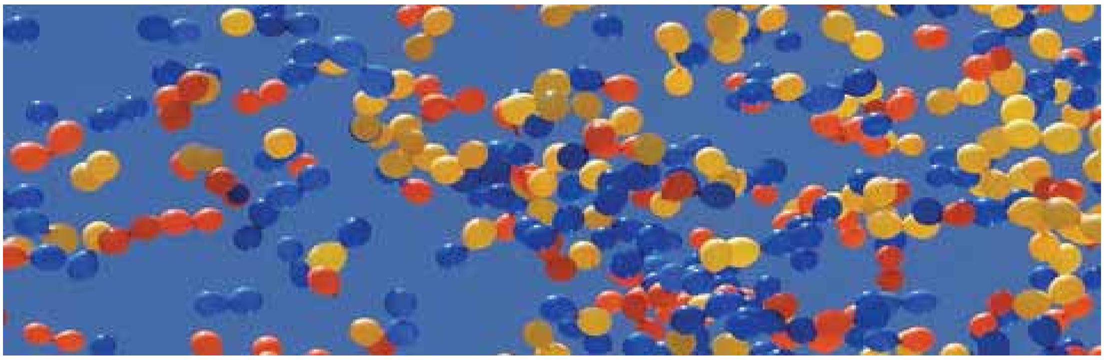
Lifelong Disability Entitlement Scheme



Transformational Change in Disability Funding
"our right to take responsibility"

Disability Care and Support

Productivity Commission

Submission on behalf of the
Lifelong Disability Entitlement Scheme

A Project of Social Enterprise Partnerships

The **Lifelong Disability Entitlement Scheme** is a proposal for transformational change in the funding of long-term care and support for people with disabilities - without the uncertainty, risk and loss of control associated with an insurance scheme.

It requires the Commonwealth to legislate for a schedule of *lifelong minimum disability entitlements* for all people with diagnosed disabilities. The schedule comprises seven payments - six fixed-amount annual or one-off payments, and one variable annual payment adjusted for support need factors over the course of a lifetime.

The Scheme would replace all existing state and commonwealth disability programs. It would direct all payments to a nominated agent of people with disabilities, rather than to service providers or to a monopoly insurance company.

Disability is a part of everyday life. It is not a 'liability' or 'risk' to be insured against. People with disabilities and their families have struggled for decades to be socially accepted as part of mainstream life. To treat disability as something to be insured against is at odds with, and runs counter to, its social acceptance.

Self-direction and personalised control of supports by people with disabilities and their families is a basic human right. We do not think this right to take personal responsibility is compatible with an insurance scheme which treats decision-making about eligibility to supports as a 'liability management' prerogative of an insurance company.

Our view is that such decisions should not be made by an insurance company.

The emphasis in the **Lifelong Disability Entitlement Scheme** is on social relationships, participation and self-direction - and the provision of funding entitlements designed to maximise these features over a lifetime for each and every person with a disability and their family.

What follows:

- Outline of Entitlements/Benefits
- Case Study: Example of Entitlements/Benefits
- Key features of a Lifelong Disability Entitlement Scheme
- Easy comparison with NDIS
- Raise taxes? or Cut out the middle men?

Outline of Entitlements/Benefits

At the heart of this proposal is a requirement for the commonwealth to legislate for a schedule of lifelong minimum disability entitlements.

This schedule would be akin to the Medicare Benefits Schedule, a published compendium which outlines the medical entitlement every Australian can expect to receive in ill health.

The schedule would comprise seven payments:

Disability Support Entitlement
Supported Living Payment
Circle of Support Payment
Person-Controlled Information and Management Tool
Small / Micro-Business Development Grant
Respite Entitlement
Disability Capital Account

These payments would be made to the nominated agent of each person with a disability.

All of these payments (with the exception of the Disability Capital Account) may be pooled at the discretion of the person with a disability and their family.

1. Disability Support Entitlement

Every child or adult who is diagnosed with a disability would be eligible for a *Disability Support Entitlement* (DSE) from the time of diagnosis until death or until the disability has ceased to disable.

The DSE would be an annual payment intended to cover the cost of support entitlements in home care, therapy, aids, equipment, home modification and access arrangements, and access costs to specialist services, applicable to all diagnosed disabilities, with adjustments by factors of age, sex, multiple disability and health status, locational disadvantage, and life-cycle-stage over the course of a lifetime.

The amount of the annual entitlement would be based on historically-determined average costs incurred by people in similar circumstances over the course of a lifetime. It would range between $6,000 and $100,000.

People with a disabilities would receive an annual DSE payment made to their nominated agent (see the Key features section below).

2. Supported Living Payment

Every person with a disability from the age of 18 would receive an annual *Supported Living Payment* of $6,000.

This payment would be for the purpose of acquiring support in living arrangements, whether the person is living on their own or sharing a house or living with their family. Best practice in various international supported living models provides for a pooling of similar payments in small local groups of about 10, so that a group of 10 people with disabilities may jointly fund a full-time support worker.

People with disabilities over the age of 18 would receive an annual payment of $6,000 made to their nominated agent.

3. Circle of Support Payment

Every child or adult who is diagnosed with a disability would receive an annual Circle of Support Payment of $2,000 from the time of diagnosis.

This payment is a contribution towards the costs of facilitating social networks of informal support comprising family members, friends, neighbours, shopkeepers, club members, and supporters.

People with disabilities would receive an annual payment of $2,000 made to their nominated agent.

4. Person-Controlled Information and Management Tool

Every person with a disability and their family would receive a legislated entitlement to a person-controlled information and management tool.

All providers and practitioners supplying services to people with disabilities would be required by legislation to enter information on the service supplied into the person-controlled information system. This electronic record would also function as a technology platform for the management of an individual budget and support plan. It would serve as a consolidated person-centred information system which would comprise all components of an individual's support and care history.

Every child and adult with a disability would be entitled to receive an initial payment of $2,000 for acquisition of a person-controlled information and management tool and training it its use. Thereafter, an annual payment of $500 would be received for maintenance and training, paid to the their nominated agent.

5. Small / Micro-Business Development Grant

Every person with a disability over the age of 18 years would be entitled to a Small / Micro-Business Development Grant to assist in setting themselves up in small or micro-business activity.

Many people with disabilities can and should be employed in the paid workforce, but the main obstacle to this outcome is a shortage in suitable positions. This is primarily a failing of the business community in not responding entrepreneurially to the untapped resource of people with disabilities - rather than a failing of people with disabilities themselves. An increase in employment for people with disabilities will not be achieved quickly.

The Small / Micro-Business Development Grant would be for $5,000 per year for a maximum of 5 years, payable to the nominated agent of the person with a disability.

[Note: The proposal put forward by three service provider organisations for a National Disability Insurance Scheme (NDIS) contains a strong emphasis on removing people from the Disability Support Pension, and assigns 'incentives' to its monopoly insurer to get them off benefits as quickly as possible. This emphasis would seem to be a response to government budgetary pressures, rather than a response to the needs of people with disabilities or their families.]

6. Respite Entitlement

Every family caring for a family member with a disability would be entitled to a *Respite Entitlement*, assigned directly to family carers or the nominated agent of their family member, in the form of a respite service voucher, adjusted with a nature-of-disability and difficulty-in-caring rating.

The Respite Entitlement may be used to purchase in-home respite or centre-based respite according to the preference of the family or carer.

The Respite Entitlement would be for an amount equivalent to the purchase cost of six weeks of external support to allow the family or carer six weeks of respite annually.

[Note: Family carers of people with disabilities want to be supported in their caring role, so that they may combine a normal work and family life with caring for their loved ones. Family carers generally do not want to be stripped of their caring role, and replaced by uninterested low-paid care workers.

The NDIS proposal contains an underlying assumption that family carers should offload their family members with disabilities onto a care provider so they can resume a 'normal life' in the paid workforce. This seems to be both an ideological and budgetary-driven push, rather than a response to the best interests of people with disabilities.]

7. Disability Capital Account

Every child or adult who is diagnosed with a disability would receive a one-off investment of $10,000 in a high yield Disability Capital Account. Withdrawals from this account may only be made for purposes of aids and equipment purchases, housing acquisition, business development, or tertiary or vocational education.

The account may be held and managed by the nominated agent of the person with a disability, or their superannuation fund or financial agent.

Case Study: Example of Entitlement/Benefits

Carlo Costa is a 25 year old man with autism, unemployed, and living with this parents in a Newcastle suburb. He is considering moving out of home, and looking for options.

Under current arrangements, Carlo has periodic access to a Disability Employment Network provider, which involves spending a specified number of hours per month examining online vacancies at the premises of the provider. His parents would like to take steps to develop a support network for Carlo but they don't know where to start and have no money for it. They would like Carlo to think about living out of home at some time in the future, but have no idea where the support for him would come from, and are not eligible for any funded support until Carlo has set himself up in a house.

Under the **Lifelong Disability Entitlement Scheme**, Carlo would receive the following payments, which would be allocated to his nominated agent, Newcastle West Community Health Centre. Carlo has had contact with several disability agencies over the previous 18 years, but none of these is located close to Carlo's home. The Community Health Centre is 5 minutes walk from Carlo's home, and after an approach by Carlo's parents, the Centre agrees to act as Carlo's managing agent, and a man named Lawrie is Carlo's contact.

Disability Support Entitlement

Carlo's agent Lawrie would receive an annual DSE payment of, say, $12,000 for several sessions per week of one-to-one personal support, transport and accompanied support to attend a regular rock music gig, and weekly lessons from a singing teacher.

Carlo's parents organise these sessions and Lawrie makes the payments.

Supported Living Payment

Carlo's parents have managed to get in touch with several other families in neighbouring suburbs whose family members also each receive $6,000 in Supported Living Payment. Together they pool their payments to employ Rocco on a salary of $50,000 as a full time support worker for their 10 family members.

Circle of Support Payment

Lawrie receives an annual payment of $2,000 for Carlo and with this money Carlo and his family take some steps towards organising a social support network around Carlo.

Person-Controlled Information and Management Tool

To keep track of Carlo's support needs and monitor where his money is going, Carlo, Lawrie, Rocco and his parents acquire a technology platform which they install on each of their computers, and together use it to draw up, manage and plan ahead for Carlo.

Everyone is able to access Carlo's weekly support schedule, make changes to rostered support as required, keep track of money coming in and out of Carlo's support account, and allow funders access to this financial and management information system as and when they require it.

Lawrie receives a one-off payment of $2,000 to set this up, using a low-cost easy-to-use, not-for-profit system designed by family carer in Melbourne for national use. Thereafter, Lawrie receives an annual payment of $500 for maintenance and training.

Small / Micro-Business Development Grant

Carlo and two other people with disabilities from their group of 10 discover they enjoy working together, and with some supporters and family members, think they can set up a small laundry business. With an annual payment of $5,000 each, the three of them buy some equipment, take out some advertising, print some promotional material, hire a university student to do their finances, and meet some operational odds and ends.

Respite Entitlement

Carlo's parents receive an annual Respite Entitlement which enables them to pay for six weeks' worth of in-house support for Carlo each year.

Disability Capital Account

Carlo receives a one-off $10,000 investment in a high-yield Disability Capital Account. Carlo and his parents decide to grow this investment by making regular contributions themselves and inviting service clubs and friends in the area to contribute so that Carlo may be able to purchase a unit of his own in a few year's time.

Key features

The features of the Lifelong Disability Entitlement Scheme are as follows:

1. Eligibility

Eligibility for scarce resources in disability support cannot be determined in a discretionary way by bureaucrats, insurers or service providers, but must be determined independently through a legislated schedule of entitlements.

Claims by bureaucrats, insurers or providers that eligibility can be determined by 'need' without the backup of a legislated schedule of entitlements, have no credibility. Entitlements must be made binding upon governments, agents and service providers.

The commonwealth would legislate for a schedule of lifelong minimum **Disability Support Entitlements** (DSE) applicable to various forms of diagnosed disabilities, with a capacity for adjustments by factors of age, sex, multiple disability and health status, locational disadvantage and life-cycle-stage over the course of a lifetime.

The commonwealth would ensure that eligibility for the DSE includes disabilities which are currently not acknowledged or inadequately acknowledged including autism, ADD/ADHD, language disorders, learning deficits, and various neurological conditions.

2. Strict separation between service provision and fund holding

A person eligible for a Disability Support Entitlement, or their family, would nominate a managing agent to hold and the manage the DSE on their behalf. The managing agent may be a community organization, a health fund, a consumer co-operative, a for-profit financial agent, a GP or lawyer, a parent, friend or family or any other entity which has a capacity to manage the financial entitlement, enter contractual arrangements on behalf of the person with a disability, and manage their support and care relationships to the satisfaction of the person they act for. People with a disabilities would receive an annual DSE payment made to their nominated managing agent.

There would be a legislated requirement that no provider of disability services or practitioner may simultaneously act a managing agent of a DSE, on conflict of interest grounds.

The systemic conflict of interest in present disability funding arrangements whereby providers of services may simultaneously act as fund holders, gatekeepers to services, and sources of information about the service system, is a key cause of the current system dysfunction.

3. Choice of agent

A person with a disability or their family must be free to select their managing agent, and free to transfer from one to another annually.

A monopoly managing agent or insurer along the lines of the state accident compensation entities such as the TAC in Victoria is an unsatisfactory arrangement for people with disabilities. The state accident compensation bodies are monopolies, and their 'clients' have no recourse in the event of an unsatisfactory ruling save legal action. For this reason, entities like the TAC are constantly embroiled in legal battles with disgruntled clients.

4. Person-controlled information and management tool

All providers and practitioners supplying services to people with disabilities purchased with a DSE would be required by legislation to enter information on the service supplied into a person-controlled electronic information system. This person-controlled electronic record would also function as a technology platform for the management of an individual budget and support plan. It would serve as a consolidated person-centred information system which would comprise all components of an individual’s support and care history.

A nominated managing agent of a person with a disability would also be required by legislation to use this person-controlled information system. It would, in turn, enable online transparency and accountability to funders.

A person-controlled information and management tool would be a legislated entitlement for each person with a disability and their family.

[Note: The NDIS proposal contains no requirement for a person-controlled consolidated information system. It may be assumed that the monopoly insurer will contain sole ownership and control over a person's support and care history.]

5. Requirement for a per person unit cost

All providers and practitioners supplying services to people with disabilities purchased with a DSE would be required by legislation to offer a ‘per person unit cost’ for all programs and services, so that people with disabilities or their agents may purchase with full knowledge of the cost.

[Note: The NDIS proposal is silent on how payments from an insurer would be made to providers, but the origins of the proposal in three large service providers (The Spastic Centre, Yooralla and Disability Services Australia) may be taken to mean that providers such as these would receive payment in their preferred method, namely, block funds from an insurer per 'client'.

The NDIS proposal contains no requirement for an open disclosure of costs. It can safely be assumed that the monopoly insurer will restrict knowledge of costs to a closed information loop comprising the insurer and service providers.]

6. Disability Support Information Service

Commonwealth legislation would also establish an independent **Disability Support Information Service** to provide comparative price and service quality data on service providers and practitioners, respite services, and supported accommodation services. This entity would be a statutory authority independent of providers, with authority to require information from providers and practitioners in receipt of DSE money for public disclosure.

[Note: The NDIS proposal contains no information about how a functioning retail market in supports and services would be developed and regulated.]

Easy comparison with NDIS

This easy to use table compares the main features of both proposed schemes:

	Lifelong Disability Entitlement Scheme	**National Disability Insurance Scheme**
Eligibility	Legislated schedule of minimum entitlements	Assessed by an insurance company on the basis of 'need'
Choice of agent	People may choose their agent and freely transfer on an annual basis	A single monopoly insurer
Cost structure	Full and open disclosure of unit costs for supports and services	Unit costs subject to contractual arrangements and closed information loop between insurer and providers
Conflict of interest	Legislated prohibition on service providers acting as fund holders	Silent on the provider/fund holder conflict of interest
Person-controlled information and management tool	Legislated entitlement to a person-controlled electronic record and self-direction management tool	Decision-making falls under the prerogative of 'liability management' on the part of an insurance company
Retail market	An independent Disability Support Information Service to supply online comparative price and quality data	Silent on how a retail market would be developed and regulated
Family carers	Has a stated goal of supporting families in their care role	Has a stated goal or reducing dependence of people with disabilities on their families and increasing dependence on formal providers of care
Work and benefits	Builds self-direction and self-generated incentives to move into business or employment activity	Assigns incentives to an insurance company to move people off the Disability Support Pension
Social relationships	Assigns payments to facilitate social networks and social relationships as the key to a good life	Silent on social relationships, views people with disabilities as detached isolated beings to be managed by others

Raise taxes? or Cut out the middle men?

The NDIS proposal would increase the tax levy on personal income by 0.8% to raise $4billion to meet 'unmet need' for disability services.

It is impossible to gauge how much additional money is needed because the existing service system is plagued with duplication, inefficiency and waste. There has never been a national audit of the duplication and waste in disability across the $20 billion spent in portfolios of health, welfare, education, housing, transport and employment services in the public sector across three tiers of government.

This $20 billion figure excludes the replacement and supplementary spending on these services in the private sector made to avoid waiting lists and unresponsive providers.

All available research and anecdotal evidence suggests that the duplication and waste in current disability funding arrangements is **massive.**

This is because the current funding model is provider-centred and silo-driven - which means that all tiers of government make funding allocations by program type (home care, therapy, social support, transport, etc) rather than to actual people for the things they actually need.

This means, for instance, that an allocation from the Commonwealth for one hour of home care will begin life in Canberra as a bucket of money tagged for home care across the nation. It will then be broken down by state and territory, and passed to state and territory governments, who in turn will invite and receive applications from service providers to re-issue this money to eligible recipients in their patch. After an assessment of each provider's risk and financial management provisions and personnel capacity, contracted providers will then institute their own assessment procedures and waiting list management protocols.

The result is that ***it costs the Commonwealth $55 to provide one hour of home care funding which eventuates as an end-of -the-line payment of $18 per hour for a home carer for a person with a disability.***

In other words, when all the middle men have taken their cut, $55 in taxpayers money for disability support becomes $18 in the pocket of a home carer for one hour's support for a person with a disability.

If a national audit of the disability service system were undertaken, it would be possible to know what savings might be made from an overhaul of the existing system, and how much additional spending, if any, is required to meet unmet need.

But in the absence of such an audit, the proponents of NDIS expect politicians to go to the voters and taxpayers to ask them to cough up for a tax increase of 0.8% of personal income to raise an extra $4 billion for investment in a system without knowing how much taxpayers' money disappears through inefficiency, duplication and waste.

In no other field of government investment would such a proposal get past first base.

In other fields, an Inquiry into the performance of existing organisations and models, and the scale and scope of system inefficiency, would usually take place first. But in the Commonwealth's current Inquiry into a long-term care and support scheme, these areas of examination are excluded from the Terms of Reference.

We think a much simpler and more direct method of transformational change in disability funding would be to invite governments to eliminate significant duplication, inefficiency and waste by cutting out the middle men and putting in a place a person-centred disability entitlement scheme.

About us

The Lifelong Disability Entitlement Scheme (DES) is a project of Social Enterprise Partnerships Ltd.

Social Enterprise Partnerships is a national movement of people aiming to change the system of funding education, health care, disability, family and ageing support in Australia.

In these areas, government policy is shaped by peak bodies of provider organisations who are funded by governments to deliver government services. These peak bodies are also funded to provide policy advice to governments. It is no surprise that the policy advice offered by these peak bodies inevitably favours arrangements which are provider-centred rather than person and family-centred.

Social Enterprise Partnerships aims to challenge this closed loop in social policy and advance a paradigm shift to person and family-centred arrangements.

Social Enterprise Partnerships