea of an early investment is not opposed to the idea of an entitlement. In fact if spending more, early on, is what people need then it is also what people are entitled to. Entitlements do not need to be shaped like pension payments. As I argued in *Travelling Hopefully*, it is certainly smart to be thoughtful about the timing of entitlements.

Putting aside this positive and dynamic element of the design of NDIS, it is important to recognise that insurance and entitlements are simply two sides of the same coin. In fact the idea of social insurance, as implied by the title of the NDIS, is one of the reasons that many international observers, like myself, were so pleased and excited by NDIS.

It is certainly very helpful to imagine a decent system of entitlements being underpinned by an insurance model:

- ◆ All Australian citizens contribute by some fair means to the national scheme
- ◆ All Australian citizens are entitled to support if they need it

But, again, if we take the notion of insurance seriously it also implies being very careful to make sure any entitlements can be met by first asking for premiums to be paid at a level that ensures that it can afford to meet its liabilities. This is one of the reasons that private insurance companies generally thrive and have grown to be one of the most important holders of assets in our communities: they take great care to ensure that the total of premiums paid is greater than the entitlements generated.

No insurance system would work on the basis of creating entitlements first and then hoping it could raise enough money to be able to afford them afterwards.

Insurance systems are of course dynamic and empirical, and it may be that premiums may need to be raised in order to properly meet need. But in order to justify such a calculation the primary data will be data taken from the past - the previous effectiveness of the system at meeting people's needs effectively (or not). There is a clue to this in the

very word actuarial which comes from the Latin for book-keeper - the one who keeps a record of what happened in the past.

However actuarial thinking is no guarantee of good fiscal management, it must be combined with a well managed system for rationing entitlements.

In fact, if we further follow the logic of insurance type thinking it would seem that a smarter approach would be for the ultimate insurer (in this case the Federal government, acting on behalf of all citizens) to ensure fiscal prudence by seeking ways to push responsibility for cost control further down the system.

**This could include some or all of the following:**

- ◆ Giving the States responsibility for allocating resources fairly
- ◆ Giving local agencies (perhaps including service providers) responsibility
- ◆ Giving local communities responsibility
- ◆ Giving citizens responsibility

In fact, I would suggest that the reason that England has so far been reasonably successful in creating a robust, affordable and highly flexible system of personal budgets was that it took exactly this kind of approach. Generally the reason that individual funding systems have become unsustainable is that they either (a) try to avoid rationing or (b) they try to ration everything else instead of the money.

Often those systems that start with an aspiration not to ration end up with highly regulated, intrusive and complex systems where any sense of basic citizen entitlement has been eroded by the rationing process itself.

While many interest groups and advocates for change may like the sound of an ‘uncapped system’ it is important to realise that this is a dangerous concept, and one which will ultimately kill a decent system of entitlements. If the human rights of people with disabilities are to be realised it's important to **get real**. Any entitlement that places positive obligations on another person, or person, is inevitably capped - because it is impossible to have an uncapped positive duty.

**Citizens get this. Most people with disabilities have no trouble understanding that there is only so much money in the system. What they want is to be told clearly what they are entitled to and to have rules and natural incentives which treat them as a responsible citizens, which means:**

- ◆ The money they receive is their money and they are trusted to spend it well
- ◆ There are no clawbacks, distinct bank accounts, audit trails or intrusive planning sessions

Competent insurance systems always seek to work in harmony with these natural human incentives by developing systems that reward people who do not over-claim and which limit their liability when claims are made.

A competent system does not just ration money it rations responsibility for the money. An entitlement system does this by ensuring that citizens have responsibility to manage and control resources themselves and to benefit from all the natural incentives that come with good management (being able to spend it wisely and keep the savings). A system that avoids entitlements loses the ability to distribute responsibility. It treats the person, not as a citizen, but as a mere recipient. In the process it guarantees waste, disempowerment and dissatisfaction.

# 5. Citizen capacity

As it stands, the primary means by which the NDIS will control costs is through the use of facilitators who plan with people and then assign resources to appropriate services and supports. Although this may seem reasonable, experience teaches us that the role of the facilitator will come under significant strain.

In particular the notion that the plan, agreed with the facilitator, is the key to the entitlement turns out to be critical flaw in the design. Effectively the plan imposes upon the person a set of restrictions and invasions of privacy which are inconsistent with the *UN Declaration of Human Rights* (see Table 1).

Article of UN Declaration	Possible frustration of right
1 All human beings are born free and equal in dignity and rights...	But I have to share my life plans with a facilitator who does not need to share their plans with me.
3 Everyone has the right to life, liberty and security of person.	But I am not free to set my own plans, I must get the facilitator's agreement to my own plan.
12 No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence...	But I need to share my plans, private information, financial information and information about family and friends.
17 (1) Everyone has the right to own property alone as well as in association with others. (2) No one shall be arbitrarily deprived of his property.	But I will not get full control over my own funding; any savings I make will be taken away.
23 (1) Everyone has the right to work, to free choice of employment...	But if I need assistance to access work I will have to get agreement from my facilitator
27 (1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.	But I will need to have agreement before being able to pursue access to community life.
29 (1) Everyone has duties to the community in which alone the free and full development of his personality is possible.	But I will not have responsibility for managing my own budget to develop my life and community contribution.

Table 1 Conflicts between the human rights and the current design of NDIS

The critical design flaw in the current design of the NDIS is that it does not start with an assumption of citizen capacity. Of course it is important that there are arrangements which make sure people are safe when:

- ◆ People need help with decisions
- ◆ People may lack good friends or families
- ◆ People are in dangerous or abusive environments, like institutional care

However if you design the system from a presumption of incapacity for people with disabilities then you run the severe risk of failing to meet people's basic human rights.

People with disabilities are people who already make a positive contribution to Australia. With the right system of entitlements they will be able to make an even greater contribution. This needs to be the starting point of the design. Systems of planning or facilitation sound good - but they disguise an underlying failure of trust in Australians with disabilities.

No system should assume that everyone needs a facilitator, nor does everyone need a plan. Sometimes plans and facilitation will provide a useful, but limited, role in ensuring good support. But they should not be hard-wired into the system.

NDIS promised to recognise the rights of people with disabilities. It would be useful, therefore, to put the principles at the heart of *UN Declaration* and the *UN Convention of the Rights of Persons with Disabilities* at the heart of the design process.

This means the entitlement to support is not just a financial question. It is not just a matter of how much money. It is also important that money is transferred to people in a way which enhances other rights, rather than frustrating those rights.

**For example:**

- ◆ The right to be a full citizen and to contribute in your own way to the community
- ◆ The right to use your money flexibly
- ◆ The right to join in community life, not be restricted to services
- ◆ The right to a family life, not be stripped of support if your family is 'coping'

So, a decent system of entitlements will certainly provide enough money; but it will also provide that money in a way that is consistent with these rights.

The rights of people with disabilities already exist. Morality and history teach us that people with disabilities are entitled to the support necessary to enable them to be full citizens. The *UN Declaration of Human Rights* and the *UN Convention on the Rights of Persons with Disabilities* both make good sense and set the framework we should be working to.

## 6. Efficiency

**It is not just a question of respecting human rights. It is also essential that the right people have the right level of responsibility, at every stage, if Australia wants to ensure the best possible use of resources.**

In England, despite many problems, one of our primary achievements of our own model of self-directed support, was that it shifted control and self-direction towards people with disabilities, families and older people. One of the most important affects of this change was to radically improve people's outcomes and to reduce the overall level of expenditure. Figure 1 gives just one example from any early project of people's own increased satisfaction after being in control of their own budget:

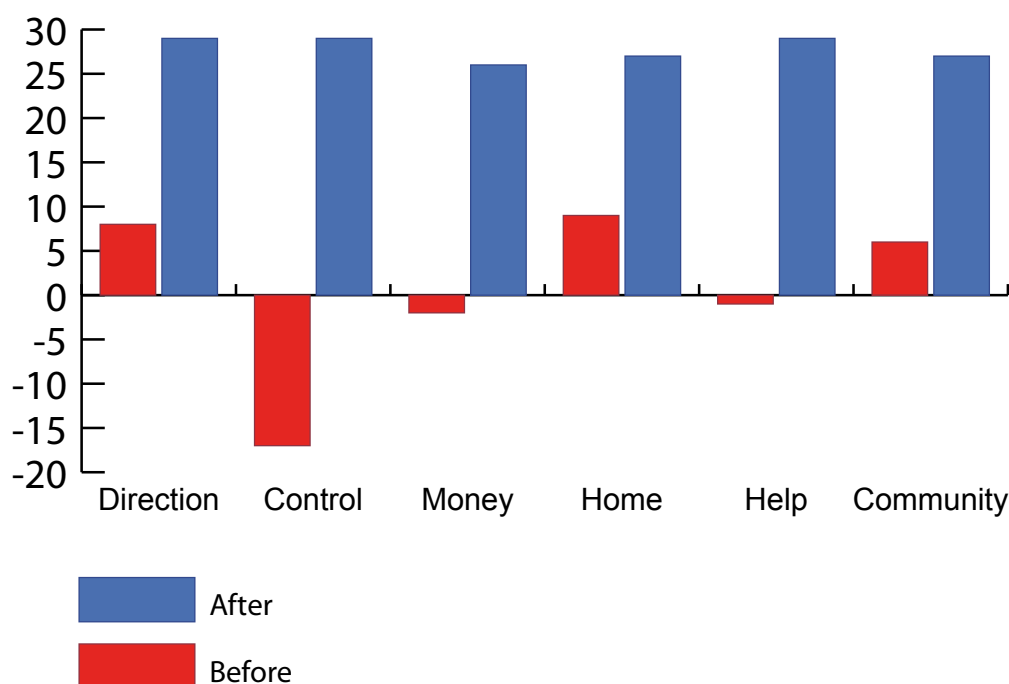


Figure 1 - Aggregated outcomes of first In Control pilot (2003-05)

There have been many different reports on the implementation of self-directed support in England. Although there are interesting variations in the quality of implementation and in the final impact, the pattern of better outcomes plus reduced spending has been consistent:

- ◆ In Control Phase I Report (covering 6 sites, n = 60) - efficiency **18%**
- ◆ In Control Phase II Report (covering 17 sites, n = 128) - efficiency **9%**
- ◆ 13 Sites IBSEN Report (13 sites, n = 203) - efficiency **6%**
- ◆ Report from Northants (n = 17) - efficiency **18.7%**
- ◆ Report from City of London (n = 10) - efficiency **30%**
- ◆ Report from Worcestershire (n = 73) - efficiency **17%**



These kinds of efficiency levels **do not flow automatically from any system of individualised funding**. For example, the Dutch model of individualised funding seems to have been more expensive than the old system. Rather, it is the details in the **design** of the system that are critical.

It seems most likely that the key to an efficient design is a system that combines:

- ◆ individualisation with
- ◆ flexibility and
- ◆ empowerment

For instance, if we look at how people spend their budgets when they have flexibility and genuine control, it turns out that their spending is a matter of making better use of natural resources:

- ◆ family,
- ◆ community,
- ◆ friendship and
- ◆ peers.

Figure 2 shows spending patterns for two groups who were previously forced to use day centres. After taking control expenditure shifts to more personalised support and to greater use of ordinary community resources:

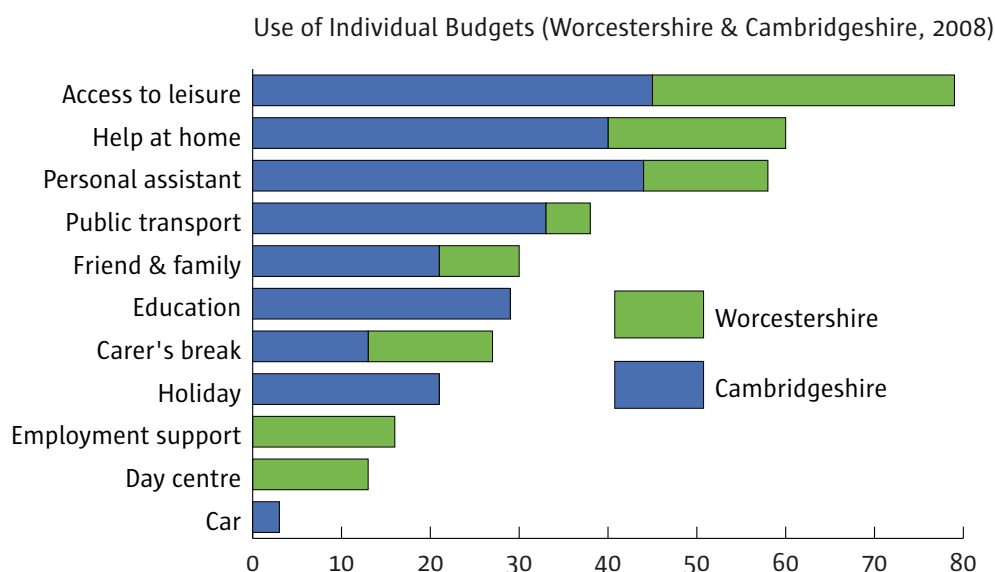


Figure 2 - How personal budgets were used in two areas

In other words, what is happening here is not primarily a 'market impact' (at least as markets are often conceptualised). It is not the freedom to choose, competition or lower prices that are directly improving efficiency - rather it is people's ability to integrate their own entitlements into their own network of private and social resources.

As it currently stands I do not see how the design of NDIS will really harness the energy, motivation and private and social resources of Australians with disabilities.

The supposition seems to be that it is the plan and the facilitator who is central. This is more likely to lead to a patronising model where anything too different from traditional services will be deemed inappropriate.

Moreover, the primary assumption of incapacity, will make both people and facilitators more risk averse. People will also learn that if they do suggest that family, friends, community or any other resources could readily provide support then those natural resources will be discounted from the overall funding package - leaving the person poorer. The tendency for public service systems to thoughtlessly means-test family, love and community will be one of the primary drivers for inefficiency in the proposed system.

Some of the disempowering features of the current NDIS design will not be obvious at first. But over time, as the system tries to control costs through indirect rationing, increasing levels of perverse control will undermine the natural incentives for citizens to make good use of their own resources.

# 7. Incentives

**It is not just citizens who are in danger of being treated as irresponsible recipients. Responsibility has been taken away from all the layers of society intermediate between the Federal government and the citizen:**

- States
- Local councils
- Service providers
- Community organisations
- Peer organisations
- Families

Interestingly there is a strong awareness within the community who are currently developing the NDIS that this could have significant negative consequences. But there also seems to have been a critical early design decision that States (and everyone beneath them) cannot be trusted to manage any resources that will be distributed by the Federal government.

However, as with citizens, so with others, this failure of trust will have a toxic impact.

**A series of problems will occur, although some will happen more quickly than others:**

- ◆ Some people, often those most complex to support, will end up needing support from multiple sources of funding. Local systems will have every incentive to push costs towards the new funding stream - often through service failure.
- ◆ Service providers will seek to push up costs and work with people and families to construct expectations that maximise the call on resources.
- ◆ Communities will find that if they have invested in more inclusive and welcoming environments or mainstream services then they will be penalised as resources shift towards people in communities that are less welcoming.
- ◆ Families will learn that love and natural support will reduce the funding that people receive, and so they will either reduce support or learn how to give the appearance of such a reduction.

These problems will grow and increase over time because the system does not exploit the natural incentives that operate for States and civil society.

**The simplest and most important of these incentives is this:**

*If we do a good job then we will save resources which we can then invest in other good things; if we do a bad job we will lose resources and we will need to increase local taxes or reduce the good things that we do.*

### The current design of NDIS seems to create the alternative perverse incentive:

*If we take less care and people's needs grow and become more expensive then they will get more Federal funding; if we do a good job and people's needs reduce and our communities grow stronger then we will be punished and receive less Federal funding.*

My own view is that the problems created by the current design are so great that it will force the Federal government to redesign the system in a matter of just a few years. However it would be much better to avoid this problem and start with the presumption that it is better to push resources and responsibility downward from the beginning.

It may be that there is a fallacy at work here which is stopping people from accepting the need for a more balanced design. Sometimes people cling to a confused notion that a centralised bureaucracy is the best mechanism for delivering equity: treating someone the same in Alice Springs and in Sydney.

But equity does not demand you treat people exactly the same. Context is important. The real challenge is to treat the States with equity and then to transfer the problem of equity to them. In other words it would seem better to apply the design principle of subsidiarity to the NDIS.

### As the Oxford English Dictionary defines it:

*Subsidiarity is the principle that a central authority should have a subsidiary function, performing only those tasks which cannot be performed effectively at a more immediate or local level.*

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Subsidiarity is important because it shifts problems to those people or agencies who have the best incentive, means and resources to solve the problem. Subsidiarity promotes efficiency.

### To develop a sustainable system Australia needs to promote:

- ◆ **Innovative supports** - this can only be driven by flexibility of the entitlement at the level of the citizen.
- ◆ **Stronger families** - this means reducing the current tendency to 'means-test love' and reducing the pressures that drive loving families into crisis.
- ◆ **Resilient communities** - this means being able to identify changes at a local level which create greater inclusion and mutual support within our communities.
- ◆ **Accessible mainstream services** - people will still need to use other public systems and those systems may also need to reform themselves in order to promote access and personalisation.

The best way of achieving this goal is to ensure people maintain, at every level, the necessary responsibility and control over resources in order to make that possible.

All of these factors provide another reason to delegate responsibility downwards to citizens, families, communities and States. For it is only at these different local levels that natural incentives to find the right solution can be sustained. There is a severe danger that if the Federal system is designed in the wrong way it will encourage citizens, families, communities and States all to look outwards to solve problems that they are actually already able to resolve themselves.

The funding necessary to achieve decent entitlements will only be useful if it is harnessed to an attitude of local problem solving. It is therefore essential that the system also provides natural incentives at every level:

- ◆ Citizens and families who manage their budget well can keep what they save.
- ◆ Communities that invest for accessibility and remove barriers to inclusion will benefit from reduced needs.
- ◆ States that tackle problems in other public services should benefit from their good management.

People, places and governments who do not work within their budgets and where there are no real factors to explain this should not be rewarded for mismanagement. It could be disastrous for the ecology of our communities if we reward failure and penalise success. This would also further add to the pressure on NDIS. Sustainable approaches build on and support the natural and evolved ecology of a place; unsustainable approaches are not respectful of the locally evolved systems and responses, instead they strip away existing solutions.

One further point may also be relevant. Currently people with disabilities and families can express their satisfaction with local arrangements at a Federal, State and local level. Under the new system local politicians - often the best advocates for real people - will lose any control over decisions about funding. Reducing democratic accountability for families and people with disabilities seems a very negative move.

## 8. Inflationary pressures

Another economic issue that has bedevilled public services and individualised funding is the impact that any new system has on demand for that funding. It is clear that if you design a system in the wrong way you can invite new levels of demand, generate inflationary expectations and increase costs in ways that seem totally detached from the real level of need in the community. Often this money goes into services - but does not benefit people.

Usually systems of individualised funding have been developed from within local systems of funding, where existing funding levels already set the benchmark. However the NDIS, as a totally new system, and one that promises significantly increased levels of funding, faces risks that other systems of individualised funding have not had to face.

It may be useful in this context to share some of the UK's experiences of building systems of individual funding and other funding systems for disability. The background to all these initiatives is the overarching commitment to the NHS to provide universal health care, together with a much more muted expectation that local authorities will provide means-tested 'social care' or access to services for older people and people with disabilities.

Within this context the UK has seen a series of policy initiatives. Some have been good, others have been dreadful:

**Board & Lodging** - In 1980 the Conservative government created an entitlement to residential care - Board & Lodging. This led to a radical increase in spending on institutional care. In 1992 this 'entitlement for service providers' was closed down and the resources capped and transferred to local authority control. Rapid inflation in expenditure and residential care ceased almost immediately.

**Independent Living Fund (ILF)** - In 1988 the Independent Living Fund was created. This was an arms-length Quango of central government set up to give people funds for ILF. It is the closest approximation that I am aware of to the NDIA. Expenditure increased at a rate that no one expected. In 1993 the fund was changed so that entitlements now became dependent upon local authority funding (this then meant two different assessments were carried out by two different professionals) and a series of further measures were taken in order to dampen down any increase in expenditure. Despite this, growth continued. This was particularly the case where local government officers developed necessary skills and strategy and to work with local citizens to maximise the call on this centralised funding system. This system is now being terminated as part of the radical cuts programme within the UK.

**Supporting People** - From 2000 to 2003 central government invited local government and service providers to claim funds for low level support. The intention was to use this transitional period to calculate the overall level of funding necessary for support and then transfer it to local control. This transitional programme led to a rapid increase in expenditure which central government then blamed on local government, and so for many years, central government maintained its control over the funding. However, it was central government who were responsible for the design an

inflationary system - they simply transferred the blame for their own mistakes to those with less power.

**Direct Payments** - This is not a funding stream, but it is a right to take your own funding for disability support out from the local authority and receive it as direct funding rather than as a service. From its creation in 1996 it has been very popular, despite the fact that individuals tend to receive about 75% (or less) of the funding that would have been spent on domiciliary care as provided by local government.

**Personal Budgets** - This is also not a funding stream, but was a way of rethinking how current local authority funding would be managed. Begun in 2003, it enabled everyone using disability support, to be given a flexible budget (rather than a service) that could be used to purchase support or services. As described above, this approach was also associated with savings and improved outcomes. From 2007 central government announced that this model would be obligatory for all local authorities.

#### In summary we might observe the following:

1. Managing entitlements from an existing pot of funding does not create inflationary pressure; whereas opening up claims to an uncapped pot can create inflationary pressure.
2. Systems that benefit service providers or local government will be exploited the most, for they have a natural incentive to systematically maximise claims.
3. Professional care managers, facilitators or planners - even when working within a rationing system - struggle to keep inflationary pressures under control without other controls and restrictions.

On this analysis the current design of the NDIS seems to be the worst of all possible designs. Instead of subsidiarity and delegation of responsibility for fixed budgets, there will be a federally organised and funded process, within no overall budget. Moreover, there will not be a robust system of individual entitlements, but instead a complex planning process that will somehow ration resources by criteria which are not yet clear.

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#### In quick order, this may have the following consequences:

- ◆ Australians with disabilities will need to learn how to extract money from the system and to get round the obscure budget setting process implicit in the professionally dominated planning process.
- ◆ Families will figure out how to create the necessary messages of breakdown or crisis that will trigger support.
- ◆ Service providers will work closely with citizens and families in order to maximise their own call on Federal funding.
- ◆ States and other public service departments will also need to support people to maximise their call on Federal funding.

I cannot think of another system which will be so prone to inflationary pressure as this model. It exploits no natural incentive for good cost control, while inviting demand pressure from every possible source. It will inevitably lead to further erosion of every type of social capital and increase over reliance on the current human service system in Australia. It will reward communities that fail to invest in people with disabilities and the accessibility of their own local organisation, places and services.



# 9. Infrastructure

Another peculiar feature of the current design of the NDIS seems to be the willingness to increase the cost of the infrastructure of the disability service system. This may not seem obvious and I am sure that everyone involved wants to deliver NDIS efficiently; but just being present in Australia as the NDIS is being launched made me very aware of the enormous risks being taken here and the tendency for central government bureaucracies to be rather negligent of good cost control.

Although the intention must be to save money by making savings at the State level (that is, by drawing resources away from local communities and shifting them towards central government) the reality looks to be very different:

**Computer systems** - Is it really necessary to have a new computer system (Did someone really mention \$0.25 billion?) and who will really benefit from the expenditure on new software design? The real trend in business and communities is to make better use of open source software and to amend and develop systems to fit local need.

**New Federal posts** - Many new posts are being developed for people to work for the NDIA. And of course the salaries have to be competitive with existing jobs within States. Increase in the demand for jobs against a rather inflexible supply of candidates will lead to salary increases that will increase the overall level of costs within the new system.

**State infrastructure** - States will also be left with the further cost of making redundancies. However they will also quickly find that they cannot completely disinvest from disability supports because there will still be overlaps with current services to maintain and the need to pick up arrangements which NDIS will find, sooner or later, it cannot fund. The end result will be a demoralised rump service within the States.

All of this demonstrates a more general failing in the quality of the design thinking - you should always try to make the best use of what you already have. Tearing systems down and starting all over again is always expensive. It is much better to try and get better value out of the existing system - reducing resources spent at the centre, pushing resources out to citizens and communities.

# 10. Social innovation

Individualised funding is an innovation - a social innovation. It is not just a fancy rhetorical term, but a complex interlocking set of reforms with a real international track-record. To develop such a system for Australia will take careful attention to detail, good leadership and a strategy which builds capacity for the long-term. Like all social innovations, a system of individualised funding will keep on developing - it should not be frozen in time nor cast in bronze.

Whatever the rights and wrongs of the particular design of the NDIS, I find it surprising that, in the 21st Century, the current model has been designed in a way that will be so hard to improve and to change over time:

- ◆ The details of the NDIS are being written into legislation - in details that seem highly detailed - e.g. specifying how people's plans are to be used.
- ◆ There will only be one model for the whole of Australia - so there will be no capacity to learn from different practices in different States or localities
- ◆ Existing social innovations, for example the Local Area Coordination model developed in Western Australia, the Victorian system of direct payments, or the South Australian system of Self-Managed Funding will all be made redundant.
- ◆ Existing innovative support arrangements, crafted by individuals, families and communities, in pockets across Australia, are now all at risk.

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What modern systems need is more innovation, not less. NDIS should be a framework within which multiple innovations could be fostered, and from which further learning could be gathered and shared back across Australia, for the benefit of all. NDIA should be a vehicle for intelligence gathering - not for the command and control delivery of individualised funding.

What seems to be happening to the NDIS has happened to other social innovations before it. Often, when an innovation meets the bureaucratic system, the innovation dies and the bureaucracy takes over.

Public service bureaucracies inevitably promote a kind of anonymity. Taking personal responsibility for the design of a new system is uncomfortable and inevitably leads to attention that may be difficult to manage. The desire to include lots of people's opinions and widen accountability is natural and understandable.

However the danger is that the good ideas and aspirations associated with NDIS are being converted into the language and systems of a centralised bureaucracy. The principles of good design go missing. There are no individual designers who are responsible for the system, instead a strange kind of 'committee think' takes hold.

We also often find that centralised bureaucracies can become dependent on private consultancy companies who, without any real track record in innovation or public service reform, offer plausible sounding solutions. In England we have seen millions of pounds

wasted on private companies that, at best, recycled other people's ideas, but often created negative and damaging system changes. It is hard not to be reminded of the story of the Emperor and the tailors who sold him clothes spun from invisible thread.

Good designers focus on making better use of resources, and good social innovators focus on helping society make much better use of its existing resources. This is not just money. Social innovation requires a focus on people, institutions and the incentives and structures that influence human behaviour.

**It would much better to design a smarter system that uses money and Australia's many human resources well from the start.**

*Australia is in danger of making an imperfect system much worse.*

A decent system is a sustainable system and sustainable does not just mean affordable (although affordability is essential). A sustainable system is a system that does not erode all the many things that societies can't buy with money: citizenship, family, community, love and a commitment of social justice. If we simply treat NDIS as a mechanism for pouring money into people's lives we may thoughtlessly damage many of those things that are even more important than money.

It may even be that the prospect of additional resources is having a damaging impact on people's thinking. If it is not careful Australia will go from famine to flood - and when that happens one of the consequences of the flood will be to wash away all previous good practice and innovation.

The current design NDIS feels like a 1970's IBM computer mainframe - powerful, expensive and completely unnecessary. Instead Australia needs to design NDIS in the spirit of the 21st century: the cloud, laptops and smart phones - networked, easy to use, and under the control of ordinary people.

# CONCLUSION



I am sure that some will find my judgements extreme, and I recognise that systems and societies are complex. Perhaps there are factors I have not fully understood or perhaps Australia and Australians are very different to people in other countries. But when I compare the NDIS to all the systems with which I am familiar I am still left feeling that it looks like potentially the worst system of individualised funding in the world.

What makes this particularly disappointing is that the overall vision for NDIS and the values it aimed to support are good and feasible. It is quite possible to achieve:

- ❖ A national system to which all Australians contribute
- ❖ An affordable system of entitlements that people can control for themselves
- ❖ Wider social change to make it easier for Australians with disabilities to achieve citizenship

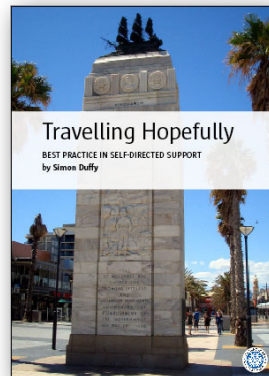
I also want to recognise that there are elements of the proposed design that are good and should be built upon:

- ❖ The insurance concept - which ideally would lead to a sensible tax hypothecation - is entirely appropriate and could be developed positively.
- ❖ The dynamic investment element - spending more, early, to reduce need and reduce long-term expenditure.
- ❖ The exclusion of financial means-testing, which ensures no disincentive for people to save, earn and contribute to Australian life.

But, beyond these elements, I think the design of NDIS needs to be radically revised - at every level. Minor tinkering and good intentions will not be enough. The problems that will emerge over time are written deep within the DNA of the current design.

My hope is that Australians begin to distinguish between the overall vision for the NDIS - which is very good - and the detailed design - which is not. I hope that it is not too late for people of good will across Australia to take stock and reconsider your options and the risks of tying yourself to a model which is already out-of-date before its begun.

# Relevant Publications



## TRAVELLING HOPEFULLY

There is no ideal model of self-directed support - the innovation is still at an early stage. This report draws together lessons from international best practice to support change and innovation in South Australia. .

<http://bit.ly/travhope>

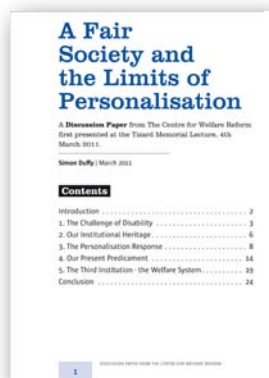


## CITIZENSHIP THEORY

Standard models of social justice do not do justice to the experiences of people with disabilities. This journal article offers a new paradigm with application to the design of welfare systems and social work.

<http://bit.ly/citizentheory>

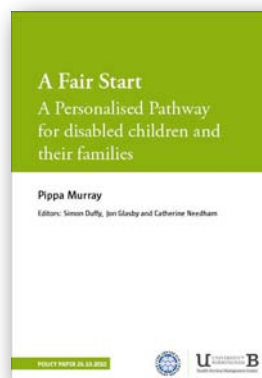
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## A FAIR SOCIETY AND THE LIMITS OF PERSONALISATION

Personalisation has been embraced by politicians as the answer to problems in the welfare system. This paper argues that personalisation is a beginning, but it has severe limits.

<http://bit.ly/perslimits>



## A FAIR START

Children with disabilities and their families can teach us how best to design many aspects of our welfare systems. In particular they show us that money - is important - but it is not everything.

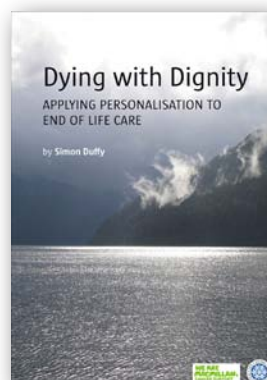
[www.bit.ly/a-fair-start](http://www.bit.ly/a-fair-start)



## MANIFESTO FOR A FAIR SOCIETY

This document sets out the case for a radical overhaul of the whole welfare system. We need constitutional reform that ensures people have rights, so everyone can contribute as an equal.

<http://bit.ly/FairSoc>



## DYING WITH DIGNITY

Too many people die in hospital when they would prefer to die at home, with family and friends. Healthcare systems need to be more flexible and to work with families to help people die in the best way possible.

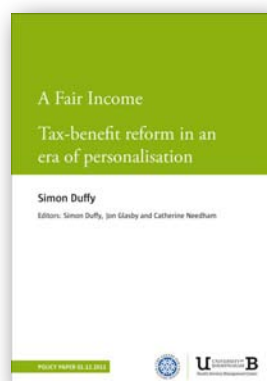
<http://bit.ly/dying-with-dignity>



## COMMUNITY SOURCING AND SOCIAL CARE

Systems for commissioning local services are damaging the framework of local communities. Instead of privatisation we need a new model for funding community support.

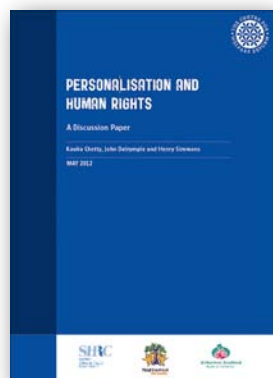
<http://bit.ly/commsourc>



## A FAIR INCOME

The benefits system creates not one - but several poverty traps. The model is out-of-date and damaging to citizens and society. It is time to build a model based on a guaranteed minimum income and fair taxes.

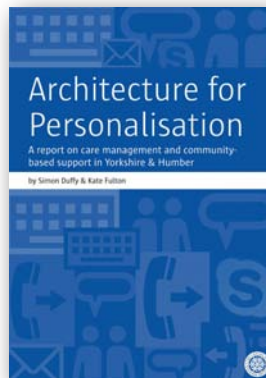
<http://bit.ly/fair-income>



## PERSONALISATION AND HUMAN RIGHTS

Whether personalisation becomes just the latest fad or genuinely supports positive change depends upon whether it is interpreted in the light of human rights. It is real entitlements, not more complex systems, that help.

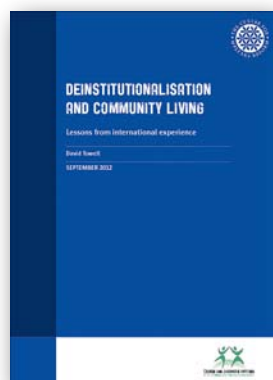
<http://bit.ly/person-humanrights>



## ARCHITECTURE FOR PERSONALISATION

Underpinning personalisation must a respect for communities, peer support and all the capacities of people themselves. It is not a new field for professionals, but an opportunity for community development.

[www.bit.ly/architect-pers](http://www.bit.ly/architect-pers)



## DEINSTITUTIONALISATION AND COMMUNITY LIVING

Deinstitutionalisation has made progress across Europe. This report describes some of its second wave challenges and the hazards faced by countries now facing urgent economic difficulties..

[www.bit.ly/health-efficiencies](http://www.bit.ly/health-efficiencies)



## LOCAL AREA COORDINATION

An Australian social innovation that is now having influence in other countries. This report defines the basic principles of Local Area Coordination and explores the challenges of implementing an innovation with integrity in a different context.

<http://bit.ly/LAC-cfwr>







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