

Redesigning the NDIS

AN INTERNATIONAL PERSPECTIVE ON AN
AUSTRALIAN DISABILITY SUPPORT SYSTEM

by Dr Simon Duffy and Dr Mark Brown



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FOREWORD



In this thoughtful and provocative report *Redesigning the NDIS*, Simon Duffy and Mark Brown make a clarion call for urgent and radical reform of the NDIS.

This in itself is not new, of course - in recent months, many commentators and analysts have made a similar call. However, what sets this report apart are the foundations on which the call for urgent reform is set.

First, the report is premised on the idea that people with disability should be co-creators in the next iteration (and iterations) of the NDIS, developing solutions and promoting innovation and new thinking to “put the heart back in the NDIS”. Citizenship, community and inclusion should enliven the next NDIS, placing people with disability at its centre and ensuring its sustainability.

Second, it is not a manifesto on what needs to be done to the NDIS; nor does it purport to speak for Australians with disabilities or, indeed, all Australians. Rather, the report seeks to encourage debate within the Australian disability sector, while also providing a much needed international perspective on the Australian system.

Third, the report sees the purpose of the NDIS as sound, and world-leading. However, design flaws often operate contrary to its purpose, undercutting the sustainability and legitimacy of the scheme from within.

Fourth, the report does not play the “blame-game”. Indeed, it sees the perverse outcomes in the current system as being due to the key actors acting rationally in their own interests – this is the tragedy of the commons.

Finally, the report is rooted in optimism. It is clear there is much about the NDIS which is good and should be kept and embraced.

It also sees the creation of the NDIS as one in which Australians can be proud, leading the world in achieving human rights for people with disability and forged by the unstinting efforts and collaboration of our disability rights movement. Its call for urgent and radical reform emerges from this standpoint.

I am delighted to have commissioned the report on behalf of Disability Advocacy Network Australia and thank the authors for the rich vein of ideas contained in the report. Some of these ideas are new and profound and there is much for people with disability and all Australians to discuss and debate.

Jeff Smith, CEO

Disability Advocacy Network Australia

EXECUTIVE SUMMARY



This report is a global perspective on the Australian National Disability Insurance Scheme (NDIS), which is the primary system for funding and organising supports for people with disabilities in Australia.

The creation of the NDIS, with its objective of ensuring people with disabilities get the support they need to be able to take their rightful place as full citizens has been one of the most important global innovations in disability rights of the past few decades. No other country has shown the same level of ambition or generosity of spirit.

The NDIS has led to many people getting the support they need to lead better and more independent lives, freed from the indignity of waiting lists and giving people choice over the services they receive. There is growing awareness of the validity of disability rights and important changes in thinking and practice that should neither be forgotten nor undervalued.

However the system design of the NDIS is flawed and it seems unsustainable. It places too much confidence in the capacity of a bureaucratic system to ration and regulate how resources are used. It places too little trust in citizens, especially Australians with disabilities, to make the best decisions about how to use these resources. No particular group is to blame. Cost pressures keep increasing as everyone tries to do their best to meet their needs. It is the design of the system, not the behaviour of any particular group, that is causing the current set of interconnected problems.

Unless there is a fundamental change to the design of the NDIS then cost increases will continue at an unsustainable rate. Currently the only cost-control mechanism are the opaque rules used to define and agree packages of support. However this control mechanism is inadequate, and the desperate attempt

to fix the system by constantly changing these rules only adds to people's negative experience of engaging with the NDIA. Eventually the growing costs of the NDIS could even put at risk Australia's commitment to disability rights and invite the policies of disability stigma that have been seen in the UK.

The good news is that the NDIS can be reformed. Fundamentally this requires different kind of thinking about the challenges ahead and the way in which good solutions are generated. We need to adopt a regenerative vision of inclusion and citizenship for all. We need to understand that people's ability to live a life of equal citizenship and reasonable security is determined by more than the money or by the services people receive. The quality of our lives is primarily shaped by our relationships, communities, gifts, passions and ability to combine all of these into a life of meaning.

8 Instead of being narrowly limited to the funding of services, tied up in complex packages, overly specified and peculiarly priced, the NDIS should be designed to invest in people, places and ongoing innovation. Instead of trying to manage an open-ended budget by the use of mysterious and ever-changing rules, the NDIS should repopulate inclusion, ensuring that Australians with disabilities, their allies and the wider community have the necessary powers and responsibilities to make the changes necessary.

The challenge is to put the heart back into the NDIS, to ensure that it operates in a more human way, so that it can now achieve the principles and vision that first inspired its creation. Australians with disabilities need to open up a new conversation about how the NDIS really works. The 2022 NDIS Review provides an opportunity for change; but whatever the immediate changes it brings about, what is most important is that the Australians with disabilities work together to develop an effective critique of the NDIS and a long-term vision for its reform.

In this spirit we propose 4 changes for the urgent redesign of the NDIS:

- 1. Create meaningful entitlements** - To make good decisions, innovate and make efficient use of resources people need real personal budgets. This means that money belongs to the person and that everyone gets the support they need to help them manage their budget when necessary.
- 2. Embrace peer support** – Isolation and individualisation increase insecurity and undermine learning and sharing. People with disabilities and their families need to be connected to each other, to learn with them and to grow in strength and confidence by sharing stories, information, training and by creating new solutions together.
- 3. Root support in community** – The current system pays insufficient attention to communities of geography or to the First Peoples of Australia. Communities have a critical role in creating, welcoming and supporting the contribution of people with disabilities. Support should be rooted in community and services should act as a bridge to inclusive solutions.
- 4. Renewed governance** - As citizens, people with disabilities should have a clear role in negotiating the overall level of resource committed to the NDIS and the frameworks for its distribution. The NDIS needs to be held accountable, not just for its cost, but also for its effectiveness at helping people achieve citizenship and supporting communities to advance inclusion. This requires rules that ensure States, communities and other allies share positive incentives to manage resources effectively.

In the coming months we hope that Australians with disabilities can work with their allies and with the Australian Government to agree the urgent changes necessary to ensure the sustainability of the NDIS. These could include reaching appropriate agreements

on the overall level of funding needed to meet individual and community need and an open and inclusive process for meaningful review and improvement, one that ensures that Australians with disabilities are guaranteed a clear role in decision-making in the future.

The NDIS needs a radical redesign both to ensure it is fit for purpose now and so that it can adapt to a changing world, new challenges, opportunities and a better vision for all Australians. It is time to leave behind the bureaucratic mentality that dominates the current system. Australians with disabilities deserve a dynamic and inclusive approach to ensure that every Australian counts. The work of inclusion and citizenship is ongoing. There will be further changes to the NDIS and the NDIS should continue to evolve to play its part in ensuring every Australian really does count.

PREFACE



In order to support the independent review of the NDIS the Disability Advocacy Network Australia (DANA) commissioned Dr Simon Duffy of the SDS Network and Citizen Network to offer an international perspective on the NDIS. Simon was joined in this work by Dr Mark Brown, a researcher at the Summer Foundation, and someone who currently uses the NDIS.

The purpose of this report is to:

- Put the NDIS into a wider global context and the historical development of systems of self-directed support and independent living.
- Identify the strengths and weaknesses of the NDIS in order to improve its future design.
- Offer useful tools and evidence for the disability movement to strengthen its ability to engage in debate on these issues.

The authors write:

We hope that this report will be useful to the NDIS Review Team, established by Bill Shorten and led by Bruce Bonyhady and Lisa Paul. But our primary objective is to encourage debate within the Australian disability movement. It is important that the NDIS genuinely supports disability rights and is enabling everyone to live a life of citizenship. Currently, for all its achievements, the NDIS is not fulfilling its potential.

In our view the NDIS is a world-leading development in disability rights; but it suffers from a significant design flaw, which we fear will make the NDIS unsustainable if it is not urgently addressed. It is possible that this problem would not have occurred if the design of the NDIS had been subject to more careful scrutiny and

testing, and if people with disabilities had been vital partners in the development of the design. Important public policy developments, like the NDIS, should be developed in partnership with the people who are most directly affected by them.

The central purpose of this report is not to specify solutions in detail; instead we are hoping to both explain the urgency of the need for reform and to offer a vision of the kinds of positive reforms that are possible. We have avoided using some of the technical terms that are commonly used in discussions of the NDIS (e.g. investment in Tier 2, improvements in the National Disability Strategy etc.). This is partly because we've written for the general reader, in Australia and abroad, and we don't want to assume any background knowledge about the technocratic details of the NDIS. But this is also because we think that this is a good time to be ambitious. We would like people to think about the possibility of a radical redesign of the NDIS—keeping what is good—but rethinking some of its basic assumptions, from first principles.

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To underline the idea that this is about improving the design of the NDIS we've applied the kind of coding commonly used in software to reinforce the idea that this is about redesigning something that is valuable and good. This is the same approach adopted by the Federal Government when it launched the current review (Shorten, 2022). We call the current system NDIS 1.0, a system which has design problems that need to be addressed quickly. NDIS 2.0 is our outline of a better system that has the capacity to ensure the sustainability of the NDIS. NDIS 3.0 is our effort to sketch future reforms and to encourage the reader to see the process of reform and redesign as ongoing.

We also need to acknowledge that this report does not begin to capture the experiences of the First Nations of Australia, a community that has been particularly poorly served by the current design of the NDIS. We only hope that our conclusions, which focus on the need to better respect the role and rights of communities, may prove useful in advancing their own rights in the future.

As Simon was the commissioned author and offers the international perspective on the NDIS the writing is sometimes in the first person singular, to reflect Simon's perspective. However Mark's contribution is significant and substantive and this report should be cited as jointly authored as:

Duffy S & Brown M (2023) *Redesigning the NDIS: An international perspective on an Australian disability support system*. Sheffield: Citizen Network Research.

Thanks to Disability Advocacy Network Australia (DANA) and the Summer Foundation for their considerable support. Thanks to colleagues from the global Self-Directed Support Network for their advice and support. Thanks also to Esko Reinikainen of System Change Finland for offering technical support on the mapping of system dynamics.

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Thanks also to those who offered ideas and information but preferred to remain anonymous.

Dr Simon Duffy and Dr Mark Brown

NDIS 1.0

Without doubt, the National Disability Insurance Scheme (NDIS) is one of the most important global developments in the journey to achieve human rights for people with disabilities. In disability policy I cannot identify any other transformational change with the same ambition, scale and vision. Australians should be proud of creating the NDIS. Its achievements include:

1. **Universality** - The NDIS exists for all Australians who are born with a significant disability or who acquire one before the age of 65.
2. **Positive vision** - The reforms were inspired by a positive vision of Australians with disabilities as active citizens and contributors to the life of Australia.
3. **Well-funded** - The reforms led to significant extra funding, some of which is linked to a hypothecated tax, and which has had widespread public support.
4. **Individualised** - The system is designed around individualised funding which allows people choice and control over who provides support and a degree of self-management.
5. **Portable** - People have the freedom to live and work anywhere in Australia and to take their NDIS support package with them.
6. **Not means-tested** - The NDIS has no means-testing for services and does not create additional poverty traps for people with disabilities.

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The work of decades

As Rhonda Galbally has outlined, these changes were achieved after considerable effort. It has taken many decades of planning, organising and alliance-building for the disability movement in Australia to achieve these changes (Galbally, 2016):

- Inspired by the development of independent living movement in the USA, the Australian disability movement began to emerge in the 1970s.
- There was a growing recognition of the need to end institutionalisation and a largely effective programme to close the large institutions.
- In New South Wales (NSW) and Victoria no-fault disability insurance schemes offered an important model for funding support for people with acquired disabilities, one which has provided a template for the future.
- There was a growing carers movement that has been increasingly effective at putting political pressure on the political system.
- A large and well-organised service provider sector has developed and it is highly effective at lobbying government.

- The Every Australian Counts campaign managed to create a vision for change built on common ground between people with disabilities, families and professionals.
- The National People with Disabilities and Carers Council (NPDC) introduced peoples' perspectives into the policy-making process and the *National Disability Strategy: Shut Out*.
- The Productivity Commission proposed the NDIS as a necessary investment to make the disability sector a dynamic contributor to the social and economic development of Australia.

It is particularly exciting to see how successful the Australian disability movement has been, not only at shifting government policy, but at changing the way in which all Australians think about disability and disability supports. This is in stark contrast to the situation in the UK, the USA and in most of Europe. In these countries, even when there have been policy and practice improvements, the public attention given to disability rights is extremely limited and very shallow—not potential front page news!

Clearly an important factor in this shift has been the work that went into constructing a wider alliance with families and service providers and the creation of the Every Australian Counts campaign. This alliance then created a narrative for reform that stressed the universality of disability: everyone can become disabled; disability is part of life; every person has the right to live a good life and everyone has a contribution to make. Personally, this strategy was very inspiring for me and we used it when building the Learning Disability Alliance and Learning Disability England. Today my work at Citizen Network is inspired by the same sense that we need a bigger, more generous and inclusive vision for the future—one where everyone counts.

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The initial design

The vision that inspired the development of the NDIS is rooted in human rights and the rightful demand that people with disabilities are included as full citizens. But the detailed design of the NDIS is based on specific technical assumptions about how best to achieve these (and other goals). This is a brief summary of some of distinctive design features of the NDIS:

- The National Disability Insurance Scheme (NDIS) was established by the *National Disability Insurance Scheme Act 2013* (NDIS Act); this Act specified many of the design features of the NDIS in great detail.
- The National Disability Insurance Agency (NDIA) provides support if you are under 65 (or older if you acquired your entitlement before 65). In other words this support system is distinct from the Aged Care system, which support people who acquire disabilities later in life.
- There is no overall budget for the NDIA; the funding is determined by the aggregate cost of what is deemed 'reasonable and necessary' for each individual participant.

- Eligibility for the NDIS is generally restricted to people with 'long term' impairments that make it difficult to carry out vital tasks and participate in the life of the community. Although there was an assumption that early intervention, particularly for children with disabilities, may lead some people to leave the scheme.
- The NDIS Plan is the central control mechanism. An individual's NDIS plan is created or approved by the NDIA. The plan specifies the individual's budget, how it may be spent, the personal 'goals' it relates to, the timeframe, and the arrangements for holding and transferring funds. Amounts are determined by the price of eligible services, for eligible needs, in accordance with a range of different budget categories.
- An NDIS Plan must be formulated after some consultation with the individual participant (or their nominee); it must give consideration to their individual goals, requests, and evidence about individual circumstances. However, the individual does not need to agree to a plan for it to come into effect. The individual does have the right to dispute the plan within 90 days through an appeals process, which may lead to a tribunal ordering amendments to the plan. After 90 days a review or reassessment of a plan can be requested, but the NDIA may not grant the request.
- Individual participants can choose which registered service providers provide their funded supports and the terms of that arrangement, to the extent there is choice available in the market. Funds are released in accordance with the NDIS Plan, typically to services directly, although self-management or intermediary management is possible and this brings certain additional flexibilities, including the use of non-registered providers. Unspent money is returned to the NDIA, it does not carry over, and it isn't treated as belonging to the person.
- The NDIA must create or approve a new plan before the old one expires (typically after one or two years). The NDIA isn't bound by the logic of their previous plan, so a new plan can be radically different to the previous one, and plans may be inconsistent between two people in the same circumstances.

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The design is essentially a scaled up version of a no-fault injury statutory insurance scheme, similar to state-based transport or workplace accident schemes, but for a much larger and more diverse cohort of people with disability. Statutory no-fault injury insurance is rightly viewed as having been an important innovation, much more effective and humane than requiring seriously injured people to fight for compensation in the courts: However, I am not convinced that this model represents the pinnacle of fairness, efficiency or innovation. It also seems likely that, while the model may work well, at a State level, for a relatively small and well-defined group, the model may not be as effective at a Federal level.

Emerging problems

Today the considerable achievements of the NDIS are being overshadowed by a growing sense of crisis. The NDIS was introduced by a previous Labor government, but it has largely been managed under a Liberal–National government. During that time there were numerous problems: costs growing faster than expected, unexpected changes to the administration and governance of the scheme, negative experiences for participants using the scheme and efforts to introduce new elements into the design, most notably independent assessors. This last effort at reform led to a sustained and successful campaign to resist those changes.

After the re-election of a Labor government the Minister for the National Disability Insurance Scheme, Bill Shorten announced a major Independent Review of the NDIS (Shorten, 2022a):

“The NDIS Review will look at the design, operations and sustainability of the NDIS. It will also look at ways to make the market and workforce more responsive, supportive and sustainable.”

The review’s purpose is described in its terms of reference but it is probably fair to say that the two central themes of the review are (Shorten, 2022b):

1. Addressing the **negative experiences** of people who use the NDIS. As Bill Shorten puts it: “For too many people the Scheme has developed into a source of **stress and anxiety.**”
2. Addressing fears about the **affordability and sustainability** of the scheme: “We want a Scheme that is sustainable and efficient while delivering for people with disability”

Over several years, Australians with disability and their allies have spoken up about their negative experiences via reviews and inquiries, research projects, the media, and other means. This report does not aim to describe these experiences in any detail; instead our goal is to try and understand why these problems are happening.

Similarly, there is a vast literature on the costs of the NDIS and we do not attempt to synthesise or analyse that data. In public affairs, statements about spiralling costs or sustainability can be exaggerated for political effect or they can fail to reflect important changes in need. However, when it comes to the NDIS there does seem to be considerable room for genuine concern. As one of the most recent report from the NDIS says:

“Scheme expenses are estimated to be 1.48% of GDP in 2022-23, increasing to 2.55% in 2031-32.”

National Disability Insurance Scheme: Annual Financial Sustainability Report 2021-22 p. 5

Additional costs were always expected and part of the purpose of the NDIS was to meet previously unmet needs. However the NDIS also seems to be experiencing ongoing cost increases that were not expected, and costs keep increasing, despite many efforts to control them. Moreover the benefits of these increased costs are not always clear: There are still groups who seem to be getting too little and there are still many institutional services.

Nor are these problems entirely unexpected. In 2013, after examining the initial plans for the design of the NDIS, I wrote a paper outlining a series of concerns about the design of the NDIS. One of my biggest fears was that the system would create significant incentives for ever-increasing costs. Looking at the NDIS from an international perspective, I said:

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

Duffy (2013a) Designing NDIS, p. 26

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My concern was not merely about the extra expenditure, it was rather that this extra expenditure would keep growing in ways that would create other negative changes, and that it would eventually undermine the sustainability of the scheme. Others shared these concerns, for example John Walsh, one the key advocates for the NDIS, has also warned of these dangers.

In my view the fact that the NDIS seems to keep growing as a share of GDP is very worrying. When the NDIS began there was certainly the need for new expenditure; but after any initial growth a sustainable system should be relatively stable as a share of GDP. This is because GDP describes all priced economic activity and, other things being equal, spending that increases in line with GDP is sustainable. However when spending increases above the level of GDP things can quickly get very difficult; for this means either higher levels of taxation or cuts to other public services: and it is all citizens, including people with disabilities, who use those services and who pay those taxes.

It may be tempting to think that increased spending is always a good thing for people with disabilities; but we should also be very cautious of treating the size of the NDIS as a good measure of how well the NDIS meets people’s needs. It is quite possible for costs to increase without any benefit to the person. The price of a service does not determine the quality of a service; many costs are hidden from view and cost increases can be symptoms of waste, duplication or too much bureaucracy. The fact that private equity investors and insurance companies see the NDIS as a likely source of profit is a very worrying sign (Weinman, 2023; Wilkins, 2023).

In fact the most important reason to be wary of simply accepting rising costs is that it is likely that increased costs mask other concerning changes. These changes are often changes beneath the surface, changes in society, changes in other public services or changes in relationships, and these changes may have very negative impacts. For example, rising costs can be caused by:

- Funding for services that enable some people to make money, but which may be of questionable long-term value for people and communities.
- Legalistic or combative advocacy that increases the cost of meeting needs, creates unhelpful risk avoidance or defensive practices.
- Reductions in prevention or in the natural support provided by people, families or communities or reductions in support from other public services.
- Redefinitions of need or the promotion of new kinds of needs in order that businesses profit or that other parts of government can reduce their own costs.

This may seem an unduly bleak way of framing the problem and I am not implying that this is driven by bad intentions. The intentions that led to the creation of the NDIS were good. The daily actions of individuals and groups using to the NDIS are also driven by positive intentions. However, as I hope we can show, the design flaws currently built into the NDIS are creating a situation where good intentions are having bad outcomes. Essentially the NDIS is putting people in a situation where responsible, and prudent actions are working against the long-term interests of the scheme as a whole. This phenomenon is sometimes called the tragedy of the commons—when society doesn't ensure the sustainability of a common good and individual behaviour works against what is in everyone's best long-term interest (Hardin, 1968).

The political risk

Ultimately the problems inherent in the design of the NDIS are not just economic problems. The most important problem is that the growing cost of the NDIS will eventually break the bond of trust between people with disabilities and society as a whole. Unless these problems are addressed economic pressure will almost certainly undermine political support for the NDIS.

In fact a strong case can be made for treating sustainability as a fundamental foundation of any system for human rights. The NDIS budget is the price a civilised society should be willing to pay to ensure that all citizens get the support they need to live good lives and play their unique part in the life of the community. In other words, if we take disability rights seriously, then we must also take seriously the responsibilities that we all share as citizens to pay our fair share of taxes and to contribute in other (non-financial) ways to supporting each other as equals.

However, a fundamental condition for people to take seriously their responsibilities is that these responsibilities are reasonably stable and well

defined. People will not accept responsibilities that keep increasing or fluctuating; especially if they do not correspond to real improvements in the quality of people's lives or benefit for the whole of the community. Rights are real, but they can only be brought to life by the duties they imply, and many of these duties imply costs that must also be defined and constrained.

People do not cope well with escalating or uncertain obligations. Increasing taxes each year or cutting other public services or entitlements to pay for NDIS will encourage some people to think that the NDIS is being unfairly privileged over their own needs or the needs of others. People may not be willing to say this at first, especially if there is strong social pressure to be respectful to people with disabilities. However this is unlikely to hold stable for long.

The UK provides a very chilling example of what can happen when the media, politicians, and the financial forces that lurk behind them, realise that people with disabilities can be stigmatised and that their services can be targeted for cuts. The UK also shows how quickly such changes can occur. They can even occur behind a veneer of respect for human rights. The seriousness of the matter can be judged by reading several UN reports on the failure of the UK to respect the rights of people with disabilities (and other disadvantaged groups, like migrants) (UNCRPD, 2016; UNCESCR, 2016).

Up until 2010 it seemed that UK policy was becoming increasingly progressive, with major reforms of social care (supporting people with disabilities of all ages) wider anti-discrimination legislation and efforts to improve the social security system. However, in the years leading up to the 2010 General Election, there were a growing number of newspaper articles talking about disability fraud in the benefit system. This was despite the fact that disability fraud in benefits is absolutely insignificant. Terms like 'skivers', 'scroungers' and 'fraud' were widespread on the front covers of tabloid newspapers. Politicians started to talk about how to tackle this non-existent problem and when the Conservative–Liberal Democrat Coalition Government came into power in 2010 it unleashed a programme of 'reforms' that have had a devastating impact on people with disabilities: not just by cutting services, but also by creating a culture of fear and suspicion for people with disabilities (Duffy, 2013e; 2014b; Saffer et al. 2018).

It is difficult to summarise all the negative changes of the past 13 years, but in essence the UK has seen spending on social care (which has a much wider scope than the NDIS) fall sharply as a share of GDP (Duffy & Peters, 2019). Benefit changes have led to punishing sanctions for people with disabilities and a system of 'independent assessments' that was driven by the desire of government to reduce eligibility for support (Burgess et al. 2014). Alongside this, the loss of legal aid, diminished advocacy, growing hate crime and a culture of fear has meant that it is very difficult for people to seek support to realise their rights (Inclusion Europe 2014; Benstead, 2019). The human price of these reforms is paid in increased suicides, depression and the increased use of antidepressants (Duffy, 2022).

There are other worrying signs that the rights of people with disabilities are not strongly protected and that fear and stigma can increase the pressure towards modern forms of euthanasia. For example, laws in Canada and the Netherlands that allow for assisted-dying seem to be encouraging people with disabilities to end their own life because they fear that they are becoming a burden to others (Reinders et al. 2019).

It is important to note that the stigmatisation of people with disabilities did not arise because of expenditure pressures. However, at a time of general economic anxiety, with threats to social solidarity, some politicians and their allies in the media, have exploited public ignorance and background prejudices to create a compelling narrative of disability fraud that is still a powerful force in UK society.

Australia is certainly not in the same position. Today, bi-partisan support for the NDIS remains strong. In 2018 polling suggested there was 80% public endorsement of the NDIS (Knaus, 2018). But this is not support for a limitless increase in costs. Increases to the Medicare levy to fund the NDIS do not poll well and government has not been willing to keep increasing the levy (Probyn, 2018; Kehoe, 2022). Moreover political alignments can change. If the current Australian Government is unable to create a sustainable system then it may be tempting for opposition parties to create political capital by criticising the NDIS more directly. Recent targeting of the NDIS by politicians like Pauline Hanson, could be the start of a process that could seriously threaten public support for the NDIS.

In my view it is important to face the challenge of achieving system sustainability head on. This means understanding what is creating the current instability in the system. If Australians with disabilities do this and then help solve these problems the long-term success of the NDIS will be secure.

However if these problems are not solved then it is not only the future of the NDIS that will be put at risk. Australia has shown the world that it is possible to be bold and generous and to take the human rights of people with disabilities seriously. However if the NDIS is not designed in a way that demonstrates the sustainability of those rights then many observers will conclude that it is too difficult to take disability rights seriously and that means-spirited rationing is the best we can manage. So the whole world needs Australia to succeed and to create a better version of the NDIS, one that is fit for purpose now, and for the future.

THE PROBLEM

The purpose of the NDIS is sound: it should be quite possible for a community to provide resources to ensure that people with disabilities have lives of full citizenship. However a system is more than its purpose. It is my belief that the design of the NDIS is flawed and that it is actually in conflict with its own purpose. Even if resources were infinite then the NDIS would still be designed in a way that undermines its own purpose; but because resources are not infinite the system will become increasingly costly and so it will not survive in the long-run. Urgent and radical reform is required.

These are strong beliefs, and they are not shared by everyone. Some believe that the current system can be fixed by increasing the level of resources spent on the implementation or by increasing the overall budget to reach the point where the pressure to keep increasing spending will diminish. On this view the problems facing the NDIS are teething problems, only requiring more time, money or a further change to the rules. For example, some blame: NDIA understaffing, lack of validated assessment tools, underdeveloped computer systems, a misapplication of Local Area Coordination principles or other technical issues that may only require a technical fix.

I am not sure I can prove that these more optimistic opinions are false. However I think that if we pay attention to the detail of how the NDIS operates then we can identify 5 major problems that suggest the NDIS is suffering from more than teething problems:

1. The overall budget for the NDIS is open-ended. This means that when the system's costs increase they must be passed on to the government, and then onto the tax payer. This becomes a critical weakness if costs are not effectively controlled elsewhere.
2. The system for defining resources is unclear and insecure. People are not given clear and well-defined entitlements and there is no long-term security for people. This means that people are forced to keep claiming what they may need — in case they don't get what they do need.
3. The level of funding in each person's plan is determined, not by need, but by the price of the disability services that are deemed "reasonable and necessary" by the NDIA. Service providers, whose funding is subject to the same insecurity as people with disabilities, must maximise their prices and do everything they can to help people succeed in making claims for NDIS funding.

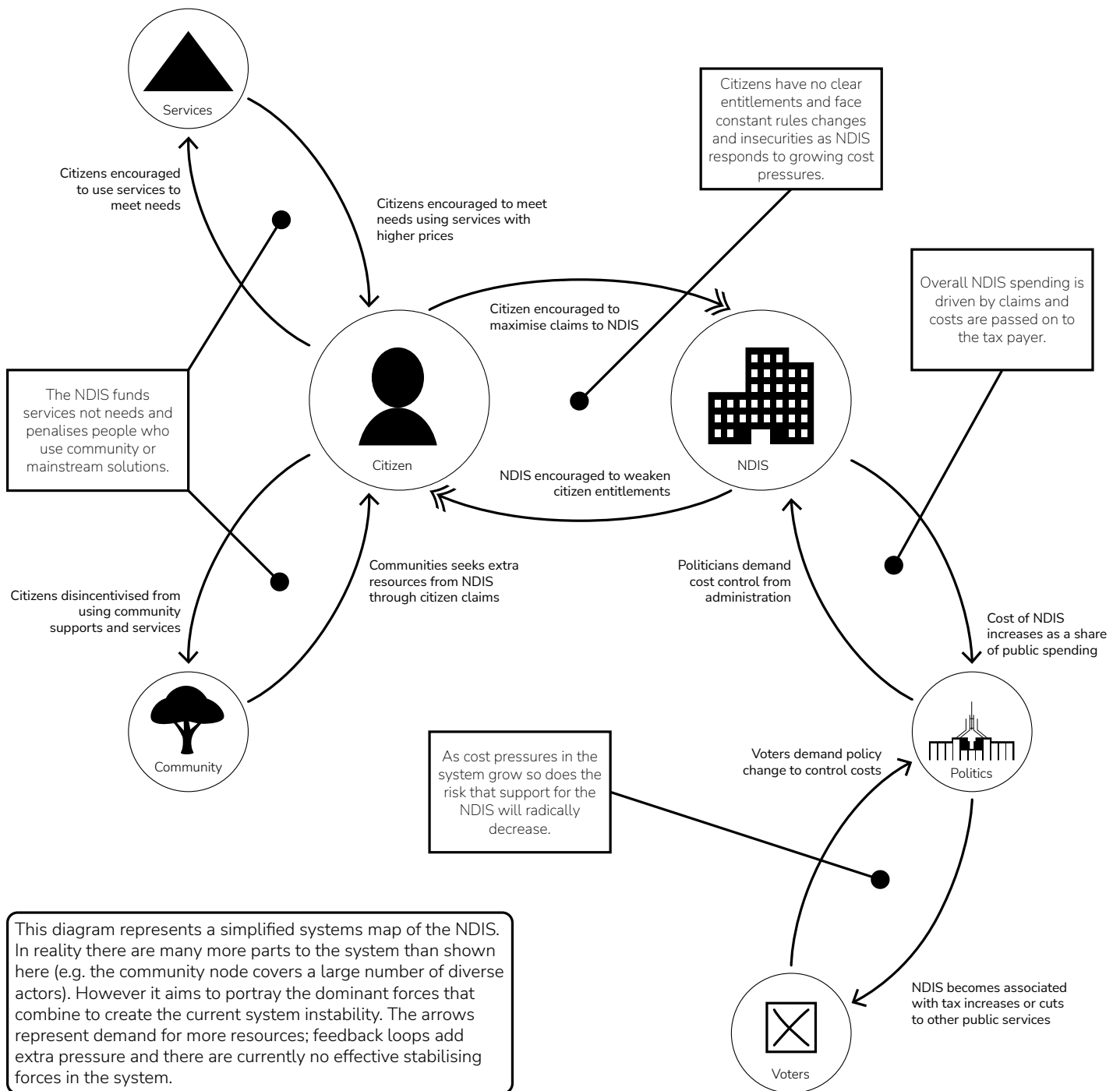


FIGURE 1. The unsustainable system dynamics of NDIS 1.0

4. The NDIA reduces funding if there are other forms of support available from the community. This means that communities (families, neighbourhoods, local areas, States, civil society organisations or other public bodies) all benefit by withdrawing support, and by helping people make successful claims against the NDIS instead.
5. The role of the NDIA is narrow. It is focused on controlling the rules by which funding applications are agreed. But not only are such rule changes likely to be ineffective they are also likely to drive more fear and insecurity into the system, which only creates further cost pressure.

Figure 1 is an attempt to demonstrate the underlying system dynamics of the NDIS. It shows that, increased pressure in one part of the system tends to increase pressure in all the other parts of the system. This is a classic example of an unsustainable system, one where there are no disciplines or checks within the system to bring it into balance.

This analysis also helps explain why the system can feel so painful for many who use the NDIS. The system makes people jump through ever-changing hoops, because the hoops are the only tool the system has to try and control costs: However painfully, people must learn how to adapt to each change in the rules, and so in the end the pressure on costs continues, although often in ways that are patchy, painful and perverse. Not everyone will be successful in accessing the resources they need. As Natalie Wade suggested, it's like the story of *The Princess and the Pea*, the mattresses are piled higher and higher, but the point of comfort is never reached.

This is perhaps the most important thing to understand. The poor experiences of people using the NDIS and the ever-growing costs of the NDIS are two sides of the same problem: a badly designed system that creates cost inflation and undermines responsible action at every level.

What is critical to understand is that this is a system problem. It is not the people who are at fault; the rules of the system create the problem. Pointing the finger of blame at people with disabilities, families, communities, services, States or public servants is the wrong response to this kind of problem. The system encourages everyone to behave in ways that then increase the cost pressure on the NDIS. This plays out in different ways and we can see how if we examine the NDIS from the perspective of those who need the NDIS.

Safeguarding State and Territory resources

Although the NDIS is a national scheme, States and Territories are still important. They still play an important role in providing other local services, including many services and supports that impact people with disabilities. They have ongoing responsibilities to their communities and to the people using their services, so when the Federal Government changes the system and starts

to provide a more generous level funding for disability services it is natural that the State will:

- Stop providing those services or offering support for those services
- Provide advocacy and support to people claiming Federal services in order to bring more resources into the State
- Look for new solutions that take advantage of generous Federal funding and reduce demand on State funded solutions

One example of this kind of change is that once someone is seen as eligible for some NDIS funding, then further NDIS funding is seen as the obvious solution to any barrier they face. However this may not really be the best solution. Many people do not need extra paid support; what they really need is for more people to be sensitive to their needs. For example, creating inclusive schools that can respond to many different learning styles is good practice—for everyone—but it doesn't necessarily require significant extra funding or support packages for every child with extra needs. However, if this is a route for bringing in extra resources then this is the route that will be taken (Read & Black, 2022).

There will continue to be many example of this kind of pattern. States, schools or other services should not be blamed for following the incentives created by the NDIS. From the perspective of the State or Territory this behaviour is highly responsible: it maximises the resources coming into the State; benefits people with disabilities within the State or Territory; while reducing the pressure on the State's own tax payers. After all, States and Territories gave up funding as part of the NDIS agreement between state and federal governments. As the system stands, it would be irrational to do anything else.

Safeguarding by service providers

There is a similar pattern of behaviour going on for service providers. Many providers are now being blamed for “price gouging” or abusing the system. However these problems are largely created by the incentives at play.

For the most common service types, the NDIA publishes the rate it is willing to pay for a unit of support (e.g., an hour of attendant care). This is one area where there is very good transparency: the reasonable and necessary rate has been defined. Of course, participants could in theory take control of their funding and negotiate a lower price to stretch their funding further than their planner budgeted for. But asking for a better deal is asking a provider to accept less than has been established as 'reasonable and necessary'. It is important to remember here that for many people with disabilities and their families it is the support provider who has been their longest-standing ally. The service provider is often far more than a business to the people who use it. The service provider often provides a relationships of care and commitment that may have existed for many years, often through times of considerable difficulty and challenge. Moreover, many agreements commence under circumstances of challenge and difficulty—there's been recent acquisition or onset of disability, needs have

increased, other supports have fallen through, equipment has broken and needs urgent replacement. The conversation with a participant is about whether a provider can help and not about what it costs.

In addition, many providers are aware that they may sometimes need to provide services without being paid promptly or at all, on the basis of their allyship with clients. Their own ethical standards or community expectations means providers don't want to turn away clients who are in a crisis. Anticipating this, they seek to build a financial buffer by accepting higher margins. Such buffers are also insurance against possible changes to rules and requirements for providers, diminishing workforce support, or economic downturns.

Providers also safeguard by staying close to the NDIA and things it appears to endorse. In theory, providers are not dependent on the NDIA. In theory, they serve participants in a marketplace of support services, and this is who most providers care about serving. But to serve clients one must stay in business, and the NDIA are undoubtedly perceived as the power player. I have an abiding memory of going to visit the NDIA office in Perth. The new office was sited in a residential area, but after the office had been set up many of the service providers, who rely on NDIA funding, then moved their offices into the area immediately around the NDIA office. Effectively the service sector colonised a large zone of a residential property in order to be as close as possible to the source of power, information and money—the NDIA. This behaviour may be unseemly, and when people tell stories of artificially high prices for services they may think that the provider is somehow to blame (Evans, 2023). But the reality is that providers are trying to survive in a complex world and their chance of survival is largely based, not on their links to community, not on their relationships with people with disabilities, but on their ability to interpret and live by the funding rules set by the NDIA.

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Safeguarding your needs

For people with disabilities and their families these problems with the NDIS design create even bigger threats. What may be hard for outsiders to understand is how much uncertainty the current system creates alongside its benefits. The questions people must ask themselves include:

- Can I describe my needs in the right way to get the support I need?
- What kind of evidence do I need to provide?
- What kinds of help will be allowed, and which disallowed?
- Will I be able to keep any of this support or funding in the next year?
- Can I change something that isn't working?
- Can I do something better when I get the chance?
- If I need less support can I risk telling anyone?
- If I need more support will that be recognised?

The NDIS is providing more money, but it is doing so in ways that are unpredictable and insecure. What makes this particularly unusual from a global perspective is that there is no reliable interface between the NDIA and its participant. In most systems of individual funding the interface between people and the administration offers one of two possible kinds of security:

1. A relatively simple entitlement defined by an administrative system, working to clear and public rules.
2. A more flexible entitlement defined by a social worker or some other professional, relying on an ongoing relationship of trust and understanding with an accountable individual.

The current NDIS design seems to be stuck somewhere in the middle of these two options, offering no reliable mode of security. Your NDIS Plan defines your entitlement temporarily, but it is subject to rules and systems that are far from clear. Experts like Marie Johnson believe that the NDIA is increasingly using AI technologies to automate systems of assessment and that these are creating serious risks for participants (Sadler, 2021). Even if you do have a relationship with a Local Area Coordinator or a similar person, to help you develop your plan, these professionals have no authority in the decision-making power, so that relationship offers none of the security you need.

Given this, it is essential for your personal security that when you apply to the NDIS that you play safe. You will try to describe your needs to get the support you need; you will try and get expert support or accreditation to do so; you will avoid risky assumptions about the future and you will avoid putting your existing package at risk by trying new things, even if they could provide benefits. You are not trusted with full discretion, nor provided with any incentives to take risks, make savings or trial more creative or community-focused solutions to your needs. You have no reason to believe, even if you currently receive a significant package of supports, that these supports will still be available in the next round. Change is dangerous.

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What went wrong

If I am correct then the essential flaw in the NDIS is not a lack of resources nor the lack of a particular technical fix. The essential flaw is that the whole system has been badly designed. So that begs the obvious question: what went wrong?

John Walsh, one of the experts we heard from, suggested that one of the fundamental problems was that responsibility for the NDIS was located within the same government department that is responsible for the benefit system. In other words the stigmatising culture and negative assumptions about human nature that are often prevalent within benefit systems has infected the NDIS. It is his view that the NDIA needs to be a very different kind of agency: more dynamic and broadly-based:

“The central Canberra bureaucracy is a crippling anachronism of control and prescribed welfare. For the NDIS to survive and thrive it requires a fundamental ground-up rebuild, with true hypothecated aggregate funding linked to GDP (from birth to age 65), and a truly independent and innovative governance body, supported by high quality reporting, research and data.”

Certainly what is striking from an outsider’s perspective is that the designers of the NDIS had an unusually high level of confidence in the ability of a centralised agency to deliver significant social change merely by creating and administering rules for funding for service packages. To me it feels like the NDIS has depopulated the world of inclusion:

- Instead of giving people a stable entitlement on which to base their own life plans, the NDIS asks them to invent plans in order to justify the receipt of funding that is now inextricably tied to services, even when services may not be what people need.
- Instead of incentivising creative action across the whole community, the current NDIS design behaves as if the NDIA is the architect of citizenship, treating an administrative planning process as a substitute for finding your way in the world.
- Instead of encouraging the creation of a more inclusive, accessible, and accommodating Australia, it creates a separate parallel NDIS world, especially for people with disabilities.

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This means that the NDIS is not just financially unsustainable, it is also undermines the vision for inclusion and citizenship that actually inspired the creation of the NDIS. It is self-defeating. It is time for a very different approach.

REGENERATION

When a positive campaign, like Every Australian Counts, succeeds there is often a large gap between the goals of the campaign and what is actually achieved (Duffy, 2016). Even in ideal circumstances, governments struggle to achieve the policy goals they set themselves; policies are often based on false assumptions about how the world works and how best to achieve the desired goal.

Worse, ideal circumstances are very unusual, and more often there are other forces, outside the control of our campaign, that can distort the policy-making process. The desire of some to make money or to protect departmental or organisational interests often pulls a good policy totally out of shape. Taking stock, it is clear that NDIS 1.0 achieved many positive things, but its implementation has also been fraught with difficulties and it is quite possible that it is politically and economically unsustainable. So a new version, NDIS 2.0, is required.

However specifying the changes necessary can be difficult. The solutions may not be obvious. It is really important for the Australian disability movement to think through:

- What do we really want to achieve? What is the true purpose of the NDIS?
- What changes in approaches seem most likely to help achieve this goal?
- How do we work together to achieve these changes? How do we keep learning and adapting?

It can be somewhat disappointing to find that the work for human rights and inclusion never ends. We need to be constantly making the case for human rights, making rights real and advancing and protecting them in the years ahead. We may learn more about what is helpful; but new challenges and problems will continue to emerge. But this is also what true citizenship means: it's a responsibility to keep working together to create a world where everyone can be included and supported to have lives of meaning and value.

New thinking

Often the greatest challenge is not political, it is conceptual. We are often trapped by the way we think about things; we use the wrong mental models and debates become polarised around ideological questions that are no longer relevant.

For example, over the past few decades governments around the world have been encouraged to think of themselves as a businesses and to adopt the principles of business when organising public services. There has also been greater reliance on automated systems and rule-based decision-making. Being business-like is often equated with being less human. These policies has certainly benefited some large businesses; but they have rarely benefited citizens. Often we seem trapped in a confusopoly of privatised services, ineffective regulators and increasingly unaccountable bureaucracies. But perhaps we are reaching the end of our tolerance for these failed policies.

Consumerism, privatisation and bureaucratic control don't seem to be the right way to respond to the problems we face today. I suspect that we need a fundamental change in the kind of thinking we apply to help us face the challenges of the future. We need to give more importance to the natural world, to our relationships, to communities, in all their diversity, and to the quality of our own citizenship. If we do not change our thinking we will keep applying the wrong set of mental models to solve the problems we face, and will keep repeating our mistakes.

An encouraging sign from a different field, is the growth of regenerative agriculture. Increasingly farmers are coming to realise that the 'modern' form of agriculture, which dominated post-war farming, is accelerating environmental destruction and global warming. Industrial farming is fundamentally extractive: controlling the design of seeds; stripping away the nutrients from the soil; replacing them with chemicals; poisoning insects and plants to boost production and focusing on whatever attracts the greatest subsidy or short-term profit at the greatest possible scale. Industrial farming leads to depletion of the soil, reduced plant diversity, species extinction and lower levels of nutrition in food. As the basic structures of nature are weakened farmers must prop up production with artificial and costly additions to the soil, provided for profit by the chemical industry. This is a perfect example of an unsustainable system: it is not only increasingly costly, it also undermines the essential productivity of natural processes.

However new patterns of farming are possible, ones which respect species diversity, strengthen the nourishing qualities of the soil, take carbon out of the atmosphere, produce nutritious food and are sustainable economically. It turns out that the earth is nurturing and self-sustaining, but to benefit from it you must treat it with respect.

Perhaps we can take a leaf out of the book of regenerative agriculture and think about what we really need to nurture the kind of society and supports that were originally envisioned by those who worked so hard to create the NDIS. Perhaps, if we apply this new kind of thinking into the NDIS Review, and into ongoing public policy, we can safeguard the sustainability of the NDIS.

Citizenship for all

In his review of global systems for self-direction, Lynn Breedlove notes that there is a clear division between systems that see themselves as promoting the value of equal citizenship for all and those that pursue a more limited goal of offering ‘choice and control’ over services (Breedlove, 2020). Currently the NDIS seems to focus on the delivery of services. Having choice and control is seen as important part of the system of ‘market management’ but it is not aligned to a larger vision.

In fact it is hard to get a clear sense of what the NDIS is meant to be achieving or how its success is being evaluated, beyond the provision of more services. This makes it quite hard to evaluate the success of the NDIS:

- Are people taking up more roles in paid or voluntary work?
- Are people growing their network of friends and family?
- Are people getting homes of their own?
- Do people feel their lives having meaning and value?
- Are people leaving institutional care and living more independent lives?

These are just some of the objective measures that would help us understand whether the NDIS is effective. Note that these are not measures of inclusion, they are also highly sustainable goals, creating the conditions for further contribution, mutual support and legitimacy. On the other hand, if the NDIS is creating institutionalisation, social isolation and dependency on professionalised supports then it is likely to be also increasing the long term cost of the NDIS and reducing the value of the NDIS for Australian society.

Surely the true measure of the success of the NDIS is that more people with disabilities are taking their rightful place as full and equal members of Australian society. This is called citizenship - this has nothing to do with having a passport - it is about taking your place as a valued and equal member of society (Duffy, 2017). One model that Australia could adopt or adapt is the *Keys to Citizenship* which provides a framework for personal and collective reflection on how to build a life of citizenship (Duffy, 2003; Duffy & Perez, 2014):

1. **Meaning** - Are we happy with our lives? Do we have goals that matter to us?
2. **Freedom** - Can we make our own decisions? Do people around us understand our desires?
3. **Money** - Do we have enough money to live on with dignity? Can we control our money?
4. **Help** - Can we give and get help from others? Is the help we get positive and respectful?
5. **Home** - Do we have a home of our own? Do we choose who we live with?
6. **Community** - Are we playing our full part in life of the community? Are we valued by others?
7. **Love** - Do we have family, partners, friends, colleagues, neighbours? Are we loved? Do we love?

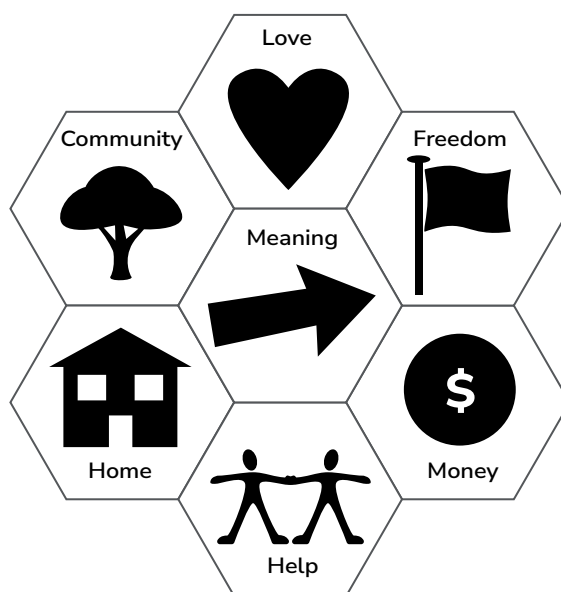


FIGURE 2. Keys to Citizenship

The *Keys* framework is utterly universal. It is not a special framework, created only for people with disabilities, but many people with disabilities and families have found it a helpful way of imagining how they can create their own life of equal value within society. For example, one Australian father of a child with disabilities, talks about the *Keys to Citizenship* like this:

“I had discovered what I feel is a significant piece that brings everything together that not only provides a roadmap to guide us towards where we should all be as people, but as part of that roadmap, it provides a framework from which to understand where we have come from.”

Kalemkeridis M (2022) Reimagining Disability In Family Life.

The *Keys* framework creates a sustainable model for social change. It creates demands for justice, but demands that are naturally constrained and reasonable. For example, people need money to be a citizen, but only enough money. Excessive wealth and poverty are both hostile to citizenship. Fundamentally the model seeks to maximise our agency and purposefulness, within the context of our relationships and the communities we can build together.

Liberating safety

Another essential element of a good life is safety—safety from abuse, exploitation, neglect, and other serious hazards. Safety is important for everyone. Feeling safe is a necessary condition for our motivation to pursue anything else. When your primary concern is for your own survival or for that

of a loved one, then an NDIS that focuses on citizenship may seem irrelevant. For many people these are everyday fears:

- Will someone know what to do if I start to choke, fall or have a seizure?
- How would I protect myself if someone tried to hurt me?
- Who will look after my son or daughter when I no longer can?

For many others, safety is a concept that only seems to be used as an excuse to restrict and restrain people with disabilities, ostensibly 'for your own good'. When safety and safeguarding are emphasised, many people brace themselves for another reduction in their autonomy and the imposition of new checks, controls and increased monitoring. In practice the effort to reduce one risk often increases others, as well as undermining the pursuit of personal goals (Duffy, 2013d). For many, autonomy feels like the basis of their safety.

These two perspectives seem to be in unavoidable conflict; but reconciliation is possible. For real safety only comes through citizenship, by creating a society where people look out for each other and where we always seek to nurture each other's capacity for freedom and agency. Safety is created by community and community is created by citizenship. It cannot be created by bureaucracy.

When a society protects all its citizens, it also frees them to explore, connect, innovate, and appreciate the life they create together. A world where people with disabilities are full citizens is one where there is a collective responsibility for safety, especially for those who cannot protect themselves, and this safety unlocks a sense of peace, freedom, and opportunity. A liberating sense of safety of this kind frees up individuals and families to connect with their community; these connections provide the additional safety of a community looking out for you.

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Real wealth

If we are to create a society of citizens, we need to understand the essential capabilities that make it possible for people to lead good lives of value and contribution (Sen, 1999). A particularly useful framework for understanding these capabilities was developed by Pippa Murray, who worked with people with disabilities and families to develop a model of *Real Wealth*, outlining the factors that enable a person to be safe and to live a life of citizenship (Murray, 2010). These factors are:

1. **Gifts** - having one's own unique interests, passions and dreams.
2. **People** - being in valued relationships of love and mutual support.
3. **Community** - connecting, participating, working and playing our part in life.
4. **Assets** - having access to money, property, time and energy.
5. **Spirit** - seeing possibility and connection and creating hopeful plans.

We might think of these as the ecological conditions of human development and the interplay of all these five factors is essential to that development.

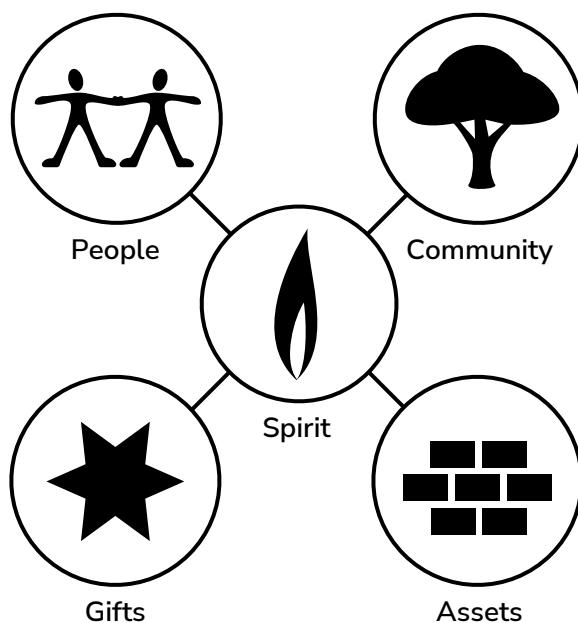


FIGURE 3. Real Wealth

An effective NDIS would be focused on strengthening all of these capabilities and doing everything possible to encourage people to build on and develop their own *Real Wealth*. However, as we've seen, NDIS 1.0 has been designed in a way that can often create perverse effects. The primary focus of the NDIS is to identify and fund services that are deemed 'reasonable and necessary' but it does so in ways that can discourage the development of *Real Wealth*:

1. If I learn new skills, try to achieve things without support or find more creative ways to achieve my goals then I may lose my entitlement to support.
2. If I build on relationships of love, family or friendship to achieve some of my goals then I may lose my entitlement to support.
3. If I become part of mutually supportive communities, like a good work situation, a community of faith or peer support, then I may lose my entitlement to support.
4. If I use my own assets, my own time, capital or money to create some kind of helpful solution then I may lose my entitlement to support.
5. If I become more hopeful, confident and creative then I may lose my entitlement to support.

All of these fears are increased by the design of NDIS 1.0 because its funding model is based on services, not needs. We can meet needs in many ways and paying for a service is often not the best way to meet a need. However, if the system only treats services, not needs, as legitimate, then all our needs have to be converted into a need for services in order to be legitimised. This undermines our ability to identify, build on and grow our own *Real Wealth*.

A truly sustainable system of disability supports would be one that actively encouraged people to build on their gifts and interests, strengthened networks of family, friends and community and provided positive incentives for inclusion, citizen action and community development. The underlying spirit of NDIS 1.0 seems hostile to what we know helps people plan creatively and optimistically:

“However to date the NDIS has failed to deliver on choice and control and the promise of being able to shape one’s own future. Instead, these constructs have been rationally and politically defined rather than understood in the context of relationship and personal agency. Nowhere is this more evident than in the absence of language and opportunity for ‘dreaming’ and ‘visioning’ in the planning and implementation processes of the scheme. The NDIS documentation and processes indicate no expectation or evidence of individual aspiration. It is no surprise that individual plans tend to reflect a closed, rather than open view of the future for people with a disability, particularly in the context of media headlines of NDIS sustainability concerns and cost blow-outs.”

Rose V, Reimagining futures in the Australian Disability Sector in Koenig O (Hrsg.) (2022) *Inklusion und Transformation in Organisationen*. Bad Heilbronn: Julius Klinkhardt. p. 289

The fundamental shift

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NDIS 1.0 has brought many benefits, but as we have argued, it seems unsustainable, unstable and often quite frustrating for its participants. There is no easy fix to these problems because its design flaws seem to be deeply embedded in its basic architecture: most people, agencies and communities have been stripped of their responsibilities and the NDIA is left only with the most limited tools to manage the cost pressures the current pressures the system creates. We need a new radically new design for NDIS 2.0 that builds in several essential features to ensure its effectiveness and sustainability:

- Treat people as citizens with rights and freedoms
- Encourage people to grow their *Real Wealth*
- Respect communities as essential to achieving citizenship
- Value, but don’t prioritise, the role of professionals

In my own work I have tried to articulate this change as a shift from the *Professional Gift Model* towards the *Citizenship Model* (Duffy, 1996). In other words the shift we need to make is from a top-down system where needs are defined and met by a system of authority outside the person’s control, towards a system where each person is supported to define their own life and the supports they need, supported with meaningful entitlements and a mixture of professional and community support.

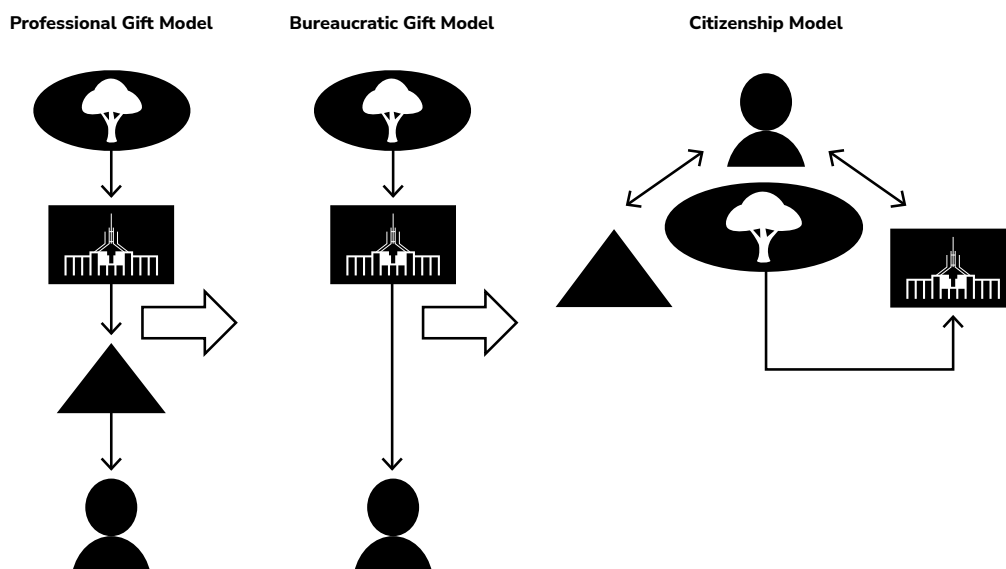


FIGURE 4. Three models for service delivery

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Going back over the last 150 years or more, institutions or professionalised services have been funded by governments and these services have in turn determined who was eligible for support and what services people would receive. Services were gifts (sometimes most unwelcome gifts), defined and delivered by professionals. People had little power to challenge or reject what was offered; they certainly were not treated as citizens with rights and the ability to create their own life or their own support solutions.

However, in the late Twentieth Century things started to change and governments started to adopt quasi-market models where services were purchased for the individual, based upon a professional assessment by a case manager or similar professional. The top-down spirit of the Professional Gift Model persisted, but it was now certain kinds of professional who were supposed to dominate the decision-making process. Services, and the professionals who ran them, were supposed to be relegated to a ‘provider’ function—meeting the needs as defined by the case manager.

The current version of the NDIS takes this quasi-market model even further. Today it is the NDIA that defines the person’s plan and there is no clear professional assigned to assess needs. Instead those professional functions have been absorbed into the NDIA’s bureaucratic process. Perhaps the NDIS 1.0 has created a new kind of *Bureaucratic Gift Model* where nobody is responsible for defining the ‘gift’ of services.

But it is the *Citizenship Model* that reflects the true values that inspired the creation of the NDIS and it offers a much better framework for developing a sustainable and stable system. We need an approach that supports people to be citizens, not consumers of services, but active and contributing members of the community. We need an approach that provides people with robust and flexible entitlements that people can use to work in partnership with professionals or to invest in their own communities. The NDIS plays an essential role in moving resources towards people with disabilities based upon their needs; but it must be open to learning, as an equal partner, alongside people with disabilities and their allies, how best to use those resources. Citizenship should provide both the goal and the animating spirit of NDIS 2.0.

NDIS 2.0



It is certainly possible to offer some examples of global good practice and principles of good system design to offer suggestions on how to improve the design of the NDIS to advance citizenship. However it is even more important that the system itself becomes much more capable of ongoing innovation (Duffy, 2014a). Individually and collectively Australians must keep learning how best to use the resources available to them and to create increasingly more effective solution. So, in order to promote innovation, NDIS 2.0 needs to be designed to create three different zones of innovation, and to understand the interconnection between these zones:

- 1. Citizen innovation** - We may not think of it as an innovation, but if we want to bring about positive change in our lives we need to innovate, do something new, challenge ourselves and use our resources (and not just financial resources) differently. Critically NDIS 2.0 must create the conditions for citizen innovation and personal change.
- 2. Community innovation** - Our ability to live a life of citizenship, with meaning and contribution is largely determined by the quality of the communities we live within. If we are welcomed, supported and encouraged to contribute we will each grow personally and strengthen the communities we are part of. NDIS 2.0 must respect the role of community and understand the conditions for inclusion and development.
- 3. Professional innovation** - There is also a field of professional and organisational practice where there is innovation and good practice. There is still much to learn about how best to provide support, what systems work best and how to work to promote active citizenship and inclusive communities. The NDIS is itself a system that need to improve, but it also needs to be redesigned to encourage ongoing professional innovation.

All of this implies that NDIS 2.0 must leave considerable room for plurality and diversity. Citizens need to be able to find the right solution for themselves, in their own unique circumstances; communities need room to develop better solutions and learn from other; and there needs to be enough space in the development of NDIS 2.0 to allow Tasmania and Western Australia to each explore different approaches. In retrospect, perhaps it would have been better to allow states, like Western Australia, to develop their own version of the NDIS (Bartnik et al. 2023). The First Nations of Australia should be also able to develop approaches that make the most sense in their own cultures. Portable

entitlements and a shared commitment to equal citizenship makes sense, but uniformity for the sake of uniformity does not make sense—it simply kills learning and innovation.

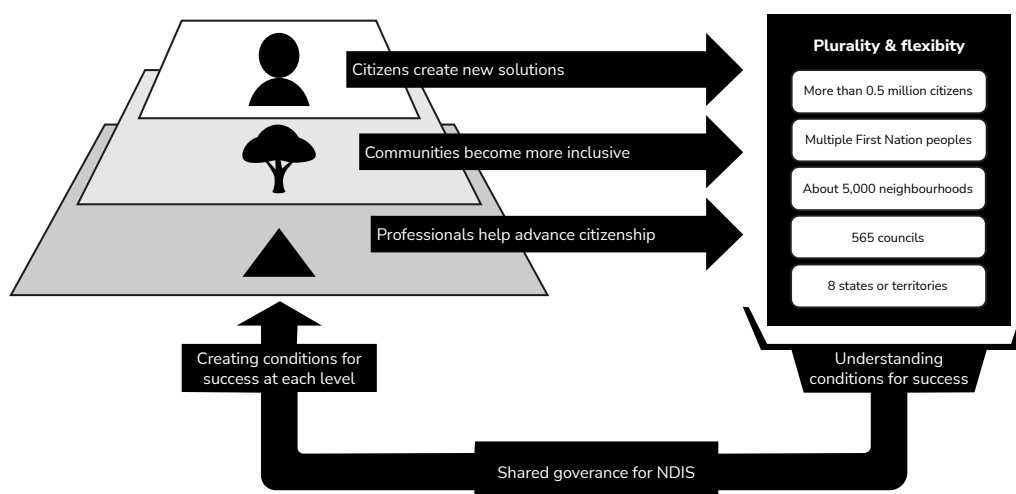


FIGURE 5. Three zones for innovation

Using this framework we would like to suggest a series of reforms that would improve the NDIS and increase its effectiveness, efficiency and sustainability:

1. Create a system of personal budgets and self-directed support to ensure everyone has clear and meaningful entitlements they can control.
2. Encourage peer support at every level, particularly for people with disabilities and families, to enable them to get mutual support and to drive the process of community change.
3. Make the funding system sensitive to communities of place and culture and increase the opportunities for communities to create new solutions for inclusion.
4. Establish a system of collective governance for the NDIS, enabling open discussion and negotiations on available resources and strategy.

We hope to show that these four areas of reform are critical reforms that can help the NDIS re-establish itself as a sustainable, regenerative and innovative framework for social change. There are, of course, many other improvements and reforms that are worthy of further exploration: personalised support, local area coordination, support brokerage, neighbourhood networks, supported employment, micro-boards and the use of new technologies (Bartnik & Broad, 2021; Duffy et al. 2019; Fitzpatrick, 2010). NDIS 2.0 would be a foundation for

the development of all these innovations and would seek to encourage greater integrity in their development. However our focus is on changing the more fundamental architecture around which these innovations might develop.

Personal budgets

Although the NDIS aims to offer everyone greater choice and control over their own support, in practice, it stops people using resources as creatively as possible. This means the scheme doesn't really benefit from the fact that, beyond anyone else, people with disabilities and those closest to them, know what is working and not-working about their support, have the greatest incentive to get their support right and are in the best position to reshape their support.

The current system is individualised, but it is not really a system of self-directed support that maximises everyone's level of control. Instead of offering some people 'self-management' (with some real, but limited additional flexibilities) it would be better to treat everyone as self-managing, but then ensure that the system was designed to make self-management as easy as possible and to ensure everyone can get the additional support they need.

Systems of self-directed support have been developing for nearly 60 years and there is a lot of evidence about what makes these systems work well (Fleming et al. 2019; Duffy, 2018; 2021a). We have included the *Global Standards for Self-Directed Support*, published by the SDS Network, as an appendix to this report. One of the most important features of a good system of self-directed support is that everyone has a clear personal budget.

Currently the NDIS does not give people a real budget, because they're not truly free to pursue good outcomes for themselves in a practical and agile way. Because the budget is so tied to their 'individual plan' and the opaque processes that created it, using the budget is riven with anxiety about how the next plan will be affected. This does not create the conditions for good decision-making, risk-taking, creativity or for identifying possible savings or efficiencies.

One useful solution to this problem is to create a transparent approach to resource allocation (Duffy, 2015). The global literature on self-directed support does not provide any clear empirical evidence as to the benefits of any particular resource allocation, but it does suggest that it is very useful if people know their own budget and can lead the process of shaping how it is used. These principles might be useful to apply and test in the development of NDIS 2.0:

- Rather than a line by line budget allocation, a real budget improves clarity for people with disabilities and anyone in the system who is making an assessment of need.
- Budgets can be correlated to broad descriptions of need and subject to reasonable human judgements, with accountability.

- Empowered with knowledge about their budget people can work, with peer, family or professional support to make (and adjust) their own plans to find good solutions to fit their own circumstances and objectives.
- A process of checks and balances can be created to help people to revise their budget if the budget cannot be made to work.
- As the NDIS works now, most people with disabilities will have a lower budget, and fewer people will need a higher budget.
- A transparent system would enable better cost control, providing clearer evidence on what is working, what needs to change and enabling meaningful negotiations at the Federal level.

Given the problems of cost control currently experienced by NDIS 1.0 I can understand why the NDIA would be very concerned about making the resource allocation process transparent. I also understand why people with disabilities might be fearful of a system that was too simplistic. However my experience of designing transparent and flexible systems is that they can bring many benefits, some of them quite surprising. For instance, when developing systems for local authorities in England, we found that mostly people worked to the initial budget and saw significant life improvements (Duffy, 2005). Moreover, of the minority who wanted to amend their budget, most thought that their indicative budget was too high and they moved to a lower budget. I suspect that this is because people with disabilities, like most citizens when they are treated with respect, are highly responsible and want to ensure that there is no waste. It helps if people believe that any savings that they help achieve are going to benefit others.

Another important detail for NDIS 2.0 is the need to ensure that the cut-off point for people who are eligible for personal budgets is not too severe. Closing down options too severely for this group is likely to create more pressure for people to seek personal budgets when that is really not really the most appropriate solution. One solution might to ensure that NDIS 2.0 can respond to the relatively large number of people who will be on the edge of eligibility with short-term grants and flexible funding.

Another strategy for improving NDIS 2.0 would be to give people a much higher level of budget security. In fact the built-in system of annual or two-yearly reviews (reviews which might radically reduce or remove your budget) is one of the most peculiar features of the NDIS, especially as the NDIS is defined as being for people with “permanent impairments”. If people know that their funding is unlikely to radically change, unless there was a significant change in health or in level of need, then people could plan properly, take risks and explore what works best for themselves.

Similarly, if people also were allowed to bank any savings that they made then people would be in a much better position to take responsibility for their own budgets. The current system effectively infantilises citizens, taking away all the natural incentives that encouraging responsible action. Again, one of the most consistent findings in the global research on self-directed support systems

is that people with disabilities tend to be far more careful in managing their budgets than services or bureaucracies. If people are allowed to keep the savings they generate, then people tend to maintain a running balance, protecting themselves against future difficulties. However systems often see these savings as ‘under-spends’ which they then try to clawback. How much more intelligent NDIS 2.0 would be if it incentivised these savings, rewarded responsibility and created incentives for greater fiscal control across the whole system.

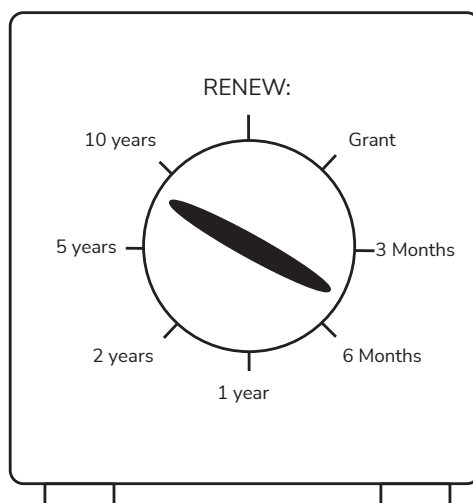


FIGURE 6. Setting variable lengths for personal budget

In addition to clear budgets, and increased security of funding, people should have much more flexibility in how they can use their budgets (Keilty, 2020; Dickinson et al. 2022a). Funding flexibility is what allows innovation and innovation is what creates the conditions for greater efficiency. It is only when people can do something unexpected and outside the norm that we can discover how to do something better. As Frank Zappa puts it:

“Without deviation from the norm, progress is not possible.”

One way to reinforce these changes would be to abandon the idea of an NDIS Plan and the expectation that it is the responsibility of the state to track every expenditure that someone makes in their own life. In fact the idea that people with disabilities, unlike other citizens, must constantly share private information about their lives is highly questionable and seem to be in conflict with the UN Declaration on Human Rights:

Article 1: “All human beings are born free and equal in dignity and rights”

If so, why do I have to share my life plans with a government agency employee who does not need to share their plans with me?

Article 3: “Everyone has the right to life, liberty and security of person.”

But I am not free to set my own plans; I must get the agreement of a government agency to my own plan.

Article 12: “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence.”

But I need to share my plans, private information, financial information and information about family and friends.

Article 17: (1) “Everyone has the right to own property alone as well as in association with others. (2) No one shall be arbitrarily deprived of his property.”

But I do not get full control over my own funding and any savings I make will be taken away.

Article 23: (1) “Everyone has the right to work, to free choice of employment.”

But if I need assistance to access work I have to get agreement from a government agency.

Article 27: (1) “Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.”

But I need to have agreement from a government agency before being able to pursue access to community life.

Article 29 (1) “Everyone has duties to the community in which alone the free and full development of his personality is possible.”

But I do not have responsibility for managing my own budget to develop my own life and my community contribution.

Again the research literature constantly reinforces the importance of flexibility to people with disabilities. However systems are constantly tempted to try and control how people use their budgets, despite the fact that the evidence suggests that people, and those closest to them, are the best decision-makers.

Now it may seem that self-directed support is only relevant work for people who have a great deal of competence at planning, managing money and making complex decisions. But this is not true. For people who need extra support in these kinds of management decisions all that is required is that there is another trusted person or agency willing to take on some or all of these roles and work in partnership with the person (Duffy 2003; 2013d; Smith & Brown, 2018; Stainton et al. 2021). There are many organisations in Australia, including support providers, that have already demonstrated that personal budgets are a completely universal model (Fitzpatrick, 2010; WAIS, 2012; Walker, Fulton & Bonyhady, 2013).

The principle that must be pursued is that for each individual the system must seek to ensure that decisions are made as close to the person as possible and in a way that supports, instead of fettering, the person's ability to find the right solutions for their own needs. Management from a distance never works. Talking about personal budgets may seem confusing and rather technical. But what this is really about is making human rights real. A meaningful human right is a right that is converted into a clear entitlement, and entitlements are only useful if they help the person create a better life for themselves. The current system seems locked into the *Professional Gift* mentality, where the system knows best; but all the evidence is that the person, especially with the right support, knows best. The NDIS needs to move away from delivering packages of services, and instead ensure people have meaningful and useful entitlements (Duffy, 2021).

Peer support

One of the most striking aspects of the shift towards greater control and freedom for people with disabilities is that we often forget that sustainable progress always comes from collective, not individual action. The modern world is highly individualising, but social progress comes from collective action and the integrity of social change is only assured by collective action (Evans, 2003). As Jane Addams puts it:

“The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life.”

The most important kind of collective action for people with disabilities—but not just for people with disabilities—is peer support. Peer support means being able to connect with, get support from and, very importantly, give support to other people living through similar experiences. The value of peer support includes:

- You hear from people who really understand what you are experiencing.
- You trust people who have shared life experiences more than others.
- You can get practical assistance and reliable information from people you can trust.
- You can be challenged with new ideas and better understand what is reasonable or what is wrong.
- You can make a contribution back and increase your own confidence and sense of value.
- You can grow into leadership roles and help safeguard advance in human rights.
- You can find paid work, building on your peer support and personal experience.
- Together you can challenge systemic injustices.
- Together you can design better collective solutions to solve common problems.

Peer support is not a service that can simply be purchased or commissioned by the NDIA (or any other body). Peer support, if it is real, is part of community life. It may benefit from some ongoing financial support and it may find other ways to sustain itself, but it must be based on the real leadership of people themselves.

There are many good examples of peer support and for people with disabilities this has often come in the form of a Centre for Independent Living (CIL), which has been a central aspect of the work of achieving independent living for people with disabilities since the 1960s (Zukas, 1975). Often the work of the CIL can become increasingly functional and sometimes the spirit of mutuality can be lost. In the UK the combination of a drive towards commissioning CILs by government and procurement rules that did not pay attention to the reality of community life led to CILs becoming businesses, rather than genuine hubs of peer support (Duffy, 2013c). This is a danger Australia must guard against.

However Australia is certainly leading the way in family peer support. The work of Plumtree, in New South Wales offers an exemplary model of what can be achieved when people come together to learn together, grow in confidence and develop the skills to negotiate effectively with professional services and the system (Mahmic & Janson, 2018). One of many great strengths of this model is that families of children with complex disabilities can learn together that medicalised or institutional services are often counter-productive.

Another model of peer support that is emerging globally is the movement of people with mental health problems and disabilities into active community groups, focusing not just on mutual support, but also on community and system transformation. For example, PFG Doncaster is a group from the North of England which has generated a significant level of community action led by peer supporters. They do not take mainstream life (with all its inadequacies) for granted, instead they are changing what mainstream life means and leading the wider process of community change. They have created a hub where many people in the community get support from each other, without going near existing public services, and they have created many innovations in mental health support. A recent report on their work demonstrated that this peer support community has generated activity and value far in excess of the money invested in it by government (Duffy, 2021). People with disabilities, coming together as equals and offering each other support, creates significant and irreplaceable value.

Peer support could also be built into existing processes for helping people claim and manage budgets. It would be quite possible for the NDIA, local area coordinators or other actors in the system to encourage people to offer peer support and to refer people to others willing to provide peer support (Duffy & Fulton, 2010). There is no good reason why the process of engaging with the NDIA should not be peer-led. In fact, given that there is a need for a much more local infrastructure for support then it might make a great deal of sense if the development of new forms of local support, coordination and even allocation of funding, were led by people with disabilities themselves.

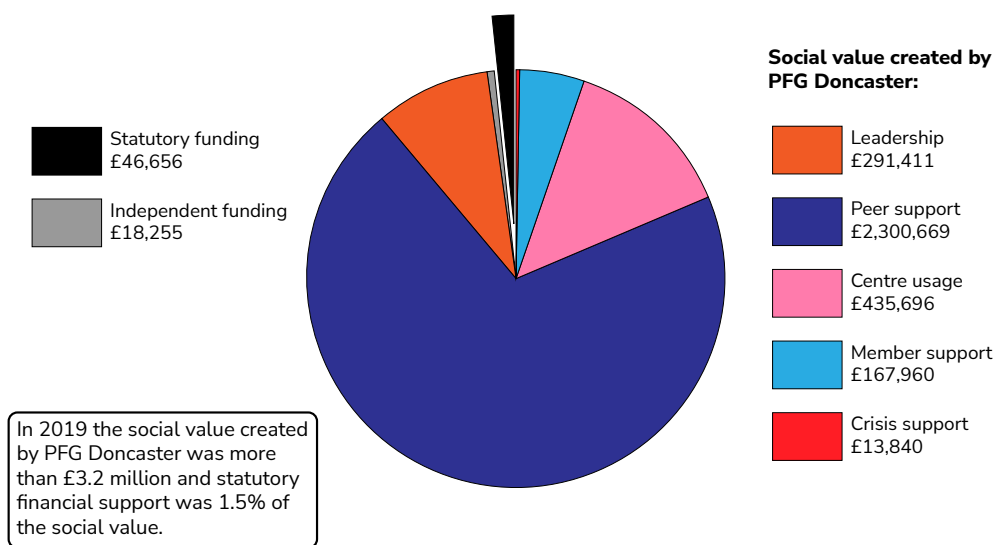


FIGURE 7. Example of social value created by peer support

Inclusive communities

Earlier we made the strong claim that the current NDIS design has had the unfortunate effect of depopulating inclusion. The tacit assumption built into NDIS 1.0 was that the centralisation of power and responsibility within a Federal bureaucracy, combined with the limited choice and control offered to people with disabilities, would be enough to create the kinds of communities we need to ensure everyone can be a full citizen. But this was never going to work.

I suspect that the bureaucratic culture created by NDIS 1.0 is having other multiple negative and unforeseen effects (Campanella et al. 2023; Lavelle, 2023). For example, the high level of fraud in the current system is surely a function of the impersonal nature of the current system (Dickinson, 2022a). Fraud grows with hierarchy and lack of accountability; keeping things smaller, more human and transparent is the best protection against such abuses. NDIS 1.0 also seems to be hostile to common sense. For example, Carmel Laragy reflected on the peculiar behaviour she’s seen in residential care settings:

“When I ask about it, what are they doing, how are they helping their residents, what sort of lives they have, what opportunities are they helping them to create, they say: ‘Oh, that’s not our role. That’s for the LACs. We don’t have anything to do with their life. We just provide the accommodation and we can’t take them out in the community bus anymore, because it’s only individual funding, which is a curse. We can’t get them to do anything as a group.’”

This is a good example of the kind of *Cogworld* created by bureaucratic systems and described by John O'Brien in his study of how innovation and humanity are being driven out of the US disability support system by the increasing use of intermediary agencies to cap costs and generate profit (O'Brien, 2015).

Instead of encouraging people to be responsible and creative the system seems to push people into subservience to the rules (sometimes even into imaginary versions of the rules). We must always be alive to the dangers of bureaucratic thinking and the loss of humanity and basic common sense that this entails. Instead of all this NDIS 2.0 must repopulate the world of inclusion. The first two steps have been covered above: ensuring people with disabilities are truly empowered with real entitlements and encouraging people to connect and work collectively through peer support.

But the work of inclusion is not only the work of people with disabilities. For example, in their original form, as developed in Western Australia, Local Area Coordinators have shown that they can play a powerful role in making inclusion real (Bartnik & Broad 2021). Taking that role back to its original purpose would be very helpful. But, the work of inclusion cannot be delegated to just one professional group. Everyone should be working to create inclusive communities and respect human rights.

Instead of focusing on only one group it may be more useful to sketch out some of the kinds of people and organisations who should be active in the development of a more inclusive Australia and think about how all of these groups could be more positively engaged in the development of better solutions. Even in a world where people with disabilities have maximised their personal agency there are several other important groups to consider:

- **Families** - For families with children with disabilities it is critical that they receive peer and professional support that orientates them towards inclusion. Families provide the bedrock of support for everyone. Their role needs to be respected as an essential element of the rights of the child and as the platform for personal development and citizenship (United Nations, 1989). Family support should be orientated towards inclusion and support needs to be family-centred and mindful of the needs of the whole family (Mahmic & Janson, 2018; Murray, 2010; 2011).
- **Schools** - Schools should support the family in supporting the development of the child into a life of citizenship, strengthening confidence, relationships and skills (Cowen, 2010). For children with disabilities an inclusive educational environment is likely to be the most rewarding and effective; however this also implies that schools must be capable of adapting themselves to educate every child effectively. Educational policy makes an enormous difference in whether all children are included or some are excluded from the mainstream (Heir T et al. 2016; Robinson, 2009).

- **Neighbourhoods** - In many post-industrial societies neighbourhoods may not seem to be important. They have been bypassed by the development of forms of commerce, work, public service and entertainment systems that operate on a larger scale, but which also tend to isolate people from their immediate community of place. However there are good reasons to think this phase of development is over (Russell & McKnight, 2022). The COVID pandemic illustrated the power of community in a crisis and the existence of powers and potential within community that often lies latent (Duffy, 2020). Our local community is certainly the place where our own citizenship is likely to be most fertile, and in a world of increased automation and of environmental, democratic and economic crises, it is our capacity to cooperate at the most local level that will best ensure our ability to survive and honour our responsibilities to each other (Duffy, 2023).
- **Business and civil society** - People with disabilities have a complex relationship with civil society organisations and businesses. Some organisations provide some status and resources by offering employment, advocacy or supporting people to be active citizens in their communities. Other organisations may play a more ambiguous role, offering support, but in ways that leave people isolated from mainstream life and dependent on professionalised care. Residential care is an example of what can often be a form of institutionalisation. It seems unlikely that a redesigned NDIS should be neutral about what kind of support it promotes. In many ways the lesson of that past few decades has been that commercialised care services have adapted to new world of individualised funding by lobbying for systems that discourage innovation, flexibility and real personal control; instead of promoting inclusion and citizenship modern funding systems can actually create new forms of micro-institutionalisation and remote control (O'Brien, 2015; Jackson, 2017). A regenerative NDIS needs to be mindful about supporting organisations that grow citizenship, and to guard against supporting organisations that encourage institutional services (Fulton, 2016).
- **State and local government** - In carrying out research for this report most of those we talked to were grateful that the new system was on a much better footing than the old State-based systems and nobody had seriously considered the possibility that local government might play a useful role in the future. The assumption that the Federal government is the dominant partner is an important Australian reality. However it should be noted that this is quite peculiar by international standards. Although advocates rightly want the portability and better funding that comes with centralised solutions it is hard to find examples where so little innovation is allowed at the local level. (Although New Zealand also has a highly centralised disability support system.) Even small countries, like Iceland (with a population of 300,000) devolve most services to a municipal level (with an average size of about 3,500.) Would the First Nations of Australia not benefit from having far more control over their own support solutions? Can we not achieve portability and fairer funding together with more local responsibility, democratic accountability and creativity?

In the broadest terms the challenge for a redesigned NDIS is to ensure that all of these groups are motivated to support the rights and inclusion of every person with disabilities (including the vast majority of people with disabilities who are not entitled to personal budgets from the NDIS). Contrary to some of the current discourse, most people and groups do want to do the best by people with disabilities; however, as we've discussed, the current NDIS design makes claiming for funding from the NDIS the most obvious and effective route to achieve this goal: it benefits the person, it benefits the organisation and the costs fall on the Federal government. These perverse incentives become super-charged when profit-seeking is the central function of the organisation and where there is no wider sense of responsibility and stewardship for the available resources.

The challenge is to continue to incentivise positive action for inclusion, while also encouraging a more regenerative approach, one that does not create the same strain on the whole system. One possibility would be to create community wealth funds for inclusion which were managed at a local level and led by people with disabilities. This fund could be used flexibly with funding that would not be subject to clawbacks, but where savings, income generation and efficiencies could be safeguarded for the benefit of the community. In addition, this fund could be designed so as:

- Its size reflected the level of need in the community
- The fund would be reduced if the level of personal budgets were higher than average
- The fund would be increased if the level of personal budgets was lower than average

Given that we certainly have the data to know what a broadly fair geographical allocation should be, it would then seem possible to balance out individual and community funding. In places where the aggregate of personal budgets was lower than the community investment would be higher, and vice versa. This would take away the perverse incentive for communities (in the broadest sense) to claim personal budgets instead of investing in accessibility and inclusion.

Innovation is only possible if you have the means to do things differently, and it is only likely when you have a natural incentive to do things better. This is true for citizens, it is true for organisations and it is true for government. The next stage in the design of the NDIS needs to make sure that all the key stakeholders have the means to innovate and also the incentive to do so.

New governance

Whatever the destiny of the NDIS and the wider social policy context in Australia, one thing is clear. Australia's achievements in human rights are a direct result of the capacity of Australians with disabilities to gather their own forces, to advocate clearly and to build alliances with others. Maintaining this momentum is essential. Progress is not inevitable; the challenge is to go further and to think more deeply about what is required in a changing world.

Currently the Australian government is committed to try and achieve recognition of Aboriginal and Torres Strait Islander Peoples as the First Peoples of Australia in the Constitution of Australia and to establish legal structures to protect their Voice. This kind of constitutional innovation is an important effort to protect a minority perspective.

Perhaps it won't be necessary for people with disabilities to seek exactly the same constitutional protections, particularly as Australia is party to the United Nations Convention on the Rights of People with Disabilities; but safeguarding the true purpose of the NDIS demands that people with disabilities have an active involvement in the design of the NDIS. If we have learned one thing from the development and design of the NDIS it is that it is not enough to have won the political battle to establish a new policy. Details matter, the precise design of policies matters, and it is essential that there is ongoing development to ensure that good intentions are converted into truly regenerative strategies. This also means being prepared to engage with the costs and constraints of any policy and being willing to engage with different interests and different perspectives.

Having people with disabilities central to the administration of the NDIS will certainly be helpful (Wright, 2022). But perhaps the issues go even further. What if there was an open and regular review of how public policy was achieving human rights that could take regular submissions from the different groups involved and which had responsibility for advising politicians and administrators? Realising human rights means discussing how to achieve them, and this is an ongoing issue; there is no one-off technical fix. As Natalie Wade observed, legislation should not drive policy-making and it is wider issues of public perception and understanding that must always precede the law and guide the detailed policies put in place.

Citizenship for people with disabilities means having a stake in understanding how the rights and responsibilities of citizenship are being realised and having the chance to shape and reshape policy in order to achieve the best possible balance of measures:

- **Purpose** - Define policy goals and evaluating whether these policies are successful.
- **Functionality** - Understand how the system works and work to improve those systems.
- **Sustainability** - Ensure the system is affordable and has support for the long-run.

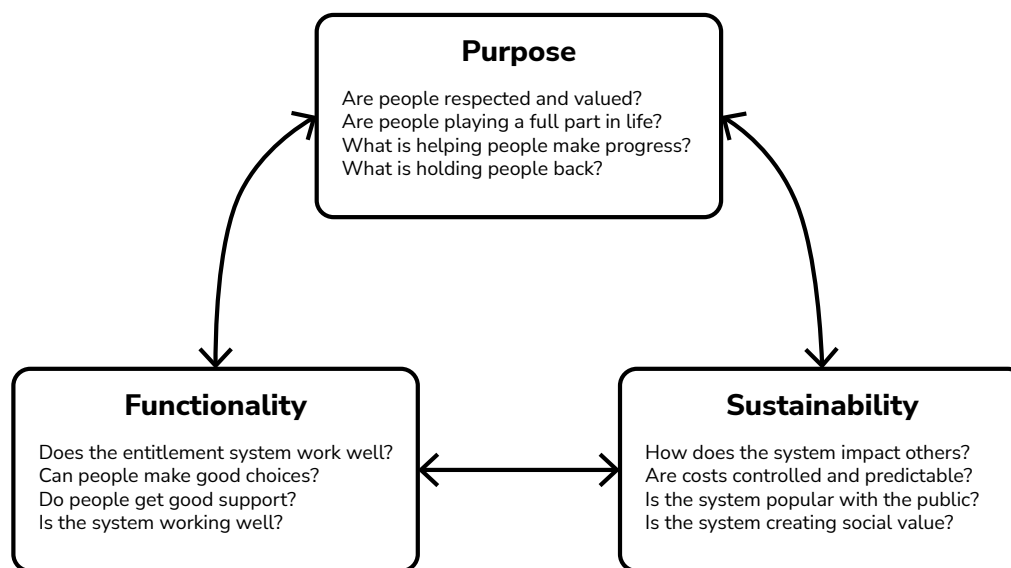


FIGURE 8. Designing the NDIS together with Australians with disabilities

The NDIS exists because Australians with disabilities got organised, defined what they wanted, built alliances and worked with the political system to make change happen. This an amazing political achievement. However, whenever a group fights to achieve an important policy development there is always a danger that, just as the goal seems to be achieved, the movement loses momentum and the delivery of the change is handed over to a political and bureaucratic process that it cannot influence. This is what happened to the NDIS in 2013. In the rush to make something happen decisions about the details of the design of the NDIS were taken away from the disability movement.

If people with disabilities are co-developers of the NDIS then in the future it would be natural to see the system working within an overall budget that has been agreed with the disability community. All such agreements would be revisable and would need to be reviewed in the light of the evidence. Surely this would be an acceptable way to reconcile some of the current tensions:

- People with disabilities co-create NDIS 2.0
- NDIS 2.0 is designed around a sustainable budget based on current evidence
- NDIS 2.0 delivers meaningful and secure entitlements that individuals can control
- The criteria for defining individual entitlements are clear and open to review and testing
- Individual entitlements are balanced with community entitlements, managed by people with disabilities in their own communities

It may take significant change to the current system to introduce these new dynamics, and there may not be a willingness to make all the necessary changes immediately. However, this does not mean that the disability community must just wait for reforms to be enacted. There are many opportunities to take positive actions that don't require permission from the government or from the NDIA.

We can adopt the mindset that citizenship is an entitlement and expect this to be recognised in mainstream settings. We can start to build peer support solutions within and across all the communities of Australia, helping each other and cultivating our capacity to advocate collectively. We can dream up innovative models of support and test them wherever possible. We can build evidence for what works and what doesn't and expose the best and the worst practices.

The current review of the NDIS provides an excellent opportunity to tackle the problems within the NDIS, but also to reaffirm its value. Creating the NDIS was an amazing achievement, an achievement of the disability community, but an achievement that would not have been possible without support from the vast majority of Australians. Now is the time to ensure that what was achieved can be sustained for future generations.

NDIS 3.0



The NDIS is incredibly valuable and significant global innovation, but one that requires a significant and urgent redesign. We have suggested some of the most urgent changes that could be made relatively quickly to improve its design and create a sustainable NDIS 2.0. This involves a very different way of thinking about how best to achieve the goal of citizenship for all: with more plurality, more trust and more respect for the process of learning and innovation. The full benefits of this different approach would be harvested in the years ahead.

But we want to end this report by looking even further in to the future. In social policy there is often a mistaken belief that we are just one fix away from the ideal policy. But the reality is that the world is complex and changing, we are always learning and we can often only feel our way forward one step at a time. However, despite these limitations, we should start to see the NDIS as one part of a bigger story about citizenship and how we can all live better lives, together, in the years ahead.

This issue is particularly important to consider when we acknowledge some of the other things that are happening in the world. The world is under enormous environmental strain caused by human actions that we are struggling to change. Global and local economies are struggling with debt, inequality, extreme concentrations of economic power and fragile supply chains. Democracy is under pressure in many countries; authoritarianism, nationalism and extreme right-wing politics are on the rise. Australia has many gifts and resources, but it is unlikely to be insulated from these compounding problems.

We also struggle to look upstream and address the issues that drive many of the problems we experience in our lives today and which often seem to be getting worse. At this time it is vital that we don't just think about the problems one system but that we think about how this is connected to nature, society, community and our own citizenship (Duffy, 2016).

Just as the world of farming is discovering the need for a regenerative approach, we also need to think about regenerative social policy. We need to solve problems in ways that tackle the underlying causes of those problems.

Perhaps, more profoundly, we need to change our behaviours so that improve the capacity of all human beings to contribute to a better world. Systems, algorithms and bureaucratic mechanisms can do no more than redistribute resources and the authority to use them; the real business of life, of inclusion and of citizenship is an essentially universal affair. Every time we leave someone out and treat them as if they have nothing contribute to the bigger picture we are undermining our ability to create the world we need. Inclusion and human rights demands citizenship for all and by all (Duffy, 2022c; 2022d).

For these reasons I think it may be useful to set the reform of the NDIS within a wider context. I also hope that advocates, seeking to defend the values that inspired the NDIS, may want to look beyond the technical problems we've described and consider new strategies for progressive change. Perhaps we need to find a better way of describing what we are trying to achieve. Maybe our goals need to be expanded so that they are relevant to all Australians and this might also demand new ways of thinking about how to ensure that human rights are protected as essential components of public life. Maybe new allies are needed.

One indication that we still have much work to do to shift our thinking and values is that the language used by the NDIA to justify and explain the NDIS is largely stuck in a late 20th century paradigm. The bureaucratic language of NDIA reports is the language, not of rights, but of participants, insurance, actuarial predictions, evidence-based decisions, demand and supply. The NDIS has turned into a technical machine, supposedly controlled by people with high levels of expertise; but in reality it's a machine that cannot achieve its intended purpose.

The central focus of the NDIS has become the delivery of services to people. But services, while important, are not the fundamental stuff of life. What really matters are our values, our relationships and the communities that nurture our development. It is for this reason that when we talk about the NDIS, what we need from it and how it is organised, we should consider more than funding for services. We need consider how it makes rights real, what its impact is on our citizenship and family life and how it advances the creation of inclusive communities. Nor are these matters that can simply be bracketed and dealt with by some other strategy. The NDIS is a major system of financial investment and control and it must be evaluated in terms of the things that really matter (Duffy, 2022b).

Advocates should certainly evaluate the NDIS in terms of its success in: making a reality of disability rights, in providing people with meaningful entitlements and the support necessary to manage their responsibilities. But it is also important to understand how the NDIS generates rights and responsibilities for everyone. Inclusion needs to be everyone's business.

The problem is the inefficiency of our downstream responses to upstream problems and the gravitational hold those responses have over our resources and attention.

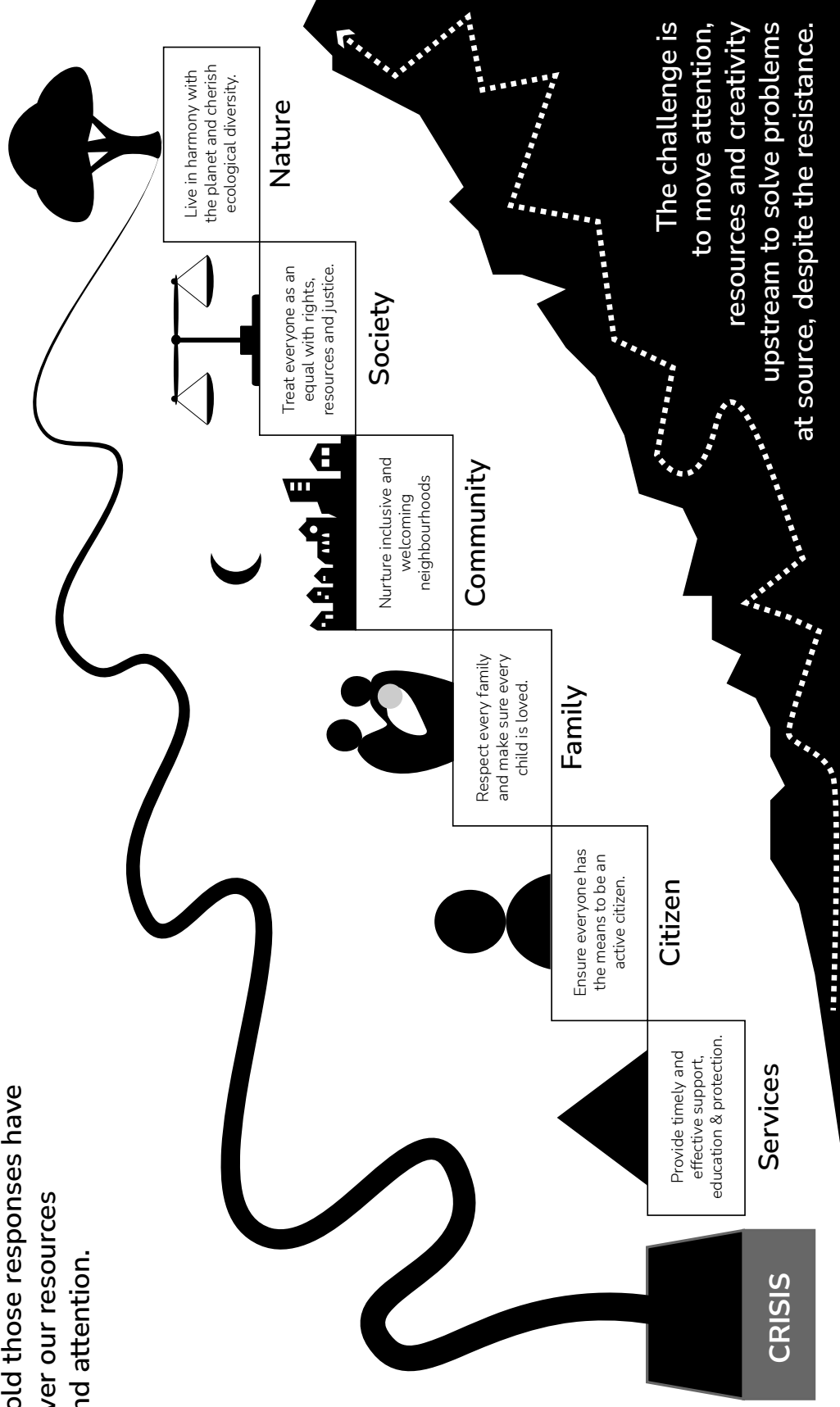


FIGURE 9. The challenge of responding to upstream problems

In fact, the NDIS might be a staging post on a journey to a range of better social policies for all. There is only space for a brief outline of these possibilities here, but the following policies might all be ways of moving from NDIS 2.0 towards NDIS 3.0—a more universal approach to progressive social change:

- **Prevention and inclusion** - The main focus of the NDIS has been on providing services to people with a "permanent and significant disability" (NDIA, 2022). But, as discussed above, the distribution of disability means there will be many people on the edge of eligibility for NDIS. Moreover this group all have genuine needs that if not met by support, grant-funding or suitable adaptations, will then mean they will become eligible for NDIS support, but at a much higher cost. Excluding people with lower needs can easily become self-defeating. Much better to make it easier for people to get rapid and low-cost supports, ideally integrated into local communities. Note that this can also mean providing 'individualised funding', such as a small grant that the person or an ally controls.
- **Integration with Aged Care** - Does it make sense to treat disabilities acquired before or after the age of 65 as requiring fundamentally different social policies? If someone acquires a disability after the age of 65 then surely we should treat them as a citizen with rights to independent living and inclusion and to the relative benefits of the NDIS model (Lynch, 2008). If we want to radically reduce institutional care and shift towards citizenship, inclusion and community development then surely the existence of unduly institutional care for older people increases the relative legitimacy of institutional care for everyone.
- **Integration with basic income** - There is a global movement towards the creation of a system of universal economic security, called basic income (Standing, 2017). This means that everyone would be guaranteed enough to live on. Such a policy could have profound benefits for people with disabilities, reducing multiple poverty traps and disincentives for earning, saving and family formation and reducing the stigma of receiving benefits (Duffy & Elder-Woodward, 2019; Duffy & Wolff, 2022). Some of us have even argued that personal budgets, disability benefits and basic income could be brought together into a system of Basic Income Plus (Richardson & Duffy, 2020). This would certainly be a reform in the spirit of Every Australian Counts.
- **Disability and gender** - One of the most important themes emerging in the global discourse about disability rights is an increasing awareness of the need to understand its intersection with the rights of women (Quinn, 2023). Support, whether provided by family or by paid staff, is still primarily work done by women, either for free or, if paid, at lower salary rates. We need to find ways that respect all the social, economic and cultural rights at stake (Hunt, 2017). Arguably a system of universal basic income might also provide a better foundation for gender equality.

- **Neighbourhood democracy** - The idea that local government might have an active role to play in achieving inclusive communities was treated with shock by many when we were developing this paper. But can we really imagine that the kind of world we need to create together is going to all be driven by the decisions of centralised bureaucracies? Is it not time to consider the role that genuinely democratic and participative structures might play in shaping our distinct communities? Perhaps the current systems of local democracy are insufficient to the task; but maybe that means we should start to reimagine the role and function of democracy at neighbourhood and other levels (Whillans-Welldrake, 2020).

The ideal of Every Australian Counts is fantastic. The creation of the NDIS has taken Australia closer to making this ideal real and it has raised the global bar for disability rights. Today the challenge is to root the NDIS more deeply in the soil of Australia, to ensure it can be sustained and valued by all Australians and that it plays its role, not only so that all people with disabilities can achieve their rights, but so that people with disabilities can play a full role in establishing and protecting the rights of all. Every Australian does count and every Australian needs to play their part in making this true.

GLOBAL STANDARDS FOR SELF-DIRECTED SUPPORT

We all have the right to live a life of freedom and full community inclusion. These fundamental rights were articulated in the Universal Declaration of Human Rights in 1948. The 2006 Convention on the Rights of Persons with Disabilities underscored that human rights apply to all people regardless of disability or chronic illness. To ensure human rights for all, we must organize systems that maximize autonomy of the person to make choices and exercise control over their supports.

The following are essential elements of a self-directed support system:

1. A dedicated budget, individualized and controlled by the person with any support they choose, used flexibly and creatively to promote the person's best life
2. Access to legally recognized supported decision-making that minimizes substitute decision-making and the loss of legal agency
3. Outreach and education on self-directed supports, beginning in early childhood
4. Clear and simple information on self-directed supports, widely available in the mainstream, tailored for cultural responsiveness and relevance, and fully accessible
5. Practical administrative processes that minimize participant burden
6. Person-centered planning – a process of identifying what is important to a person with strategies to support what's important – that demonstrates a commitment to peoples' capacity and value
7. No cost assistance with technical aspects of self-directed supports, including help meeting program requirements and assistance with locating, hiring, and managing staff
8. Information and resources for families, friends, and other allies to support the person
9. Respectful employment practices that recognize the rights of staff to a fair wage and to be free from exploitation
10. Peer support – mutual aid for wellbeing and navigating the system – bolsters participation, promotes equitable access, and drives innovation
11. Transparent, sufficient, fair resource allocation based on a person's priorities and needs
12. Portability of self-directed funding and eligibility across jurisdictions within a country

13. Comprehensive and genuinely independent advocacy to protect human rights, privacy of personal information, freedom to make big and small life decisions, and safeguarding from harm
14. Practices that ensure all people have the option to control as much or as little of their supports as they choose, based on the presumption of personal capacity
15. Quality practices and outcomes measurement that support continuous learning and improvement and hold systems accountable to the principles of self-directed support
16. An orientation toward equity in access, respect for people’s cultural identities, and positive outcomes with particular attention to groups that are historically marginalized and underserved
17. Disabled people and those with chronic illnesses are fundamentally trusted and have principal roles in the oversight, governance, and administration of support systems



The SDS Network is a global community committed to sharing knowledge about self-directed support and raising the global standard of disability support services. The SDS Network is hosted by Citizen Network with a board of global experts.

You can join the SDS Network for free at:

www.selfdirectedsupport.org

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About the Authors

Dr Simon Duffy is Director of Citizen Network Research, President of Citizen Network Cooperative and Chair of Citizen's Basic Income Trust. He is a co-founder of UBI Lab Network, the Neighbourhood Democracy Movement and the Self-Directed Support Network. In 2008 he was awarded the RSA's Prince Albert Medal for his development of self-directed support in social care.

Dr Mark Brown is a Senior Research Fellow at the Summer Foundation. He has a PhD in Psychology and over 10 years experience as a statistician, data analyst and social researcher. Mark has worked as a researcher, analyst and consultant for a variety of government, private and not-for-profit organisations in the disability sector. Mark lives in Melbourne and is an NDIS participant.

Citizen Network Research



The Centre for Welfare Reform was established in 2009 as an independent think tank, based in Sheffield, UK. In 2016 the Centre founded Citizen Network.

In 2020 Citizen Network Osk was registered as a global non-profit cooperative in Helsinki Finland. At the beginning of 2022 the Centre changed its name to Citizen Network Research and integrated its work and website into the work of Citizen Network.

Citizen Network is a movement to advance equality and justice around the world. We started Citizen Network because we need to celebrate human diversity and stand up for human equality. We need to work together and to behave like citizens, reject division and create more inclusive communities that welcome people with all their different gifts.

Join us on the journey, visit: www.citizen-network.org

Disability Advocacy Network Australia

67



DANA is the national representative body for a network of independent disability advocacy organisations throughout Australia.

DANA's vision is of a nation that includes and values people with disabilities and respects human rights for all.

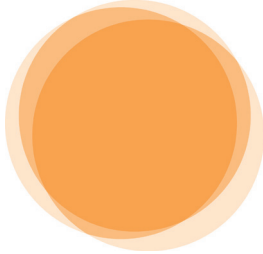
DANA's purpose is to strengthen, support and provide a collective voice for independent disability advocacy organisations across Australia that advocates for and with people with disability.

We achieve this by: promoting the role and value of independent disability advocacy, providing a collective voice for our members, providing communication and information sharing between disability advocacy organisations, providing support and development for members, staff and volunteers of disability advocacy organisations, building the evidence base to demonstrate the value of disability advocacy, and promoting the human rights, needs, value and diversity of people with disabilities.

Find out more, visit: www.dana.org.au

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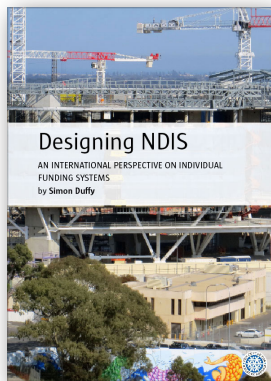


In 2006, the Summer Foundation was established to stop young people with disability being forced to live in aged care. The Summer Foundation is a systems entrepreneur. We are changing systems to ensure people with disability and complex support needs live where and with whom they choose, with access to high quality housing and support options that enhance health, wellbeing and participation.

We use 5 levers to change systems. We generate evidence including published research and lived experience. We innovate by co-designing new solutions and services. We work with government and influence people on the inside. We apply pressure from the outside by harnessing public support. Sometimes we use a legal lever and support people to fight for their rights.

Find out more, visit: www.summerfoundation.org.au

Relevant Publications



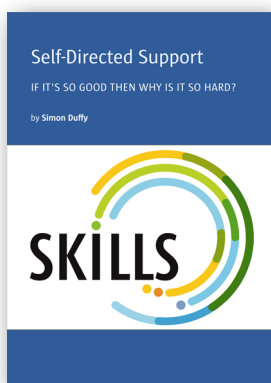
DESIGNING NDIS

In 2013 this report predicted that the NDIS would become unsustainable without radical reform.



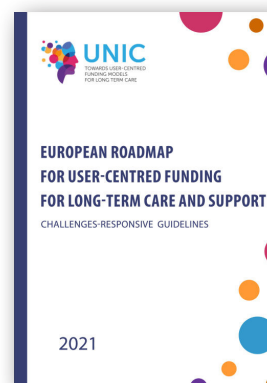
SELF-DIRECTION WORLDWIDE

Disability system reforms are driven by either the values of citizenship or consumerism.



SELF-DIRECTED SUPPORT

There has been significant progress in reforming disability support systems but similar obstacles persist.



EUROPEAN ROADMAP

The first attempt to provide pan-European guidance on developing self-directed support.

These publications and more on self-directed support are available to read at:

www.citizen-network.org/library/community/selfdirected-support



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