Travelling Hopefully

BEST PRACTICE IN SELF-DIRECTED SUPPORT

by **Simon Duffy**

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About the author

SIMON DUFFY

Simon Duffy is Director of The Centre for Welfare Reform. Simon has a doctorate in philosophy and has a special interest in social justice and welfare reform. Simon played a leading role in designing self-directed support in the UK. In 2008 Simon was awarded the RSA's Prince Albert Medal for his work on personalisation and in 2011 the Social Policy Association awarded him for his contribution to social policy. Simon is an Honorary Senior Research Fellow at the University of Birmingham's Health Service Management Centre and policy advisor to the Campaign for a Fair Society. Simon lives in Sheffield with his wife Nicola and their son Jacob.

Publishing Information

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SUMMARY

South Australia has firmly committed itself to shifting power to its citizens with disabilities. It has decided to reform its systems of funding for support and make increasing use of self-directed support.

This report offers ideas and information on best practice in self-directed support to help South Australians with disabilities and their allies to make the most of this moment.

South Australians know what a better system would feel like and how it could work. Working together you can develop a world-leading approach that does not fall back into paternalism and institutional control.

In outline this report recommends:

- Embrace the idea of citizenship - it is what people want
- Give people real freedom and control over their own budgets
- Define meaningful entitlements
- Let people be creative and develop and share innovations
- Make better use of existing people and systems
- Ensure people are linked together to provide peer support
- Encourage stronger families, communities and real wealth
- Give control to the right person
- Focus on what really improves people's safety
- Welcome leadership at every level

Success will be measured not just improved citizenship, but in a new culture of equality, inclusion and participation across South Australia.

This report ends with a series of links to other publications which may be of interest to anyone interested in reforming welfare systems.

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INTRODUCTION

It was an honour to be invited to South Australia and it has been really encouraging to see how much progress the State is making towards developing a decent system of self-directed support and individual funding. Moreover the whole of Australia is now on an exciting journey to build a decent entitlement system for people with disabilities - NDIS. It is difficult to overstate how important is the work you are all doing for the global disability movement. Much thought and many prayers are directed in your direction from people across the world.

I was invited to South Australia because for many years I have been working on how to individualise money for public services and ensure that people with disabilities (and many other groups) can take rightful control of it. All the evidence suggests that this is not only what people want, but also a great way of driving up the quality and efficiency of public services.

Since 1990 I have tried, in England and Scotland, to develop different solutions to this problem. Most of the time this work was 'under the radar' and against the drift of an official policy position that has often promoted the greater centralisation of power. However, from 2003 to 2009, I led a project in England called *In Control* and, for a few short years, the idea of shifting power and control towards people with disabilities came into sharp focus and (after many battles) the English government declared its support for this new approach.

In practice real progress in England has been mixed. However I still feel that, by international standards, we did raise the bar for what individualised funding means.

In the best places in England we now see:

❖ People and families being **trusted** to take full control over their own entitlements - their own money.
❖ Real flexibility, innovation and a shift away from institutional services and towards **community** life
❖ People and families driving decisions about their own plans and supports - really taking **control** of their own lives
❖ More **efficient** systems with people getter better value from their money without a wasteful infrastructure of brokers, planners or other professionals

But the best places in England are in a minority; and in many places it feels like progress has slowed or even gone into reverse. Partly this is because, since 2010, the UK government has imposed severe and unprecedented cuts on services for people with disabilities, including a cut of 30% on local government funding.

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But the problems in England are not only financial. In fact, some of these problems, although I am embarrassed to admit it, are rooted in my own mistakes:

❖ Many places rely on unduly **complex assessment** tools which have eroded good practice, trust and reasonable professional judgement.

❖ **Support planning and person-centred planning** has become a whole new industry with consultants developing training, templates and processes that have no value and which actually disempower people and families.

❖ We failed to persuade the government to put in place the right **legal framework** to underpin self-directed support and our law remains confused and unhelpful.

❖ We still have a system that unfairly and viciously **means-tests** people with disabilities - support is reduced if you have any income or assets that take you out of poverty, but we also means-test love and determination - excluding families that support each other.

Part of the English failure is connected to the difficulty that any government has in really understanding how innovations develop and mature. Seizing on early models of innovation and then imposing them on local government through targets and ill-informed advice has left many English local authorities with immature systems: too complex, too expensive or too controlling.

Innovations develop according to the innovation curve and early models (which often tend to be rather too complex) need to be replaced over time with simpler systems that are easier to use (Figure 1). However governments, even with good intentions, can be in too much of a hurry to let innovations mature. A government in a hurry is never a pretty sight and the results of its enthusiasm can be as unattractive as its omissions and failures.
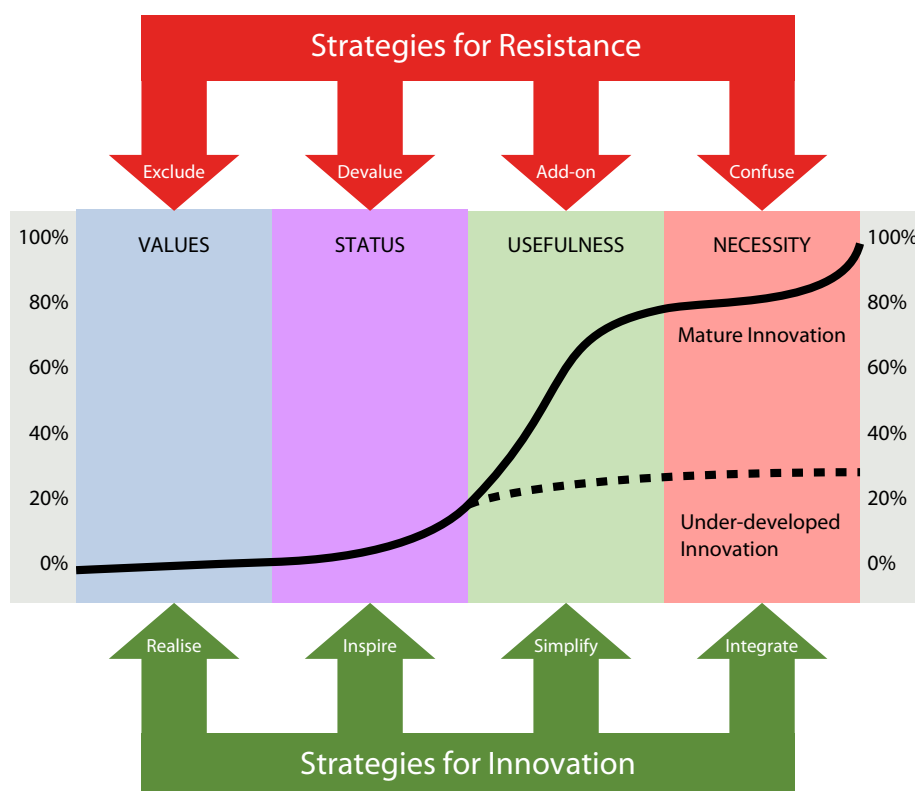
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Figure 1 - The development or corruption of innovations

It is important to distinguish fundamental principles from the processes that are used to implement those principles. The processes are just means to an end and we need to learn how to help them evolve. One of the painfully learned lessons I wanted to share with colleagues and friends in South Australia is that the process of innovation is not about fixating on some plausible sounding solution and then mindlessly implementing it. Instead it is vital to try and really understand the problem you are trying to solve and figuring out - together and over time - how to develop the best solutions.

The great designer Steve Jobs put the matter this way:

> *Design is a funny word. Some people think design means how it looks. But of course, if you dig deeper, it's really how it works. The design of the Mac wasn't what it looked like, although that was part of it. Primarily, it was how it worked. To design something really well, you have to get it. You have to really get what it's all about. It takes a passionate commitment to really thoroughly understand something, chew it up, not just quickly swallow it. Most people don't take the time to do that.*

So the bad news is that there is no simple solution that you can just implement. The good news is that developing innovations is both more fun, inclusive and permissive than that. My hope is that South Australia will see themselves as embarking on a journey with **hope** - confident that they can find progressively better solutions for building a fairer and more inclusive society within which people with disabilities can take up their proper role as full and active citizens.

Today it is Australia who holds the baton for international progress in self-directed support. No other international government is making such a clear commitment to turn the human rights of people with disabilities into a system of real and sustainable entitlements. People with disabilities around the world are hoping that you can demonstrate the feasibility of such a system.

However the very excitement generated by the NDIS is also a risk for South Australia. By drawing attention and energy to a Federal scheme, which threatens to erase most of the current systems and leadership within South Australia, you may lose the opportunity to make the most of your own determination to drive forward the cause of citizenship locally. You will therefore also lose the opportunity to influence the design of the Federal system by failing to set out what a more flexible and empowering approach looks like.

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WHERE ARE WE HEADING?

We don't innovate for the sake of innovation - we innovate to make things better - to solve the real problems that we face. So the number one challenge is to really understand what it is we are trying to achieve.

However we also have to acknowledge that, for those of us who care about the lives of people with disabilities, our inheritance is very poor. Most of the nineteenth and twentieth centuries were a dreadful attack on the rights, status and even lives of people with disabilities. Programmes of institution building, sterilisation, eugenics and - in Germany - mass murder have been the standard government-led response to the lives of people with disabilities. Even after the 1970s when institutions started to reduce in size the progress towards recognition of full human rights has been slow.

Institutionalisation was a common pattern across the 'developed' world and, as institutions were closed, the typical response has been to develop mini-institutions, or community care services, which often maintain an institutional response (Figure 2):

❖ People lack real rights to their own home
❖ Families remain unsupported
❖ People cannot control the support they receive
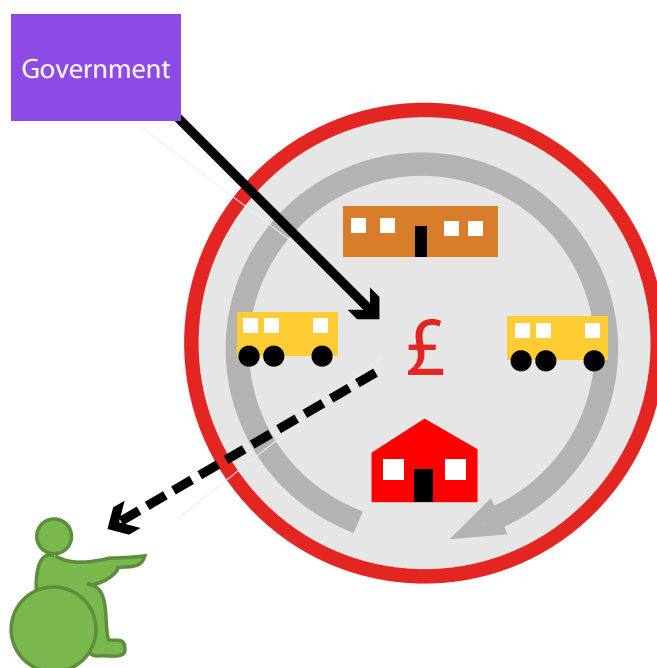❖ Services are often segregated and cut-off from community life

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Figure 2 - The reality of community care

What this means is that we cannot be confident that we really understand what it is we need to do or how we need to do it. We are not standing on the shoulders of giants. We do not have a positive track-record upon which we can confidently build. We are more like people who have just stopped digging a deep hole - we are in the hole and we do not necessarily have a good perspective on what it will take to get out.
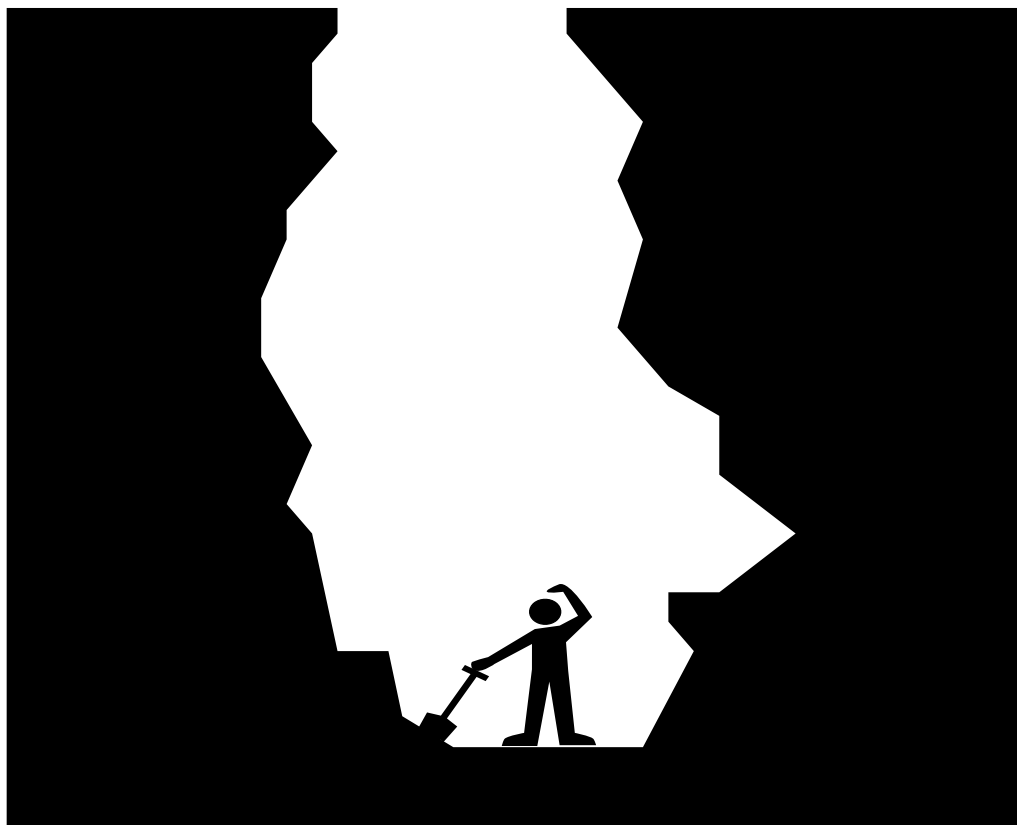
Figure 3 - Our limited perspective

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All we can be sure of is that this is a good example of the challenge set by Einstein:

> *We can't solve problems by using the same kind of thinking we used when we created them.*

However we do know some things.

There has been some progress and there has been some new thinking. For instance we can identify many social innovations that seem to have a much more positive role in people's lives:

❖ **Independent or supported living** - people living in their own homes, with people they want to live with and getting support from people they choose.

❖ **Open employment** - people getting real jobs, making friends being part of their community and taking any support they need into the job.

❖ **Peer support** - people with disabilities and families supporting each other, organising, innovating and advocating.

❖ **Self-directed support** - people getting control of their own money, as a genuine entitlement and shaping any support they need around their lives.

Importantly, we can also learn something by looking at the source of all these innovations. None of these ideas were developed by government, by bureaucracies or by professionals on their own. They were all developed and led by people with disabilities, families and allies who worked with people with disabilities.

Moreover, when you examine the ideas that inspired these innovations they are deeply interconnected and rooted in some common insights (See Figure 4). There are important differences between these perspectives, but these differences are minor compared to their central message.

Just to take a few examples:

❖ **Social model of disability** - it is important not to treat a disability as identical with whatever impairment leads to disability. For it is not just the impairment, but the way in which society treats the impairment which creates many of the risks and challenges of disability.

❖ **Social role valorisation** - people are at greater risk if the roles that they may then be forced to take up are roles that are not valued, which do not treat the person as an equal, and which can encourage disrespect and disregard for human dignity.

❖ **Human and disability rights** - we each have innate rights which should protect us from harm and enable us to live lives of meaning and value. But if society is not organised to make these rights real then people will be disadvantaged and their place in society will be undermined.
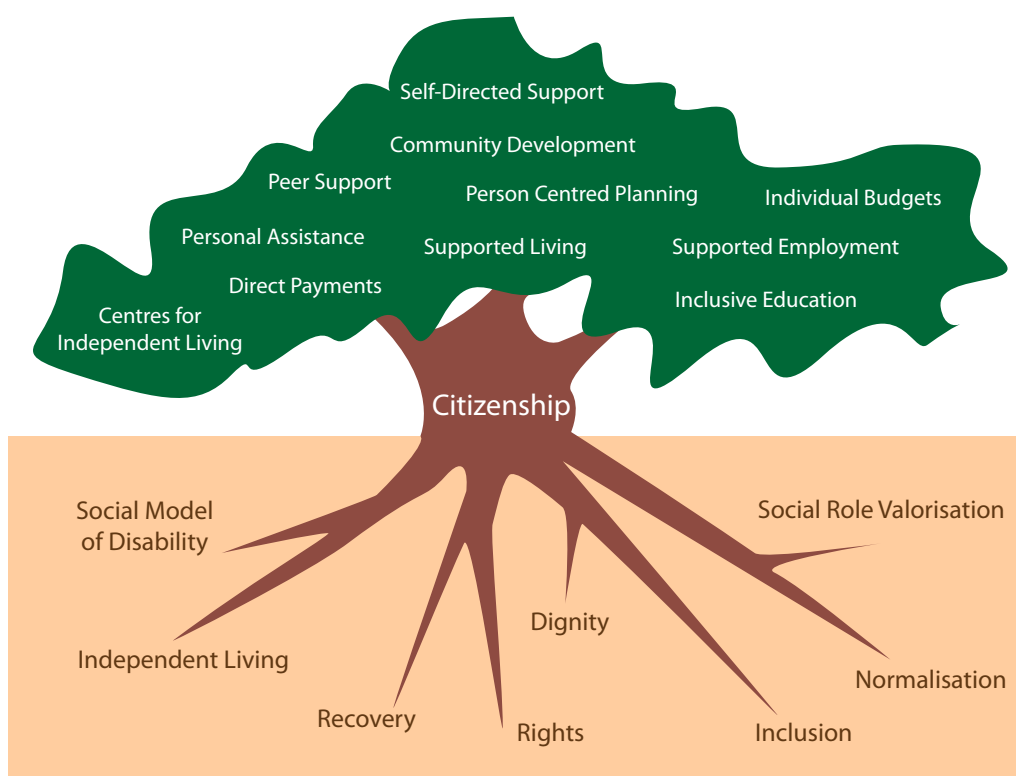
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Figure 4 - Social Innovations and their Inspirations

Personally I have always found the idea of **citizenship** useful as a more direct way of describing what a positive and socially valued life means. Importantly citizenship is a category that is relevant to everyone - not a special concept for special people. Learning how to build a society that treats everyone as a citizen seems like a really useful way of describing the purpose of our work.
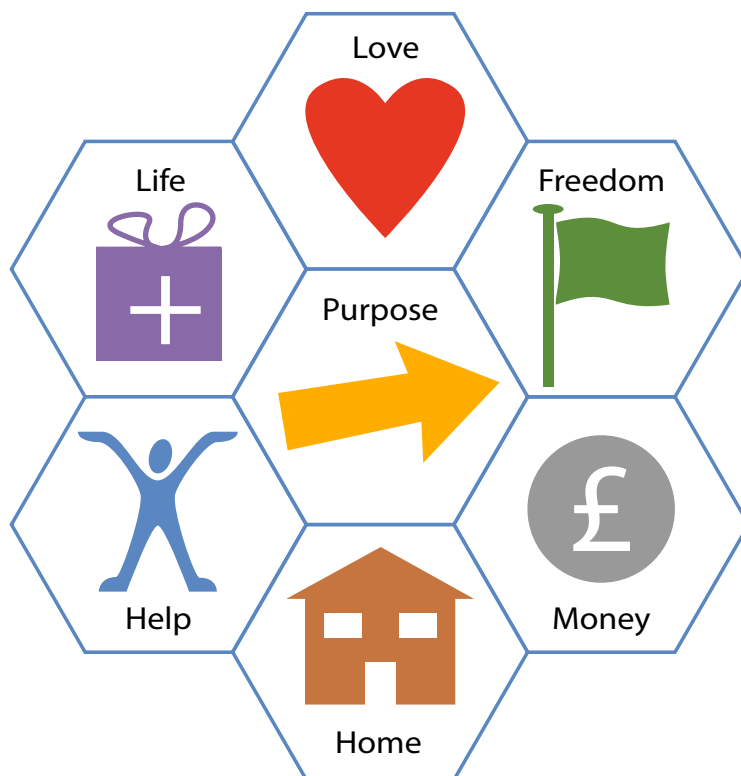
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Figure 5 - The keys to citizenship

If we take citizenship seriously we discover that a citizen has a number of different properties, all of which are open to people with disabilities - but many of which rely on us organising ourselves differently to make greater citizenship actually possible:

1. **Purpose** - citizens have lives of their own, reflecting their own unique character and their own particular gifts. When we are stuck in a rut, living an unfulfilling life, then our citizenship is at risk.
2. **Freedom** - citizens are free and independent; they can make their own choices and take their own risks. Others do not take us seriously if we seem to be living under the direction of other people or organisations.
3. **Money** - citizens need enough money (although no more than enough) in order to purse their goals and direct their own lives. Poverty and excessive wealth both cut us out of a life of citizenship.
4. **Home** - citizens have homes of their own, places where they belong. A home is not just shelter, it is a place where we can have privacy and which establishes us as a real member of local community.
5. **Help** - citizens need other people and can get the help they need. It is not needing help that threatens citizenship - it is only help that takes control over you that threatens our citizenship. Our need for help is the glue that holds a community together.

6. **Life** - citizens get involved, contribute and make a difference. Communities are built out of the contributions of free citizens and those contributions also generate a powerful sense of respect and value for each other.

7. **Love** - citizens make friends, fall in love, have families and create all the relationships that we value as the very stuff of life. Love is powerful enough to survive even when citizenship is not recognised, but a life of citizenship is a life which strengthens our capacity to love.

Taking citizenship seriously for people with even the most significant disabilities is quite possible. I wrote a handbook for practical citizenship ten years ago - *Keys to Citizenship*. It turns out, if you think hard and innovate, that you can make citizenship real for everyone. Some people need greater support, or a different approach in order to realise each key - but **citizenship is possible for everyone**. In fact many people with disabilities are better citizens than their neighbours who may be leading disconnected and empty lives.

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TEN MESSAGES

In everything that follows I will assume this idea - **the goal is citizenship**. I will try to share, as best as I can, what has been learned about making citizenship real - particularly with regard to systems of self-directed support. However - I don't think you need me to tell you what is really important. Mostly, we will know what's important if we do two things:

- Really think about our own **personal experiences** - and then follow the Golden Rule and treat others as you would be treated - or as the Bible puts it "Love your neighbour as yourself" [Leviticus 19:18]
- Really **listen** to what people with disabilities in South Australia tell you about what they want, what works and what isn't working

In fact I was lucky enough to spend some time with South Australians with disabilities and their families. They were very clear about their central messages. So I have tried to pull together and organise the messages that I heard directly from people.

1. IT'S MY LIFE

Remember, it's my life. I'm happy to get advice and would welcome information, contacts and recommendations; but I don't need you to plan for me or make me work to your plan.

I want, power and control

I don't need anybody to speak on my behalf

2. IT'S MY MONEY

I am entitled to a reasonable budget to help me live my life. I am not looking for excessive funding; but if I am entitled to that funding then that money is mine and I know best how to use it.

Money should suit our lives - not the system

We should get enough help so we can join in - be a citizen

Sometimes just a little help would make a massive difference

3. IT'S ABOUT PEOPLE

It's not about systems - it's about people. We don't want more formality, computer systems and bureaucracy. We want human relationships based on greater trust and learning together.

It's about getting the right kind of personal relationship

4. IT'S ABOUT COMMUNITY

We don't need a special world of segregated services. We need access to the wider world, its buildings, its homes, its opportunities and its services.

We have the right to join with arts, culture, community

We don't need an increase in specialist disability services

We need universal building standards for the 21st century

We want to be in community, in work, be empowered and be included

5. I'VE GOT SOMETHING TO OFFER

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We don't expect you to have the solution for every problem; we know we need to keep working at and improving things. In fact we are the real source of creativity and innovation.

We are a creative community. Don't limit us to what we've already seen - let us dream - and then come back to reality

We have the power - if something is not available then we can build what we need

6. LET'S INCLUDE EVERYONE

I may not be able to manage my money or I may not even want to - but I still want my money to be flexible, protected and managed by someone I can trust (and that could be anyone from family to professionals).

Lets build networks

Don't create dangerous eligibility thresholds that make me go into crisis to get help

7. LET'S KEEP IT SIMPLE

I don't want or need a complicated system. I know best how to spend my money and I need the right to spend it flexibly so that I can make my life as good as possible. You shouldn't: claw it back, demand receipts, demand accounts.

We want a system that is light, friendly and happy

8. LET'S INNOVATE

We want to be involved in designing and running the new system. People and families have the greatest incentive to get things right and make sure our money is used in the best way possible.

We can help you design and run the new system

9. LET'S COMMUNICATE

We all need to communicate better. Lets spend more time talking to each other, learning from one another and sharing our ideas and experiences.

Give us the chance to get our voice out there

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10. LET US HELP YOU

Together we've already made some progress, people with disabilities and families have created good solutions and peer networks. Some services are good. New initiatives like Self-Managed Funding (SMF) are important first steps.

Don't reinvent the wheel - let's make it easy to connect to each other

People with disabilities must be in control of the design of services

TEN INNOVATIONS

This is not a report about South Australia, but it is certainly informed by listening to people in South Australia and thinking with colleagues about what is next for South Australia. This report offers 10 helpful ideas - or **innovations** - that I think might be useful to you.

I have tried to write down these ideas in ways that are clear and easy to pick up and use and play with. These are not tight prescriptions, recipes or magic formulas. If you use these ideas you will almost certainly improve on them and take them further.

- Make these ideas your own
- Use your own words
- Challenge, unpick and amend them

South Australia does not need sacred cows. It does not need the next 'brilliant idea' from elsewhere which it must then mindlessly implement.

South Australia is a great place, full of great people. You can build your own solutions. These are just tools and things to help you get going.

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1. Citizenship

At the centre of the shift towards individual funding is not just the cutting up of the money into an individual amount, it is also treating that money as an entitlement - as something that is owed to the person with a disability because of their basic rights as a human being.

This is a fundamentally different way of thinking about money and the place it plays in disability services. If we think people are not entitled to their budget then why do they receive the budget? Is it some kind of gift? No, that cannot make sense.

This has been the long-standing challenge, to turn money that is simply treated as money that belongs to services into money that belongs to the person - by right. Sometimes people find it useful to think about it like this. Currently we often organise what we do and how we think according to the *Professional Gift Model*. Money is given by tax payers to government; government gives that money to services and services give their support (or money) to people. It seems to be just a chain of charity and patronage. People with disabilities must just await society's patronage and accept whatever comes off the conveyer belt at the end.

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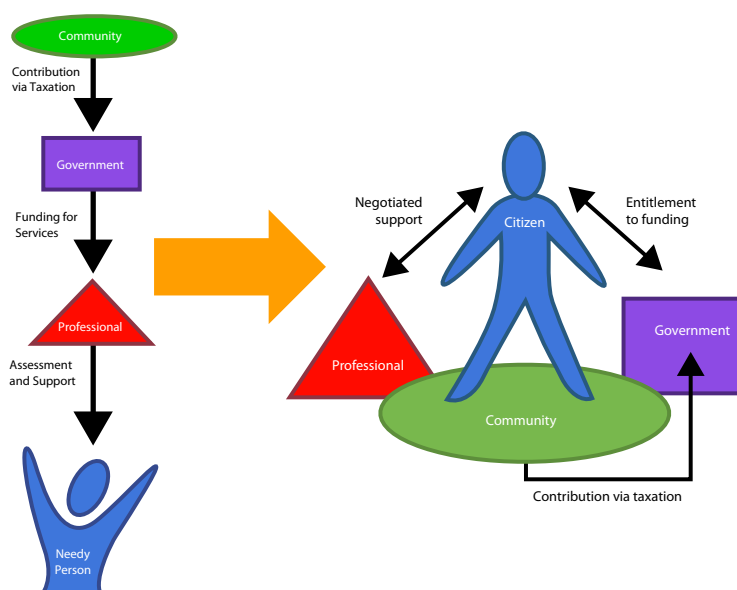
Figure 6 - From the professional gift model to the citizenship model

But this is wrong way of thinking about disability services. People get money and support because they are entitled to it. They have human rights and, ideally, the law should be organised to respect and make those rights real. That is what an entitlement is - the way in which a right is made real. This entitlement is not just a lump of money; but its also the right to control and direct how that money is used or the right to have that money controlled by someone who can best look out for your interests.

What is required is a shift from the *Professional Gift Model* to the *Citizenship Model* - a different way of organising things that puts you, as a citizen, with rights, at the centre of your own life and your own community. Services should not be there to control you or just ration out resources. They are partners in helping you get the life your want.

All this is easy to say; it is not so easy to do.

One of the most powerful fallacies, and one that will kill entitlements, and then go on to kill innovation, flexibility and real control is the 'public money fallacy'. Most systems of individualised funding quickly come under pressure from people who do not want to give up control to people with disabilities and their families or who are worried that people's bad decisions might reflect badly on them.

The **public money fallacy** can quickly lead to a range of measures, none of which look too bad at first, but which have the end result of making your systems more expensive, less effective and less respectful of people's basic human rights.

These controls include:

- ❖ Giving people vouchers or smart cards instead of money
- ❖ Making people open new bank accounts
- ❖ Making people keep receipts and systems of accounts
- ❖ Clawing back money at the end of the financial year
- ❖ Creating rules about what people can and cannot spend their money on
- ❖ Making people work to a plan or a menu
- ❖ Using a financial agency or computer system to control payments

It's easy to understand why a system that is used to being in control would only give people more control if they are prepared to accept some or all of these measures. It can seem like a natural and appropriate compromise.

But there is a fundamental fallacy at work here. The system is forgetting the fundamental fact that all systems of individualised funding have demonstrated:

People know better than the system how to use their own money. People have the strongest incentive, the greatest stake in the outcome and the greatest knowledge about what works and doesn't work.

All these rules, menus, vouchers and controls only have the impact of limiting people's creativity and the effectiveness of their decision-making. There is no rational justification for tying people up in red tape - it is simply wasteful, inefficient and disempowering.

When someone can't, for whatever reason, be entrusted with control of their own budget - then someone else must take control. But this new person doesn't benefit from red tape either. The question to ask is: **if we've given control to the person we think is most likely to make the best decisions why would we limit their ability to make the best decisions?**

Not only does the public money fallacy create inefficiency it is also illogical. Money cannot always be public money. Money moves. Governments only have money because taxpayers pay their taxes - acting according to their obligation to the law.

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Government spends that money:

❖ Buying things - giving the money to the seller - whose money it rightfully becomes

❖ Employing staff - giving money to employees - whose money it rightfully becomes

❖ Fulfilling entitlements - giving money to citizens - whose money it rightfully becomes

Government gets money and gives money (Figure 7). It cannot keep hold of that money without interfering with the basic freedoms of citizens - undermining our rights to privacy, independence and family life.
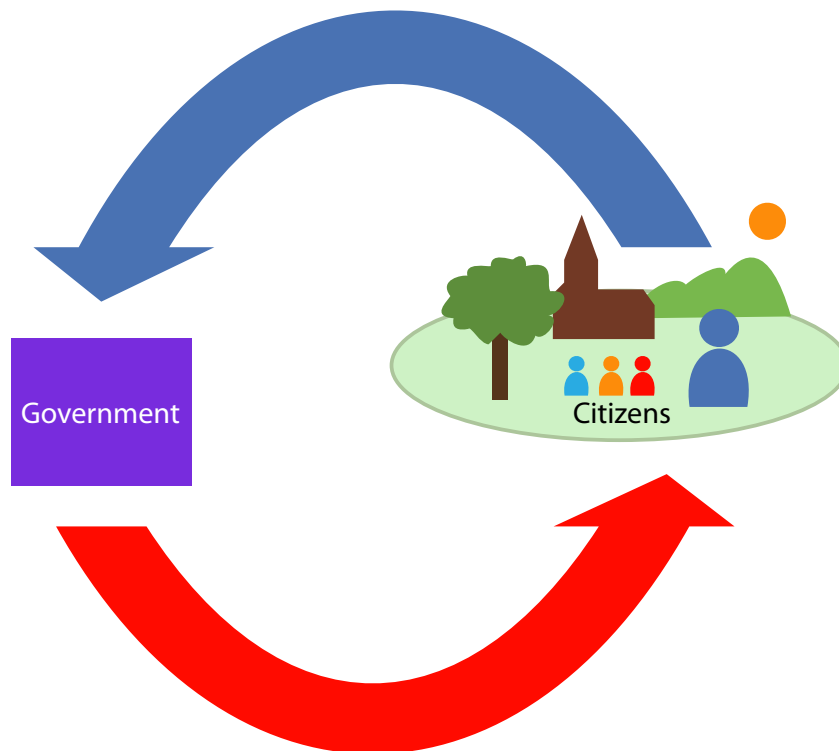
**Figure 7** - The public money fallacy

Holding on to this simple insight is a powerful guarantee that you are going down the right road.

2. Freedom

Individualising money is technically challenging, but the real challenge is to give people control over that money, and - more importantly - to enable people to have real and meaningful control over their own lives.

Sadly, human services often only offer their support at the price of personal freedom. In England we tried to change this pattern of patronising control by the use of what we called **self-directed support.**

The idea of self-directed support begins by simply clarifying that the citizen is the author of their own life and that it is primarily their decisions, plans, priorities and needs which must drive the support that they themselves organise. It is possible to picture this as a seven step process as in Figure 8.

1. Need   2. Explore   3. Plan   4. Decide   5. Organise   6. Live   7. Reflect
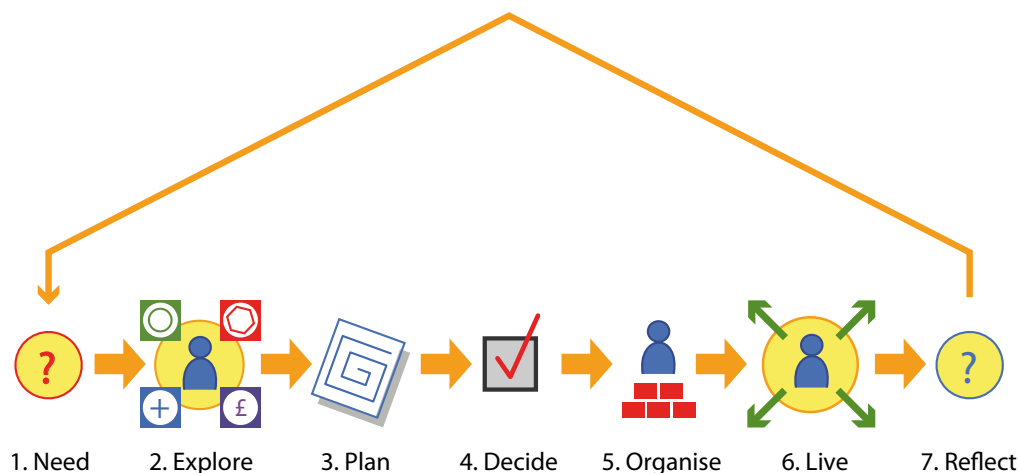
Figure 8 - Self-directed support

This seven step process of self-directed support is artificial and in real life things are more complex. But this model helps us clarify the main steps a citizen must take and, in turn, this helps us to see the very different measures the system needs to take to enable self-directed support:

1. **Need help** - we seek help when we've identified some problem that demands our attention and which we cannot resolve on our own. Smart systems recognise that personal motivation and direction come before assistance.
2. **Identify assets** - how we solve problems is by using our real wealth - the full range of assets in our lives: money, people, talents and community. Smart systems clarify any entitlements we may have as early as possible to support innovative thinking.

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3. **Make a plan** - a plan is based on our judgement about the best way in which to use our assets to solve our problem; we learn best how to plan by living our lives and making changes when we need to. Smart systems do not try and manage or control people through their own plans, nor do they seek to make plans formal or contractual.

4. **Decide to act** - once we know what we want to do we can commit, we can decide to do it. If our actions involve others then we may also need their agreement. Smart systems minimise their interference with people's natural autonomy.

5. **Organise help** - getting the help we need may take organisation, recruitment, selection and many other practical steps. Smart systems don't restrict people to organising help in just one way and discourage over-dependence on any one system.

6. **Live life** - we get help so we can live our lives, with freedom, adapting to new problems and new opportunities. Smart systems let people live, learn and change how they are supported.

7. **Learn** - over time our understanding of our needs, our goals and of our resources evolves and we become more effective at solving our problems. Smart systems both enable learning, but also find ways to share that learning with others.

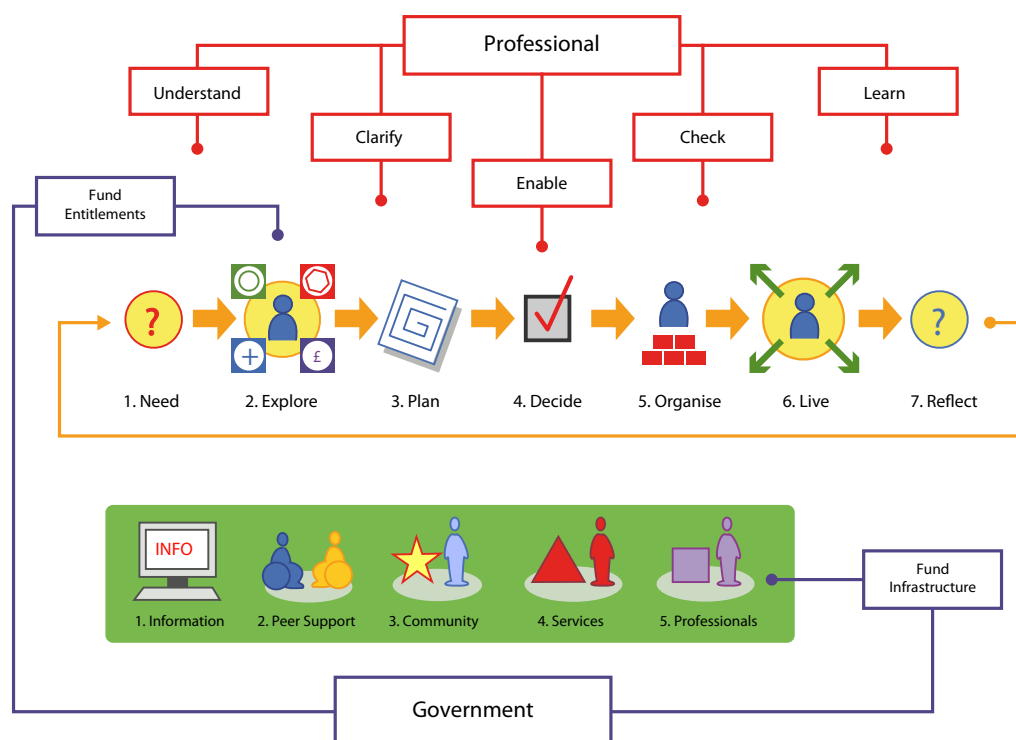Many of the innovations described below are different efforts to find the best way of making this freedom real.

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Figure 9 - Transformed system

But making this real - turning the human right to freedom into a lived experience - demands that lots of other things need to change too in order to achieve self-directed support. It requires nothing less than the total transformation of the service system, to protect and support the central authority of the citizen:

1. Making **self-directed support** central to the new system
2. Enabling **community solutions** to evolve in order to support self-directed support
3. Shifting **professional involvement** from management and control to empowerment and support
4. Shifting **commissioning** from procurement of services to investment in citizens and community

Figure 9 provides a diagram which tries to capture many of the key elements necessary in order to bring about this transformation.

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3. Responsibility

Strangely, part of the reason I think people struggle to make rights real and create a system of decent entitlements is that they think people prefer it if they are not responsible for themselves. They think that citizens want to be treated like children at Christmas, enjoying endless presents, not responsible for their own decisions or making the budget balance.

Professionals worry about capped entitlements or rationing - as if these were nasty things to do. But I have never met a citizen who does not realise **there's only so much money**.

Rationing and capping are not the opposite of entitlements. Rationing and capping is essential to a decent system of entitlements.

The philosopher Simone Weil makes this essential point like this:

The notion of obligation comes before that of rights, which is subordinate and relative to the former. A right is not effectual by itself, but only in relation to the obligation to which it corresponds, the effective exercise of a right springing not from the individual who possesses it, but from other men who consider themselves as being under a certain obligation to him. Recognition of an obligation makes it effectual. An obligation which goes unrecognised by anybody loses none of the full force of its existence. A right which goes unrecognised by anybody is not worth very much....

If this seems too complicated think about it like this:

1. I cannot have a right unless someone else has a duty.
2. But if someone else has a duty it must be realistic for them to fulfil it - otherwise its an empty duty.
3. When it comes to money this means there can be no uncapped budgets because there are no money trees at the end of the garden.
4. A right that demands someone else does something for you must be a limited right - a rationed right.

If you believe people with disabilities have human rights and part of your job is to make sure those rights are recognised then getting real about money is essential.

AGREE A FAIR BUDGET

If we are trying to develop a system of individualised funding then these philosophical considerations get turned into a very practical question - what's a fair budget?

I have written and thought about this problem a lot and I am still not sure I know exactly the right solution. I think there is a grave danger of over-complicating any solution by

trying to solve too many different problems. So here I will focus on summarising my own view of the best practical approach - and one that is most useful to South Australia:

A budget must be:

❖ **Reasonable** - it must not break the bank, it must be realistic and sustainable over time
❖ **Sufficient** - it must be enough to enable the person to help the person achieve citizenship

I used to think that complex assessment tools and Resource Allocation Systems might help calculate this budget, but I now think these are distractions which actually get in the way of making a sensible judgements about the right budget for each individual.

I now think that a better approach is one that balances sensible human judgement with a simple system to ensure that budgets balance and funding is controlled. Figure 10 gives an overview of all the things a decent system must be able to consider over time. But this does not require too much complexity for professionals at the frontline of agreeing budgets with people.
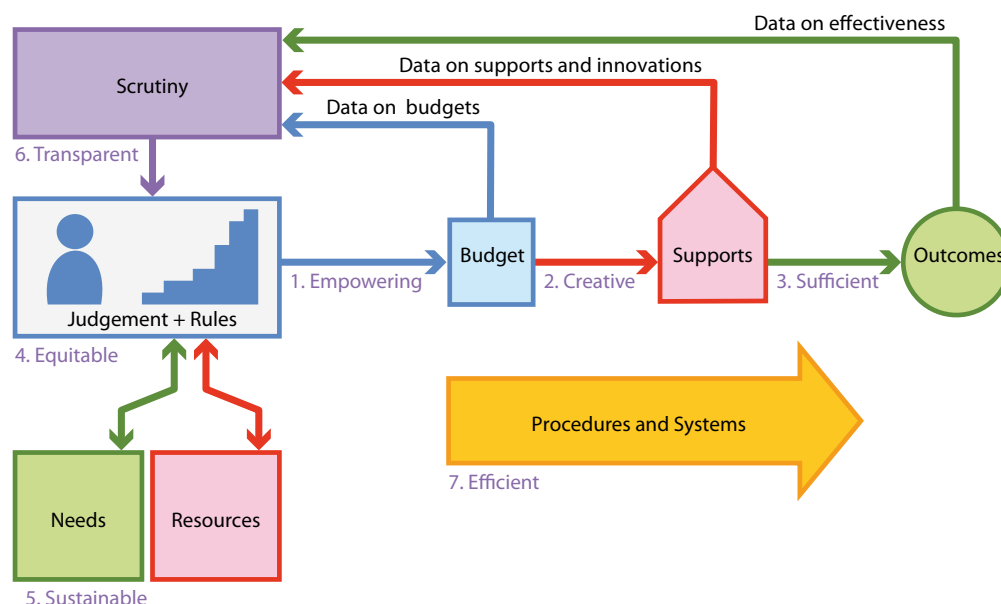

Figure 10 - The overall system for setting budgets

At the front line professionals need to keep in mind:

1. **Will the budget be sufficient?** - Does it seem reasonable in the light of the person's needs?
2. **Is the budget affordable?** - Does it seem reasonable in the light of available funding?

Making this judgement and coming to sensible agreements on budgets is not a perfect science. It is informed by practical experience and budgetary information and, I think, it is aided by some simple tools - which I will describe below.

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USE LEVELS TO SET MOST BUDGETS

Funding levels are useful because they offer a shared framework for setting budgets. This framework should:

- ❖ **Reflect past experience** - new levels should not be radically different to old levels
- ❖ **Help manage budgets** - its easy to track the consequences of changing patterns
- ❖ **Fit different groups or localities** - funding levels may vary from place to place
- ❖ **Allow for review and change** - simpler systems are easier to review and adapt

In my experience pattern of levels, for most people, seem to follow an exponential curve, with more people on low level packages and then fewer people needing higher levels of funding. At the extreme there are very small number of people and no explicit level is going to be helpful.

Figure 11 provides a simple starting framework. Again, there is no great science to this - it is probably best just to start with **current patterns of allocations** and use this as the framework. This enables you to maintain a reasonable level of 'equity over time' and avoiding a sudden and worrying change in how allocations are made.
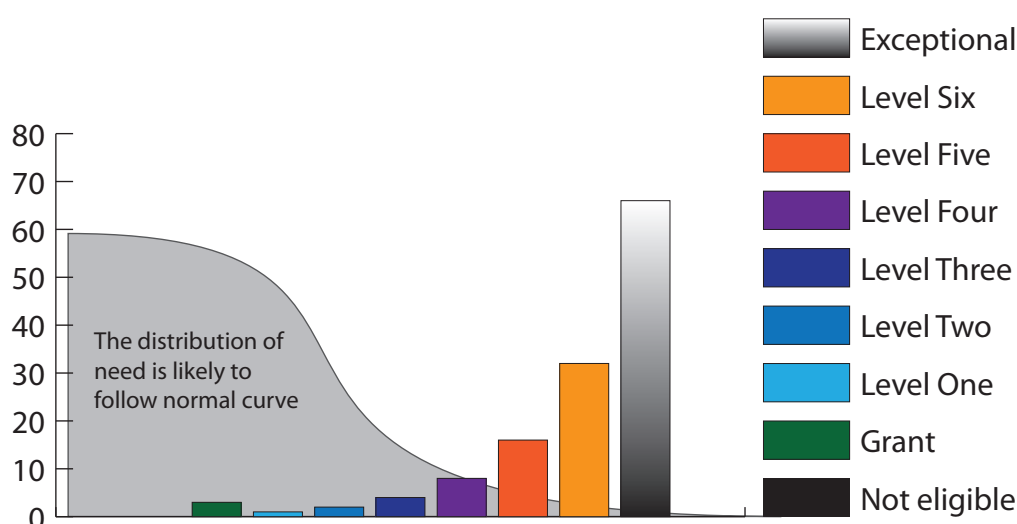
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Figure 11 - Funding levels

There is a fully worked out version of this model for services for children with disabilities on The Centre for Welfare Reform's website and we would be keen to publish anything you develop that seems to work well.

It is especially important to notice that, as needs grow in complexity, the use of pre-defined levels will become impossible. **There is no place for any formula or algorithm for people whose needs demand careful analysis and intelligent service design**. There is a danger that any such approach will create an utterly arbitrary cut-off point which will then put at risk the health or dignity of the person.

SET TIME LIMITS FOR BUDGETS

One of the mistakes we made in England was not to approach the timing of budgets in the right way. We often assume that once an assessment has been made then we are setting an annual budget that will be repeated year after year, but which also can be reviewed and amended at any time. I now think this is bad for people and for the system.

I would suggest a smarter approach would be to make all budgets time-limited and to agree a renewal date for each budget agreed. This would enable us to distinguish people in very different circumstances:

❖ People whose **needs are unlikely to change** should be entitled to a great deal of certainty about their funding - at least 10 years, perhaps even longer. The constant threat of annual assessments is wasteful and creates unnecessary anxiety.

❖ Many people can meet their needs by the use of a **one-off grant** that enables people to change their home, their lifestyle, buy equipment. Grants are highly efficient to deliver and present much lower long-term risks for the system.

❖ Some people have needs where **change can be expected** over time, slowly or quickly. It is much better to plan ahead with people and work out when is the best time to renew the budget.

Longer review dates do not imply that social workers and others wouldn't be around to support and learn from the person. But they would ensure that every opportunity communication did not raise questions about the long-term security of the funding. People know that things change, but people also need a level of security in order to act with confidence. This may also give people more freedom to innovate and try out new ideas.

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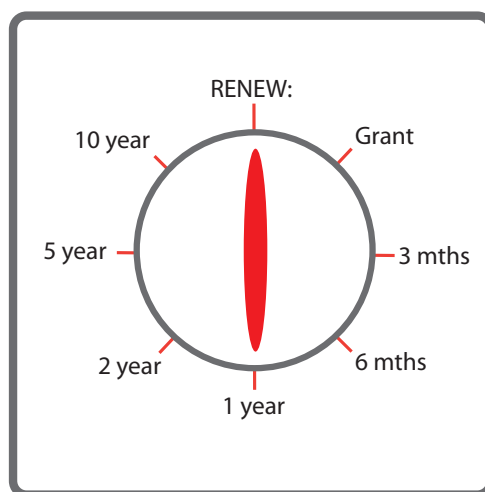
Figure 12 - Setting renewal dates

Please note that the times set out in Figure 12 have **no scientific basis**. You would need to develop your own local approach based on practical experience of how needs change.

It is also very important that people do not feel that the existence of a renewal date stops them from coming to you when their needs increase for a new assessment. People should **always have the right for an assessment of their needs**.

RETHINK THE ASSESSMENT PROCESS

Australia is not unusual in adopting processes of assessment which pretend that it is possible to do all the hard work of finding solutions right at the beginning of the meeting between citizen and professional.

The system wants to process people as if they were on a production line:

❖ Complex assessment tools
❖ Resource Allocation Systems
❖ Self-Assessment Questionnaires
❖ Many other tools that promise much, but never deliver

But of course an experienced social worker, or other professional is already equipped with something far more powerful than any such tool - **their intelligence, experience and judgement**. These human skills are developed, not by learning how to fill in questionnaires, but by working with other human beings to find sensible solutions and to make good use of existing resources.

Sometimes, in our eagerness to move away from the flaws of the old system, we can throw the baby out with the bath water - we can even blame the baby itself for the flaws in a system it did not create. This is what has happened to many social workers in England; personalisation was treated only as a tool for empowering citizens - not as a tool for **empowering professionals**. We need to do both.

One thing that might help is to abandon the idea that assessments are events at the beginning of our conversation with the citizen. Instead we could see the assessment as an holistic process of on-going learning which includes many elements:

1. **Finding out** information about the person
2. **Clarifying** entitlements and capacities
3. **Enabling** the person to plan and shape their own support
4. **Checking** arrangements are safe and sensible
5. **Learning** from the person what is working and what needs to change

This holistic approach to assessment is focused on two linked outcomes:

❖ Ensuring people are living good lives as full citizens
❖ Ensuring professionals are learning more about what this takes

Paradoxically, treating the **professional as a learner**, not as an expert, might be the key to rethinking assessments and turning them from a professional intervention in the life of citizens with disabilities and turning them into a shared opportunity for learning and development.
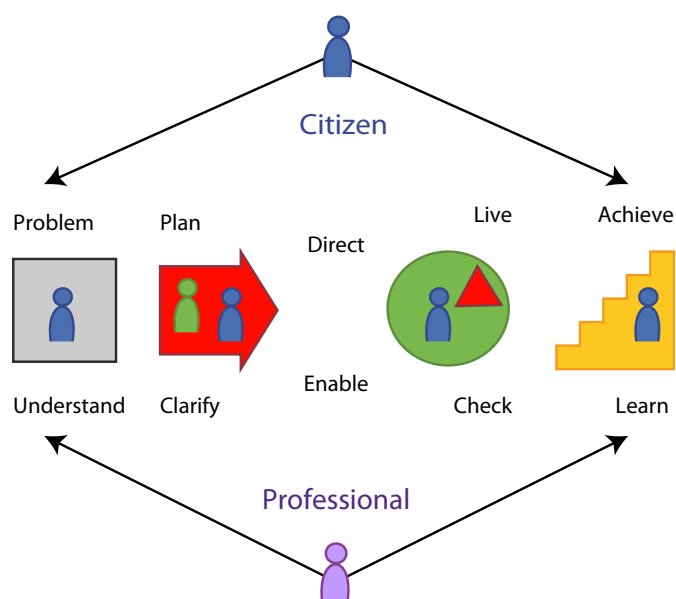
Figure 13 - Assessments are partnerships for learning

DEFINE CLEAR RIGHTS AND PROCESSES

The process by which the state allocates resources must not be imposed on people. Instead, the state must use an approach that is respectful and negotiable.

Standardised assessment tools guarantee bad decisions; but even the best professional will also make poor judgements from time to time. This should be seen not as a failure, but as a chance to learn. Good systems ensure that people have all the means necessary to listen to people and allow for challenge and renegotiation.

In the better places in England, professionals are very clear that when they clarify a budget, before someone gets the chance to plan, this budget is only an **indicative budget** - which is just another way of saying its the professional's **first guess**.

Citizens should get the chance to work to this budget, but also to come back and say:

❖ The budget was too high
❖ The budget was too low

Mostly, in England, people work to the first budget suggested. But anecdotally many local authorities reported that, in the early days, of the small number who didn't agree to that budget **more people reported the budget was too high**.

Today in England, while the government is imposing a 33% cut in support funding for people with disabilities, this is no longer the case and 'first guess budgets' produced by a RAS are now being taken far too seriously and are being twisted to enforce budget cuts. This is one of the dangers of **pseudo-scientific assessment tools**, they create an illusion of rationality and then can used to justify the unjustifiable. No assessment tool that I am aware of has ever been empirically tested and demonstrated to be accurate at determining budgets that are sufficient for citizenship.

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What is essential is that when setting your budget there are clear rules that clarify people's rights, for example:

❖ If you do not **agree** to the proposed budget, then we will work with you to explore what budget is necessary

❖ If you **challenge** the proposed budget you will be able to express your concerns to your social worker and lodge a complaint

❖ You will be able to take your own preferred **representative** with you to any meetings necessary to discuss your budget

What is critical is that a sensible balance is achieved. Budgets must be reasonable and sufficient. If someone thinks a budget is not enough to enable them to achieve active citizenship then there must be a sensible process by which concerns can be raised and agreement reached.

BE PRAGMATIC

Part of the reason why systems for allocating resources fail (this includes the system of having 'no system') is that they try and bite off more than they can chew. The number one challenge is to make fair and affordable allocations people can use to get on with their lives. Of course, this raises lots of other questions that it would be nice to have neat answers to:

❖ What factors should we take into account?

❖ What is equitable?

❖ What would be the ideal level of funding available?

But if we are not careful these extra problems can overwhelm us. The reality is that individuals and systems currently control certain levels of resources and the first challenge is to make good use of existing resources. Partly this is done by shifting resources to citizens - as they have the best track-record in using resources well. But if you are thinking about the whole system you also need to think about how to divide the total level of resources between all the different groups, services or local areas.

Instead of trying to create one perfect system that works the same for everyone (but which experience tells us will fail) it may be better to break up funding into medium-sized chunks and then allow people to make sensible human judgements.

This can be done in a pragmatic way, based on where it is natural to divide budgetary responsibility:

❖ Local teams of social workers

❖ Service providers

❖ Groups of people

❖ Where there are good points of leadership

❖ Local communities

❖ Peer groups or user-led organisations

The reality is that there is no answer to the question of how best to divide up the overall budget. All we do know is that if you do not divide up responsibility for the budget you risk leaving no one responsible in the system for the budget. This guarantees bad budget management. **There must be someone responsible, otherwise budgets begin to badly managed or not managed at all**. Very quickly this causes problems and undermine the new system.

4. Creativity

There is a seeming paradox at the heart of most efforts to implement systems of individualised funding internationally:

- When people have control they make better decisions and get better outcomes - in all studies
- Everyone seems to believe that individualised funding will only work if we help people to make the right decisions.

Of course this is not a genuine paradox. It disappears once we realise that if people do make better decisions than the old system used to make then all the systems of planning, brokerage or whatever else is proposed, were not central to success.

The most likely reason people continue to focus on this non-existent problem is that they can't really bring themselves to believe that **people might simply be better at solving their own problems than we are**.

So it is worth reinforcing why people tend to be better at making these decisions:

- ❖ People **understand** the problems they face better than we do
- ❖ People have access to a **range** of possible solutions - not just professional services
- ❖ People have the strongest **motivation** to solve any problem - its their problem

Of course some people do need support with decisions and good representation. But again, if you follow the principles of good supported decision-making, this means finding the person with strongest commitment, most knowledge and greatest motivation to make decisions with the person.

DON'T FOCUS ON SUPPORT PLANS

Ideas like support planning and person-centred planning can seem very exciting and useful. However in England we have seen millions of pounds wasted on new training courses, new planning tools and new professional roles - none of which is justified by any evidence that these things are required.

Not only are these processes wasteful they are also potentially damaging for they:

- ❖ Reinforce a message that people are not really competent to be in control of their own lives
- ❖ Reinforce dependency on professionals, planners, brokers or whomever
- ❖ Often create suspicion, defensiveness and resistance
- ❖ Waste time, which can then lead to further problems
- ❖ Undermine the application of common-sense and professional judgement
- ❖ Encourage bureaucratic interference - managers reviewing plans for their level of creativity

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Creativity is good, and it is one of the natural results of a smart approach. But it is **undermined, not enhanced, by the system now declaring itself competent to promote creativity**.

The system needs to focus instead on:

❖ Clarifying resource constraints and entitlements
❖ Clarifying and minimising rules and systems
❖ Ensuring there is someone to lead the process of thinking, planning and deciding

The only important question that a written plan can really help to answer is whether the individual or their representative is actually competent to be in control. If a plan indicates a basic failure of competence then the system will need to find someone else to take the leading role. Even then the plan is just a proxy for something much more important - what people actually do when they are in control. This is the only real test of competence.

At best a plan is just a limited piece of evidence about competence. It is certainly not a contract and must not be treated in this way. People do not plan and then stick like glue to that plan - that will inevitability cause problems. All plans are provisional and we change our plans as soon as new opportunities or problems arise.

FOCUS ON THE MARGINS

Although most people will look after themselves there are two important groups that a smart system will pay particular attention to:

1. The people who are really **thriving**, innovating and leading
2. The people whose lives are in **big trouble**

The first group don't need to be interfered with or slowed down, but they do need to be celebrated and supported to share what they've learned.

Smart systems support the spread of innovation by encouraging:

❖ Peer mentoring
❖ Peer networks
❖ Pass it on planning
❖ Planning cafes

And I am sure that there are many other ways people can, at no cost or low cost, help share experiences, inspiration and good practice.

The second group need a much more direct approach. It is tempting to think that the people who are most challenging, damaged or institutionalised might be the last people to benefit from self-directed support. But this is false.

It is almost always the case that a much more personalised, flexible and community-focused solution is the key to helping people break out of patterns of self-harm or institutional abuse. But in order to use these approaches it will be necessary for professionals and service providers to learn some new practical approaches.

The kind of supports described in *Personalised Support* are highly effective at providing high quality, cost-effective solutions for those people who challenge. It is worth focusing particular attention on the people whom we so often let down and to whom we provide very expensive, but ineffective care.

Figure 14- Work at the margins
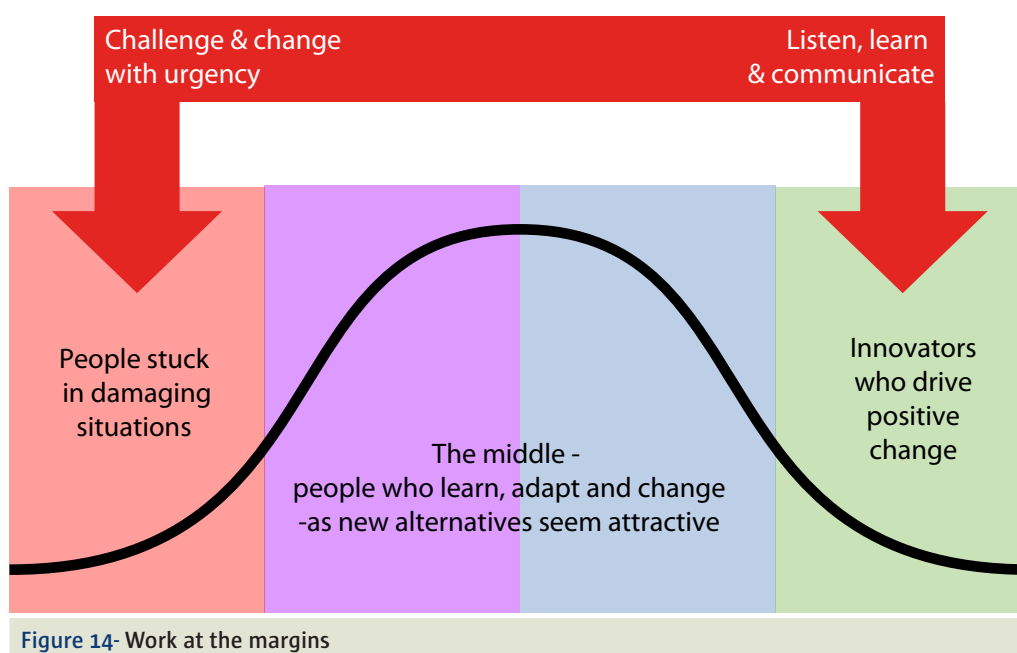
5. Assets

Sadly systems of individualised funding often waste time, money and good will by trying to build completely new systems of support by which to help people be in control. Often the end result is to maintain all the old systems and then to have a new system layered on top of the old system like a layer of sedimentary rock:

- New support brokers
- New support planners
- New kinds of support organisations
- New financial organisation

If these organisations were being developed because of the decisions people made about the use of their own budget then that would not be too bad. However, instead, they are always new organisations that are shaped and funded by the system itself.

My advice to South Australia would be to avoid this mistake and to instead focus on a three-prong strategy:

1. **Shift resources towards individuals** - including the relevant management costs - they will then find solutions that make sense to them
2. **Look to civil society to offer solutions** - this includes, but is not limited to, your existing service providers
3. **Refocus the work of your existing professionals** - build on and make better use of their best skills and attitudes

The constant threat to creativity and common-sense in this matter is the comforting illusion that there is some new structural fix that will arrive, like a knight in shining armour, to solve existing problems. The best discipline is to remember that good solutions lie in our own hands - there is the whole existing community, and there is no one else.

INCLUDE MANAGEMENT COSTS

In England, and in other countries that have developed individualised funding, there is often a temptation to reduce the money that goes directly to people and to instead use it to commission services that are then 'given' to people, but which then don't allow for choice, control or flexibility.

For instance, there seems to be no good reason for stripping out:

- ❖ **Management costs** - these allow people to purchase help to manage their support
- ❖ **Payroll costs** - payroll services are readily available
- ❖ **Insurance and finance costs** - these services can all be purchased
- ❖ **Transport costs** - people can find many ways of travelling

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This doesn't mean that there are not services that might properly be treated as infrastructure services. There's no need to be silly and to enforce a model of individualised funding where it may not belong.

There is still much to learn about how far individualised funding needs to go, but a case can be made for treating the following as infrastructure:

- ◆ Professional social work or case management
- ◆ Equipment
- ◆ Specialist support and advice
- ◆ Information and advice services

This is not to say individualised funding or vouchers should not be extended into these areas. But it is hard to see that these would be priorities for individualising, or that it would be easy to do so.

However this **does not mean people should be banned** from using their own funding in these areas. If someone does not feel that the equipment offered them from the equipment service is what they need then they are entitled to use their budget to purchase something they do prefer. If this happens quite often you may start to wonder whether your current system is doing all it can to meet people's individual needs.

It is also important to remember that services that serve many people together - residential care, day care, shared transport - are not excluded from individualised funding. However these services will need to identify a pricing structure and, if their services include valued efficiencies, then this will help lower prices and make their service more attractive.

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FOSTER COMMUNITY BROKERAGE

Instead of treating brokerage as some kind of specialist service to be added into the existing service system it is wiser to seek to identify all the different ways in which people can be supported to plan and organise their own support.

We sometimes call this *Community Brokerage* - but it means nothing more than making the best possible use of existing community resources and encouraging the further development of civil society solutions.

Many people do not need a professional planner or facilitator to help them plan. They can **plan for themselves** - and they can use the resources of the community. To support this approach we have often recommended that social workers encourage those individuals and families who can to lead planning for themselves.

However we also recommend that people are always provided with:

1. Access to useful **information**
2. Links to **peer** supporters
3. Links to relevant **community** organisations
4. Advice on most appropriate service **providers**
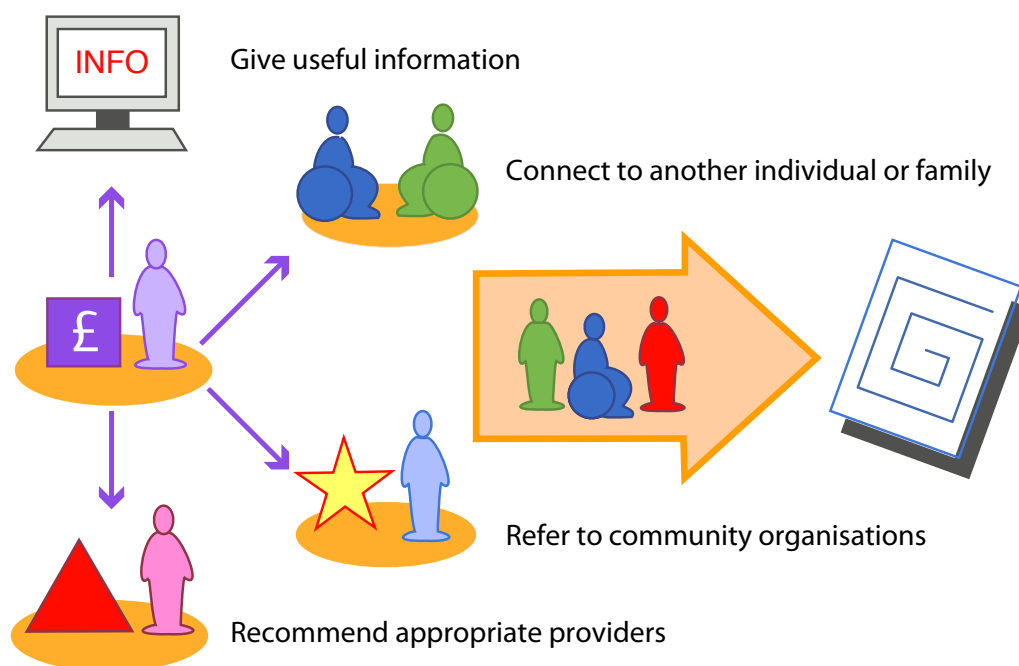
This model is represented in Figure 15.

Give useful information

Connect to another individual or family

Refer to community organisations

Recommend appropriate providers

Figure 15 - Community brokerage

RESCRIPT SOCIAL WORK

In addition it is important that social workers, or other professionals working closely with individuals, are able to work in the most empowering way possible.

The models of care management, assessment and placement which have become dominant need to be replaced with more fulfilling and empowering roles for professionals. Roles which live up to the values of social work - social justice and empowerment.

In order to help clarify how this new role would work we develop a simplified rescript of the social work role which many social workers have found useful:

Step 1 - Determine eligibility and clarify likely budget

Step 2 - Determine capacity and clarify leadership and representation

Step 3 - Planning:

a) For the majority - empower people to plan for themselves

b) For the minority - work in partnership to develop the best feasible solution

Step 4 - Check and agreeing any plan

Step 5 - Ensuring people can get the help they need

Step 6 - Learning from people what works and what doesn't
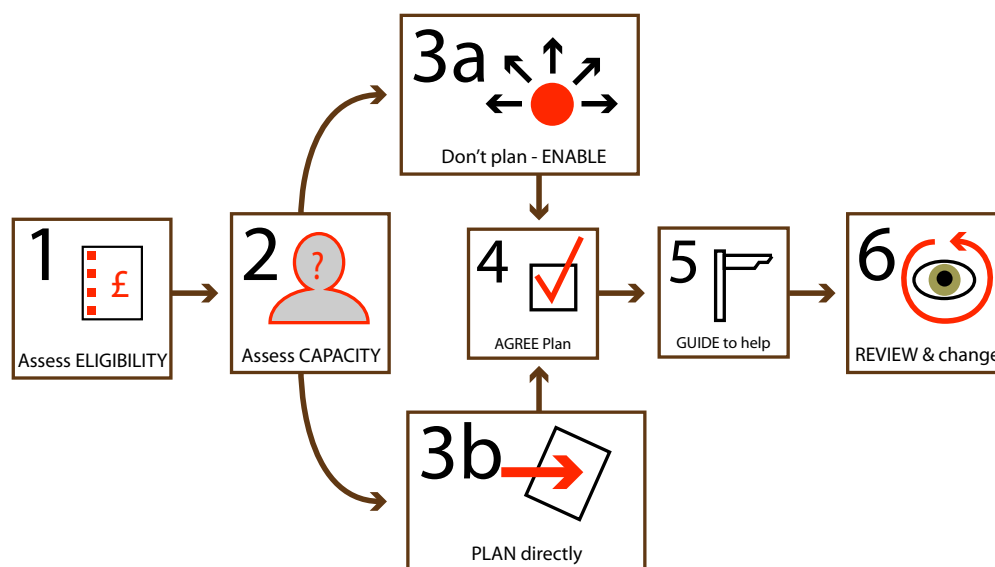
These steps are represented in Figure 16

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Figure 16 - Re-scripting Social Work

None of this implies that this all a social worker would do. It is not designed to prescribe or restrict the role of the social worker or stop common-sense. However it is designed to remind us that high quality social work is a powerful approach which, if used properly, is highly consistent with self-directed support.

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6. Peer support

All research reinforces the fact that if there is one form of support which people value above all others it is peer support. Peer support is so important that it deserves a whole chapter of its own.

Here are some things to remember:

❖ **Peer support is simple** - if you ask people most people will be prepared to help others in the same situation - especially if this is made easy and people are not expected to do too much.

❖ **Peer support is powerful** - peer support groups can often provide a quantity and quality of support which funded systems can never replicate.

❖ **Peer support is essential** - professionals should start to recognise that a failure to help people access peer support is a form of malpractice.

❖ **Peer support is varied** - there is no one model or approach and services should beware of making peer supporters work in ways which replicate their own models.

Here are just a few examples of the kinds of approaches that work:

1. **Mentoring** - peers will mentor people through self-directed support
2. **Brokerage** - peers will act as planners and advisors to help people get good help
3. **Therapy** - peers will learn techniques and share them in their networks
4. **Trainers** - peers will train and educate each other, the workforce and the wider community
5. **Assistants** - peers will provide direct and practical assistance
6. **Managers** - peers will organise additional support, manage budgets or provide other support
7. **Advocates** - peers will help each other speak out and protect human rights

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None of this is to suggest you should take peer support for granted or simply expect it to happen without support. But if you recognise its power and the untapped capacity of so many citizens then you can seek many different ways of enabling peer support to flourish.

An exciting model of peer support was developed in Doncaster, England, by a group of people with mental health problems. They developed a sophisticated approach which was rooted in something they called *Support Buddies* - giving each other practical assistance when they needed it.

Building on this the group developed a set of interconnected roles:

❖ Championing positive change in their community
❖ Advocating for their own and each other's individual and collective rights
❖ Developing new forms of innovation and social eNetworking locally and nationally to strengthen community

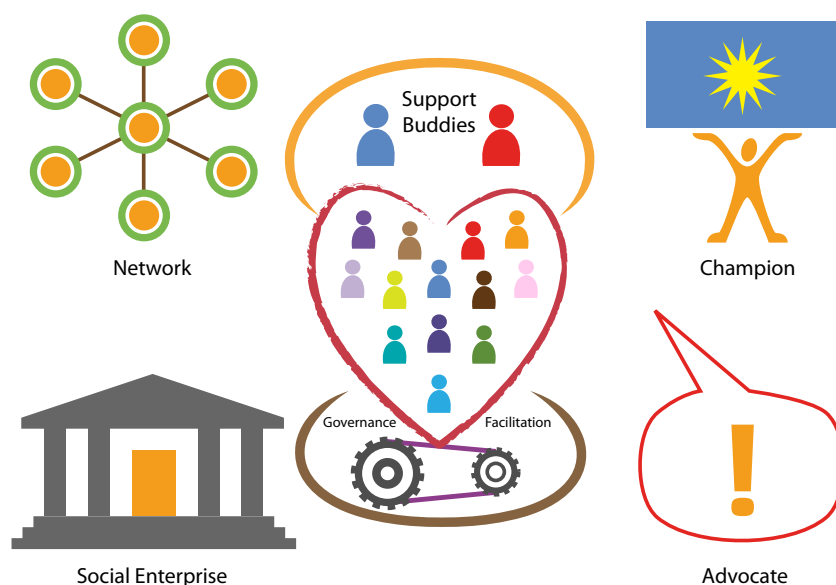This model of peer support is described in Figure 17.

Figure 17- The power of peer support

When I met people with disabilities and their families in Adelaide. Many people had already organised themselves into peer support groups. All the people listed below expressed a willingness to work with the State to develop and expand peer support.

Jayne Lehmann - wanting to support work on improving health services

Linda McGarvey - working with children and families

Barb Richardson - already developing flexible support solutions

Mel Leckie - working on advocacy & complaints

Jared Mcloughlin - working on sexual health, socialisation and inclusion

Ross Sands - working on universal design and improving access

Janet Sands - developed Plan Net as a tool for individuals and families

Ian Cummins - political decision-making - Our Voice SA

Tony Doyle - avenues to arts and creative community - people doing things together

Amber Delpin - seeking a new job

Katherine Bentley - working on independent living and advocacy for older people

Margie Charlesworth - keen to make sure people's real voices are heard

Steve Sampson of Barkuma - wanting to do something different

John Langton - Grandparents for Grandchildren

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7. Real wealth

The notion of real wealth was developed by Dr Pippa Murray and it is a useful way of bringing concepts like capacity or capabilities to life. This is pictured in Figure 18.

Figure 18 - Real wealth

Real wealth means:

1. **Gifts** - we each have gifts, talents, skills, needs and interests and these all help us to find our place in the world and build lives of meaning and of value.
2. **Assets** - we have things we can use, energy, time, money and capital and these give us the means to engage with other people
3. **People** - we have people we care about and who care about us, friends, family, partners, colleagues and fellow citizens.
4. **Community** - our community creates the opportunities that enable us to meet others, share our gifts and use our assets.
5. **Spirit** - above all we have the human spirit which gives us hope and enables us to seek creative and positive solutions to our problems.

Some people have less real wealth than other people. Some people have very little, but their **spirit** keeps them strong. Some people seem to have everything - but they cannot find it within themselves to make the most of everything they have. If we remember that

people make a good life because of their real wealth then this will help us avoid some important mistakes in developing a smart system of self-directed support.

IT'S NOT ABOUT SHOPPING

The power of individual funding does not lie in our ability to 'shop' for services. Instead it is about using the money - often a very modest amount of money - to help make best use of all the other parts of their real wealth.

This is why it is so important to try and make individual funding **a genuine flexible entitlement**. For unless this is achieved the money is likely to stay linked to standard system responses - and not do the very best work it can.

AVOID MEANS-TESTING - IN ALL ITS FORMS

If people can only get their entitlement by being poor then this is means-testing. But this is not just about money. If someone can only get their entitlement by going into crisis and having the family breakdown then this is means-testing love. If someone only gets support if mainstream services or the wider community fail to include and support them, then this is means-testing community.

It is understandable that systems may think that it is fair to give more to people who are poorer, alone or excluded - but it is vital that this does not tip into a vicious form of means-testing that increases poverty, social isolation and exclusion.

It is smarter to challenge your system to be:

❖ **Pro-family** - are families getting stronger, feeling more supported
❖ **Pro-community** - are people getting more involved, being more active
❖ **Pro-income** - are people getting richer, getting out of poverty

Currently most funding is locked into institutional provision that is damaging to family and community. The challenge is to unlock that money and **invest it in citizens, families and communities.**

AVOID PSEUDO-PRECISION

It is real wealth that is at the heart of a good life. Individual funding will inevitably only be one element of what helps someone get a better life - it will not guarantee a better life and it does not make someone have a better life.

This reinforces the earlier point that there is no precise level of funding that will be the 'right amount of money'. Systems and approaches that promise too much precision about the level of funding required are already rooted in an incoherent model of human life.

Its not the money - its people themselves - who make a better life. Money just helps.

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8. Quality

People often worry that quality will be lost in a system of self-directed support. The facts suggest:

- **Good news** - people will be safer if they are in control
- **Bad news** - people are still at risk even if they are in control

So it is important to be sensible about how you develop a smart system. Although it is tempting to talk about risk enablement and the right to take risks I think much of this debate is confused. The bottom-line is people don't often put themselves at increased risk - it is our current systems that are relatively risky.

Risks will go down - but they won't disappear and some kinds of risks may be greater.

CONTROL MUST LIE SOMEWHERE

A smart system of individual funding does not create a bias for one system of management over another. There are many ways individual funding can be managed and its important that no options are artificially reduced.

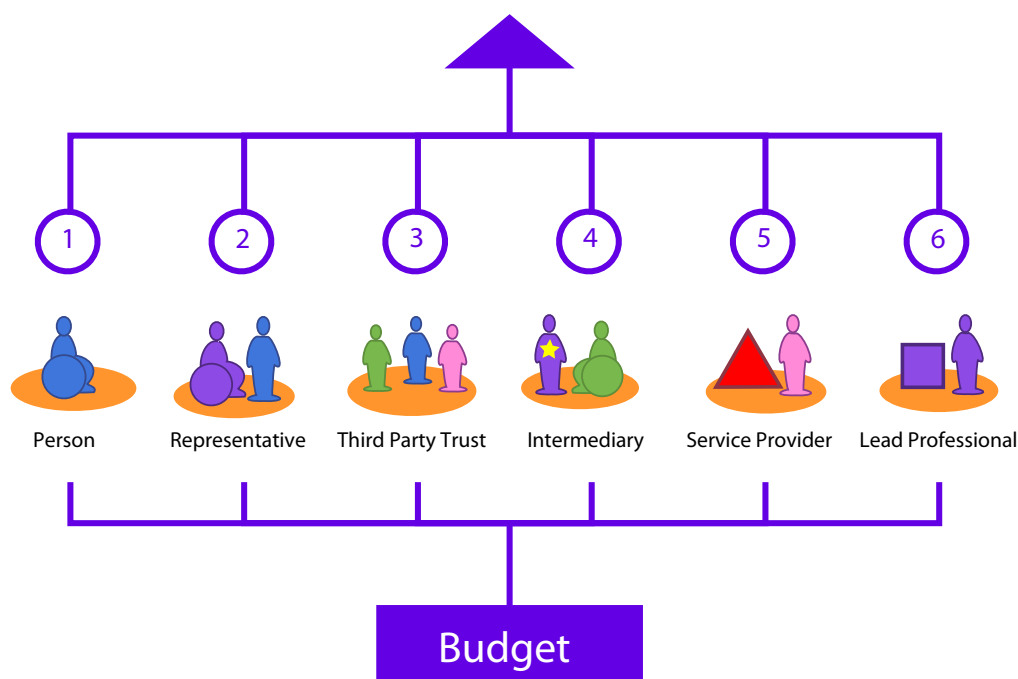Figure 19 sets out 6 distinct ways a budget can be managed. There may be others.

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Figure 19 - Options for Managing a Budget

If someone appears to be struggling to manage their budget, to make good decisions or to stay safe it may be that they need more assistance. But ultimately, if an arrangement is not working out, a smart system will **move the point of control** to someone who seems more likely to make good decisions.

It is the ability of the system to find the best decision-maker that is the best guarantee of quality. Supported decision-making principles suggest that, if this cannot be the person themselves, it should be someone who:

❖ **Knows** them well, is
❖ **Committed** to their best interests, and
❖ **Able** to make good and speedy decisions

There may be no perfect decision-maker - but in the real world it is essential that the best person possible is selected.

PERSONALISE RISK MANAGEMENT

The first instinct of bureaucracies is to manage risk by imposing bureaucratic controls on everyone. This is rarely appropriate. In fact generalised rules and systems can often drive up risk inadvertently for those people who get swept up in a general response that is irrelevant or inappropriate for them.

Good health and safety practice and good risk management, is personalised. It focuses on evaluating risks in context and seeks to develop the most appropriate response for that individual. Sometimes this means taking extraordinary measures to protect someone from harm - measures that should never be generalised or treated as the rule for others.

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STAY IN TOUCH

Some people fear that individualised funding might lead to greater isolation and risk as people move away from service systems. There is no evidence of this. However it is important that professionals do not treat someone who is using individualised funding as somehow 'outside' the system.

There may be many different ways of staying in touch - but perhaps the most important is simply to make sure that **human contact** is maintained:

❖ This is how we are most likely to spot problems
❖ This is how we are most likely to learn from people

It is particularly important to remember that **people and families are the best teachers** that professionals will ever have. They will teach us how best individual funding can be used and what people can achieve and this will help us help others.

9. Safety

There is an important wider point to be made about safety for people with disabilities - and again this reminds us that money is not the main mechanism for making good things happen or keeping people safe.

We do not have anywhere near enough evidence about what keeps people safe and what puts people at risk. But we do know that people with disabilities can experience increased levels of risk, especially if they cannot speak up for themselves, and especially if they are living in institutional environments.

For decades governments have tried to reduce the risk to people with disabilities. The main strategy has been to use regulation, monitoring and inspection as the means to reduce risk.

But this strategy is, at the very least, problematic:

❖ **There is little evidence it actually work**s - I am not aware of any evidence that the bureaucratic control of services actually reduces the real level of risk. Bureaucratic control seems plausible and rational, but it may not actually work.

❖ **The strategy reinforces damaging stereotypes** - Bureaucratic control reinforces the idea that people with disabilities do not really belong to the community, and instead require all sorts of special measures by professional services in order to be safe. This was the same myth that led to the development of the institutions where so much harm was done.

❖ **It is people, not systems, who keep people safe** - Most people's lives are, thankfully, not totally surrounded by public services. The evidence we do have suggests that people are best protected by active citizenship and their community of friends and families.

Perhaps its time to radically rethink our approach to the safety of citizens with disabilities.

FOCUS ON CITIZENSHIP NOT SERVICES

History seems to suggest that it is not the state of our regulations, but how people think about people with disabilities, that has the biggest impact on people's safety. If we apply the 7 key model of citizenship described above it does seem to offer a more helpful framework for both explaining risk and increasing safety (see Table 1).

This analysis is based on what psychologist and social thinkers like Goffman, Wolfensberger and many others have argued are the real roots of abuse. It may be still be a hypothesis, but it seems a better hypothesis than supposing that it is the duty of public services to 'keep people safe'. Instead this approach says that society needs to work harder at **protecting all citizens**, and that this in turn means **protecting citizenship for all**

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Key	Riskier when	Safer when
Purpose	You cannot express yourself or develop and share your gifts	Your life has meaning and authenticity
Freedom	You cannot communicate or express personal authority	You are seen to be in control of your own life
Money	Poverty leaves you dependent on the good will of others	You have money and the means to direct your own support
Home	You lack privacy, security and real housing rights	You can control who lives with you and who you let in
Help	You cannot get help from people you choose or value	You get help from people you want, when you want
Life	You are cut-off from ordinary life and the chance to meet people	You are part of your community, with a valued role
Love	You are without friends, family, partners or peers	You have love and people who care about you

Table 1 How citizenship enhances safety

SUGGESTIONS FOR ACTION

The following are some early thoughts about a strategy which focuses on citizenship not services. So little work has been done in this area that these are possible lines of enquiry, rather than well established strategies.

1. **Invest in research** - It would be helpful to have more real information about crimes against people with disabilities. Current evidence is patchy and thinking is dominated by an unhelpful bias towards public services, despite all the evidence suggesting services are relatively less safe. A more objective and universal approach to research on safety is needed.

2. **Supported decision-making** - For those people with disabilities who need help with decision-making it is important to protect and support the capacity to exercise authority to the maximum degree possible. Good supported decision-making arrangements should be seen as a basic human right, required for everyone where communication difficulties or intellectual disabilities creates increased risk.

3. **Control** - When people have more control then they seem to be safer. This is not a panacea that removes all risk. But the evidence certainly seems to suggest that higher levels of control lead to lower levels of risk. For instance a report by **IFF for Skills for Care** seemed to show that the risk of abuse was reduced by 50%.

4. **Leadership** - Over recent years the culture of competition and bureaucratic control has undermined the quality of leadership in public services. It is harder for leaders to think, share ideas and challenge each other. Shifting towards a more collaborative and less bureaucratic culture could increase innovation and learning.

5. **Universal responsibilities** - There is often a focus on trying to encourage staff to report or whistle-blow if they suspect abuse. The reality is that most abuse is spotted by families or other citizens or by professionals who are not directly involved in care. Within services institutional cultures quickly undermine the capacity of staff to stand up to crimes within those services. Perhaps one more radical approach would be to start treating the responsibility to stand up for each other, particularly those at

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most risk of abuse, as a **universal citizen responsibility**. Common law and (in some nation's) criminal law uses a concept of the 'duty to rescue' to impose obligations on everyone to behave appropriately when someone is at risk of harm. Perhaps if all citizens knew that harm was more likely for people with disabilities, for people who could not communicate and for people living in institutional settings then this would have a powerful positive impact.

6. **Policing** - The very concept of abuse can become problematic, particularly if we set up systems of enquiry and punishment outside the normal systems. It seems to suggest that crimes are not quite crimes when they are done to people with disabilities. Perhaps it would be more appropriate to work more positively with the policing system to ensure crimes are spotted and criminals captured.

7. **Justice** - In the UK many people with disabilities, particularly intellectual disabilities get a very raw deal from the criminal justice system. Far too many people find themselves imprisoned for minor offences, and then find themselves exploited and harmed in prison. While others find that they cannot get justice from the courts because they are not trusted as witnesses. I am not sure if the same problems exist in South Australia, but the ability to be treated fairly by the courts is a critical requirement for citizenship.

8. **Voice** - Advocacy at many levels is a vital part of ensuring fairness, justice and a voice that can represent the interests of people with disabilities. South Australia certainly has many good individual advocates and advocacy groups. But there does not seem to be a concerted or organised approach and this is likely to leave people with disabilities in a weaker social position. It is not just the State that has a duty to examine this question; it is vital that people with disabilities and their organisations work hard to strengthen their collective voice by building the right kind of alliance.

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10. Leadership

One of the most important challenges for South Australia is to lead the change to individualised funding in a way which support and develops leadership at every level.

It is tempting to hold on to your new model of individualised funding and then impose it on everyone with the message - **trust us, everything will be okay, we're in charge**.

But there are two big problems with this approach:

❖ **It's inconsistent** - you don't want to be in charge - you want people, families, communities, services to each demonstrate leadership.
❖ **It's dumb** - not everything will be okay, there will be mistakes and opportunities to make things better. You want everybody to be learning together how to keep improving things.

Change is messy. At its best it is fun, productive and collaborative. At it's worst its confusing, damaging and fragmented.

There is no recipe book for good change management and project management to a fixed formula will not get you through. Here are some thoughts based on what we learned in England from the places that did change best.

PROTECT YOUR LEADERS

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Often the key leaders of positive change go unrecognised - and that is not necessarily a problem. As Lao Tzu said:

True leaders are hardly known to their followers. Next after them are the leaders people know and admire; after them, those they fear; after them, those they despise.

To give no trust is to get no trust.

When the work's done right, with no fuss or boasting, ordinary people say, Oh, we did it.

I am not sure there can be a better guide to the spirit of leadership you need to discover. However, in practice, real leaders are necessary - and they are not necessarily the people you think.

The necessary organisational change to implement a smart system of individualised funding probably requires leadership on at least three different levels:

1. **Leadership at the front-line** - someone who can engage with people with disabilities and families, service providers and others to communicate the new ways of working and solve practical problems.
2. **Leadership in the middle** - someone who can make sure the system as a whole is organised to support the new ways of working, challenge broken systems find solutions and win allies within the system.

3. **Leadership at the top** - someone who can protect the leaders below, hold together to bigger picture and ensure that public communication and strategic direction is strong.

And, strange as it may seem, the leader in the middle is the most essential person if any significant and meaningful change is going to take place.
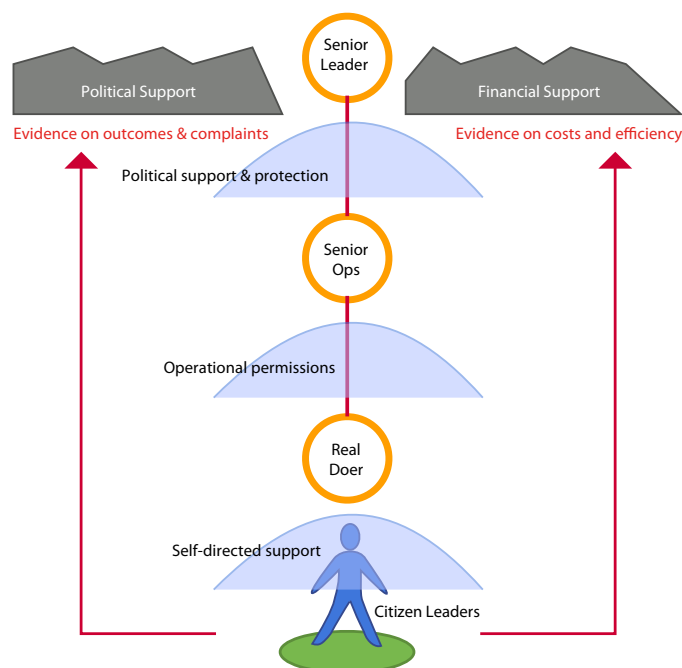

Figure 20 - The levels of leadership

Of course - at a more fundamental level- all of these form of leadership are simply efforts to unlock and protect the **citizen leadership of people with disabilities and their families**.

KEEP INCLUDING OTHERS

But this is only to think about leadership within the State. You will also want to seek out **potential leaders** in all the other spheres:

❖ Service **providers** who can convert their existing services to more personalised services

❖ **Community** service leaders who want to develop more positive forms of social work practice

❖ **People** with disabilities and **families** who want to create better support solutions or new businesses

❖ **Peer** networks that want to support and connect people with shared experiences

❖ Social **innovators** who have new ideas

❖ Local **business** people who want to get involved

Again, when I spoke to service providers at one workshop, at least 12 service providers expressed enthusiasm for working with the State to convert existing block contracts over to flexible systems of individualised funding - within existing resources.

Novita

Arena Incorporated

Community Lifestyles - Murray Bridge

Bedford

Life without Barriers

Cara

Barkuma

Community Living Project

Community Support Incorporated

Community Bridging Services

United Communities

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OWN EVERYTHING GOOD

If you can invite others to lead then the boundaries between what innovations are 'yours' and what innovations are 'theirs' starts to helpfully disappear. For the State in particular, its important to recognise, support and own good innovations - whatever their source.

One of the simplest and yet most powerful strategies is simply to **draw attention** to those individuals, services, community leaders who demonstrate real leadership. It is not theory or policy that will help people understand what is possible - but the real living example of individuals like them.

Figure 21 offers a way of thinking about this. If you imagine a series of parallel innovations that are taking place across the State then your role becomes less about defining the innovation than capturing the learning from those different innovations - in effect becoming the editors of the operating system (OS) - but learning from other about what works best.
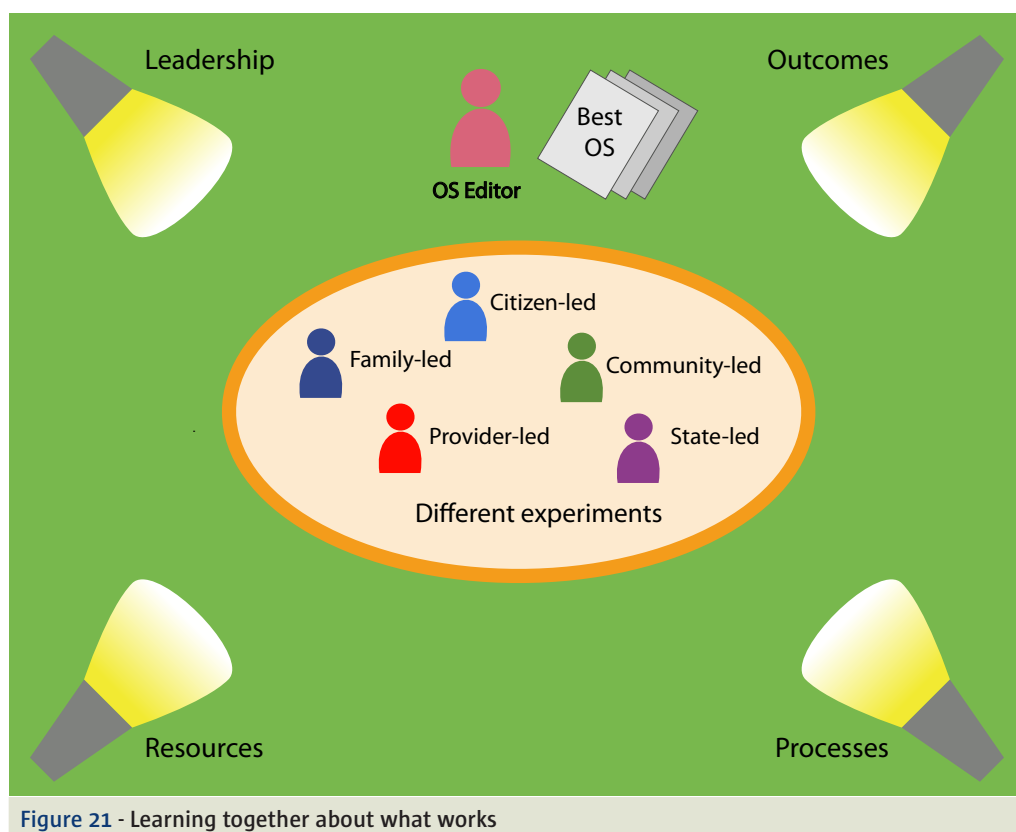
Figure 21 - Learning together about what works

This suggests that communication and PR, rather than just normal management and control, may be the key to a good strategy.

However it also requires a flexible and developing account of - **what we are learning really works**. It is more intelligent and collaborative to help people understand that you are all on a journey and that you are all learning and sharing your understanding of what helps.

❖ There are **no panaceas** - just things that make some things better
❖ There are **no magical structural solutions** - just some better structures
❖ There are **no gurus with all the answers** - we all have part of the answer
❖ More **money will change very little** - we must first use what already have better

These are not necessarily attractive messages. But everything we have learned since the institutions began to close tells us they are true.

SET STRATEGIC DIRECTION

It is tempting to try and plan out everything and project manage the change process step by step. However I have never seen this produce the desired results.

However it is helpful to maintain a sense of strategic direction and momentum by setting out clearly where you want to go:

❖ **Describe the real vision** - not in terms of funding systems - but in terms of citizenship or whatever real objectives you feel you have

❖ **Make it a vision that people can share** - use the language, ideas and hopes of all South Australians, particularly people with disabilities and families

❖ **Test your progress against that vision** - the real outcomes you care about will be people having better lives, being stronger citizens, positive social change

UNDERSTAND THE ELEMENTS OF TRANSFORMATION

This vision needs to be balanced with a focused effort on making necessary changes to a reasonable timescale.

In England we broke down the tasks we faced into a series of sub-tasks. This gave us a useful framework for change. You will have different needs, so don't take this model as fixed. But it demonstrates that a pragmatic and piece-meal approach is necessary.
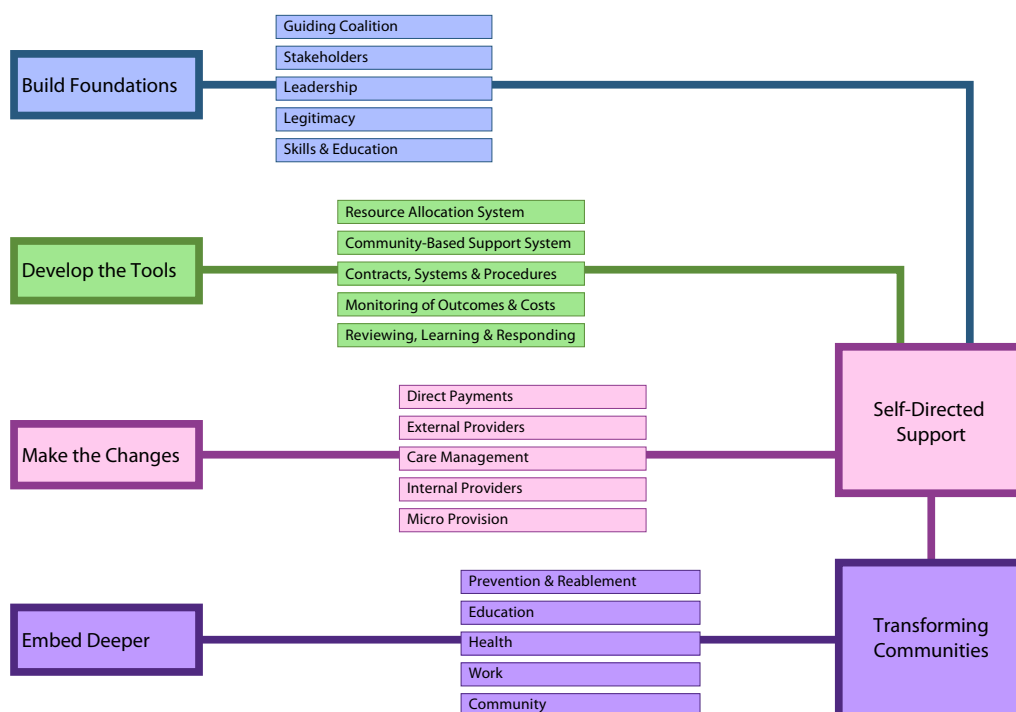
Figure 22 - Total transformation

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BE OPPORTUNISTIC AND FOCUSED

The word 'strategy' comes from the ancient Greek word for a general. This may not see relevant, but in a way it does offer a useful image. Good strategy is not about the unthinking roll out of a plan. **Good strategy** means:

❖ Making best use of all your **resources**
❖ Identifying and support your best **leaders**
❖ Noticing where significant **problems** are emerging and focusing energy to resolve them
❖ Noticing where new and unexpected **opportunities** are emerging
❖ Remembering the overall purpose and **changing** your plans as circumstance change
❖ Building critical **alliances** which serve the overall purpose

Writing a complex plan and then following it to the letter has nothing to do with leadership. It is more likely to guarantee failure, unthinking actions and demoralisation.

The changes you want to make are not going to be achieved simply by putting in place new processes or new structures. Some processes and structures are more helpful than others - but in the end **it is people, not structures, that make the difference**. Remember this and you will be okay.

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CONCLUSION

Obviously the journey I am hoping you will take has **no ending**. Instead of slick system change, that will quickly mean nothing, you will find you are on a journey of innovation and improvement where you can always keep trying something new. And where often you have to respond to new problems or your own mistakes.

So - you will never arrive - but why would you want to?

But I think, if you can go on this hopeful journey some things will start to change in some very profound ways:

YOU CAN'T TELL WHO IS WHO

When you can't tell who are the people with disabilities, who are the bureaucrats or who are the service providers then you are on the right journey. When you can **debate** and argue together but you are not divided by the system's fault lines then you are on the right journey.

YOU ARE HAPPY TO BE WRONG

When you can recognise **mistakes** and learn from them you are on the journey. When you are excited to discover someone else has a better solution to a problem that you face then you are on the journey together. Perfection is your enemy. Humility is a condition of real learning and the source of real and productive power.

YOU ARE NOT JUST SPEAKING TO EACH OTHER

When you are working together to speak to the **wider world** then you are on the right journey. Only a very few problems can be solved inside the existing box of disability services. Much more interesting solutions are available by talking to and challenging the wider community: other services, other communities and the general public.

YOU CAN LAUGH AND CRY TOGETHER

At the heart of our work are the basic realities of the human experience: life, frailty, success, failure and death. It is a privilege to be working alongside people with disabilities and their families. If we remain aloof, professional and distant we will not be able to really understand and connect with our fellow citizens. If we can unlock the **passions** that brought us into this work then this journey will be a journey we will really want to take.
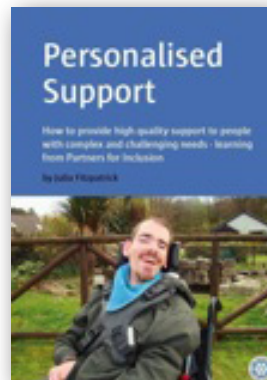
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Relevant Publications
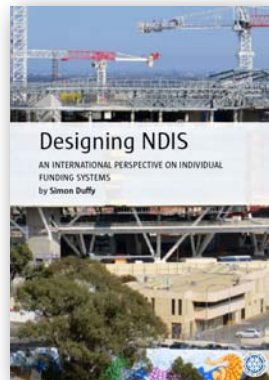
DESIGNING NDIS

Australia is currently designing a system of individualised funding for all Australians with disabilities. This report argues that the current model is flawed and draws on international experience for a different design. .

http://bit.ly/ndisdesign

PERSONALISED SUPPORT

Service providers often help people with disabilities in ways that too inflexible. This report describes innovative work to provide genuinely personalised support for people with the most complex impairments.

http://bit.ly/personalised-support

A FAIR BUDGET

How to set the right budget for people to control is subject to a lively debate in Scotland. This discussion paper offers thoughts on the principles that should underpin a fair and reasonable system of personal budgets..

http://bit.ly/fair-budget
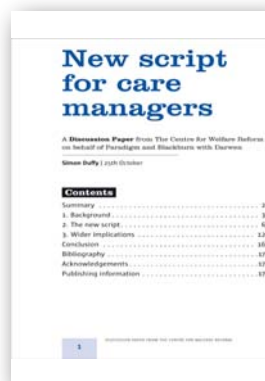
NEW SCRIPT FOR CARE MANAGERS

This discussion paper outlines how the role of the care manager can be better designed in order to be more realistic and empowering.
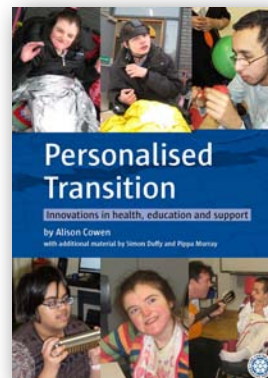
http://bit.ly/newscriptcm
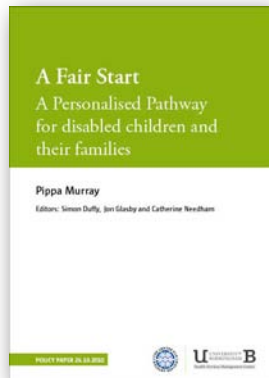
A FAIR START

Families with children with disabilities describe the kind of system that could really work for them. They do not just want budgets - but meaningful partnerships with professionals. The real wealth model is also explained..
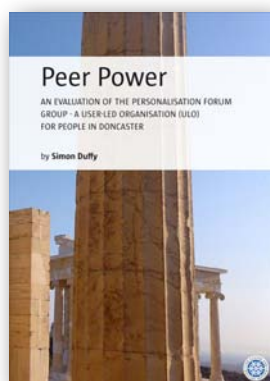
http://bit.ly/a-fair-start

PERSONALISED TRANSITION

Perhaps the most radical forms of personalisation in the UK gives families control of social care, health and education budgets. The impact is to radially improve outcomes for young people with disabilities.
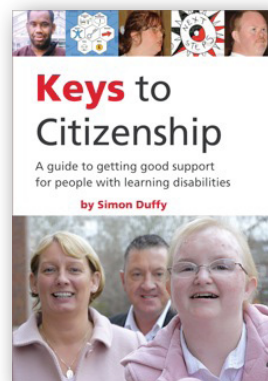
http://bit.ly/personalised-transition

PEER POWER

As a community group in Doncaster campaigned to control their own mental health budgets they found that the most powerful form of support was the support that they gave each other - peer power.
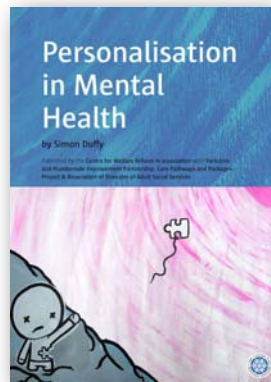
http://bit.ly/peer-power

KEYS TO CITIZENSHIP

Citizenship is for everyone. This guide is both practical and philosophical. It shows that people with intellectual disabilities can be full and active citizens if they get the right support and the chance to be in control.
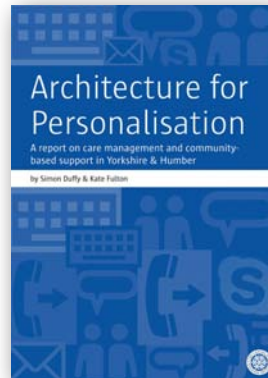
http://bit.ly/buy-keys

PERSONALISATION IN MENTAL HEALTH

Despite the evidence that personalisation's impact in mental health is more positive than in any other field progress has been too slow. This guide offers some practical ways forward.
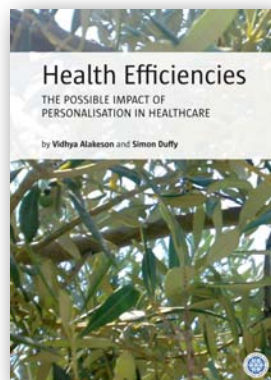
www.bit.ly/p-mentalhealth

ARCHITECTURE FOR PERSONALISATION

Personalisation requires a supporting architecture. Too often this turns into a professionalised industry. This report shows that an alternative, community-based approach is both more empowering and efficient.

www.bit.ly/architect-pers

HEALTH EFFICIENCIES

Personalisation could not just transform our experience of mental health services it could improve support to people with chronic health conditions and bring real dignity at the end of life.

www.bit.ly/health-efficiencies

PEER SUPPORT

Peer support comes in many different forms and this publication describes a range of different models that are currently helping people stay in control and to get high quality support beyond the professional system.

www.bit.ly/peer-support