Disability Care and Support

Productivity Commission

Submission on behalf of the National Federation of Parents, Families and Carers

Background

The National Federation of Parents, Families and Carers was formed in August 2007 by a broad range of parents and families from all states and territories. It aims to represent and advocate for the interests of parents, families and cares as interests which are distinct from those of governments, service providers and charities.
http://www.civilsociety.org.au/federation.htm

The Federation's public policy principles are:

1. Person-centred and family-centred arrangements should become the norm in all forms of social support, service delivery and social investment – systems and institutions should be tailored to meet the personalised needs of individuals and their families. The 'one size fits all' model should be thrown in the dustbin of history in practice as well as in rhetoric.

2. Integrated whole-of-life arrangements should encompass all forms of social support and service delivery – individualised consolidations of funding from different programs, funding streams and jurisdictions should be introduced to enable these arrangements.

3. Empowerment of parents, families and carers to exercise enhanced choice and self-determination should be established as a guiding ethic in public policy.

Submission

This submission is in two parts.

Part 1 makes a number of general observations.

Part 2 responds to selected questions 3 to 13 in the first Issues Paper. These responses are broadly in the order in which the questions are asked in the Issues Paper.

Vern Hughes
Secretary
National Federation of Parents, Families and Carers

Part 1 General observations

1. Transformational change in disability care and support is long overdue. By 'transformational change' we mean a shift in paradigm from a provider-centred system to a person and family-centred system, that is, a system where resources, information, and governance are centred not in provider organizations but in individual persons with disabilities and their families.

2. Any proposed new scheme in disability care and support which leaves funds management and information supply in the hands of provider organizations will not constitute transformational change. That will be but a continuation of the current dysfunctional system. It is our firm contention that service providers currently have a conflict of interest in simultaneously acting as gatekeepers to the service system, sources of information about the

system, providers of services, and holders of money in the system. This conflict of interest is one of the key sources of dysfunction in the system.

We are wary of any change in language which purports to signify a shift in paradigm to person-centred arrangements while actually preserving provider-centred arrangements.

3. We state that the first Issues Paper contains an underlying assumption about family carers which we do not share. This is an assumption that care and support in informal familial contexts is neither sustainable nor desirable, and that a major shift should take place towards the provision of care and support in formal settings (that is, by paid carers in organizational or institutional settings).

We reject this assumption as being contrary to the expressed best interests of both people with disabilities and their families. The emphasis in any reformed system should be upon provision of supports to enable families and informal networks of care to support their loved ones in home-based, informal, non-institutional settings as much as possible. This should include individualized funding for families for capacity-building in care and support, as well as individualized funding for individuals with disabilities.

4. We also state our disagreement with the way in which the Issues Paper refers to the likelihood of significant numbers of people with disabilities moving into paid employment. We do not think provision of a set of incentives to a funder will achieve much, except to provide an incentive to push people with disabilities into inappropriate work (read deskilled repetitive work) to reduce the number of Disability Support Pension recipients. It is much more important to install an appropriate set of incentives for employers to employ people with disabilities. The assumption that incentives assigned to a funder can hasten the flow of people with disabilities into paid employment is a flawed assumption.

5. We are sceptical about the value assigned to a so-called ‘insurance’ system of fully-funded lifecycle supports. The Australian Medicare system is not an insurance system in this sense; it is a pay-as-you-go system. The Medicare levy, the ‘premium’ in health funding, contributes but a small fraction of the public expenditure required for Medicare. Variations in size of non-levied public expenditure in health are determined by political fluctuations, not by any requirement that the system be fully-funded to cover the future health costs of current generations. Shortfalls in disability funding are also determined by political priorities, and will remain so with or without an insurance system. An insurance system is unlikely to be a mechanism for substantially increasing the resources in the disability system.

An insurance system in health financing could be desirable if consumer behaviours could be changed readily in illness-preventing ways. However, a disability cannot be prevented or eliminated or ameliorated simply with the provision of incentives to do so. If a system of incentives has a place in disability funding, then it would be in the form of incentives to an individual to change behaviours in ability-enhancing ways. This kind of incentive to self-manage in particular ways could be valuable. However, we cannot see a place for incentives in disability if these incentives apply to a fund manager rather than to an individual with a disability. To assign incentives to a manager rather than to an individual is to treat a person with a disability as an object of a managerial prerogative, rather than a subject.

Part 2 Questions 3 to 13

Question 3 Who should be the key focus of a new scheme and how they may be practically and reliably identified ?

1. We submit that a key design feature of any new scheme must be a separation of the function of determining eligibility from the function of providing support with a fixed pool of money. These two functions cannot be exercised by one entity. An insurer that holds a pool of money for disability support cannot simultaneously determine who it may assess to be in need of support, or how much support they may require.

Determination of eligibility must be undertaken independently of bureaucrats, providers and insurers. Claims 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, insurers and providers.

We contend this should be done through a legislated schedule of 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.

We submit that the Commonwealth should legislate for a schedule of lifelong minimum *Disability Support Entitlements* 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 should ensure that eligibility for these entitlements includes disabilities which are currently not acknowledged or inadequately acknowledged, including autism, ADD/ADHD, language disorders, learning deficits, and various neurological conditions.

2. We do not think the phrase ‘severe or profound’ is useful. Arguments will always exist as to what constitutes a severe or profound disability.

For example, the Victorian Government – to its shame – maintained for many years that autism is not a disability. This was simply a means of rationing scarce budgeted resources, so that the pool of eligible recipients could be artificially restricted by excluding autism.

Every funder of disability support, whether it is a bureaucracy or an insurer, will seek to ration expenditure in this way. Arbitrary exclusions based on variable assessments of ‘need’ will be commonplace in any new scheme which does not have an independent and legislated determination of eligibility.

3. The principal advantage in a legislated schedule of support entitlements is that it can be varied in the public interest by citizens through the democratic process.

The disadvantage in an insurer having authority to determine eligibility is that citizens cannot change or overturn its determinations.

Question 7 Who makes the decisions?

4. Service providers have an important role to play in the disability support system, as suppliers of specialist services and knowledge. They should not, however, have a decision-making function in allocation of resources. Resources should be attached to each individual with a disability, and used to purchase individually-tailored supports for each individual.

We submit that a person eligible for support entitlements, or their family, should nominate an agent to hold and then manage funds 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.

Payments of support entitlements should be assigned to each individual and made to their nominated 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.

5. We believe there should be a legislated requirement that no provider of disability services or practitioner may simultaneously act a managing agent of disability funds, on conflict of interest grounds.

6. We submit that all providers and practitioners supplying services to people with disabilities purchased with public funds should 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.

We reject the funding method currently favoured by service providers, of block funding per ‘client’. This method obscures the real costs of services, and prevents people with disabilities and their families from comparing price and service quality in one provider with that in another provider.

7. We maintain that the term ‘individualised funding’ has become abused in recent years by service providers, and largely emptied of its initial intent. The term initially referred to allocations of money from a funder for support arrangements for an individual, which the individual is then entitled to ‘bank’ in a third-party entity of their choice. But, partly through laziness and partly through confusion, some governments and providers in Australia have tended to collude in short-circuiting this intended process, with funders making block grants to providers for a certain number of ‘places’ or ‘clients’, and tagging these funds for use by individual ‘clients’, subject to a consultation exercise with the relevant clients. This process can not be regarded as a genuine process of self-direction or self-determination in disability support.

In some cases, these arrangements have arisen in response to claims by service providers that they need ‘certainty’ in planning business operations from one year to the next. We say that provider organisations should accept that they operate in a market for their services, and that no business in a market environment can expect their customers to give them a blank cheque. People with disabilities do not owe service providers, or their staff, a living.

Question 8 The nature of services

8. As part of a new system of disability support, every person with a disability and their family should 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 person with a disability should 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 their nominated agent.

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.

9. We submit that the Commonwealth should 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 public money for public disclosure.

10. We propose that every person with a disability from the age of 18 should 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.

The Issues Paper poses the question of how innovation in disability support may be encouraged. Our response is that innovation is best enabled by making resources available for individuals to use in voluntary co-operation with other people with disabilities and their families for mutual benefit. This approach releases the resources that are currently locked up in staff and infrastructure-intensive provider organisations, and makes these resources available for lean, community-based forms of mutual support and innovation.

11. Every family caring for a family member with a disability should 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 would be used to purchase in-home respite or centre-based respite according to the preference of the family or carer.

The Respite Entitlement should 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.

Service coordination and linkages with mainstream services

12. The key to integrating fragmented services across health, education, housing, employment, social support, personal support and transport is the creation of Individual Budgets in which funding allocations from several programs and jurisdictions may be consolidated in a single budget, held and managed by the nominated agent of each person with a disability. For this to be possible, funders must break with the current dysfunctional practice of funding only providers, and begin making payments to the nominated agents of people with disabilities and their families.

It is the silo-driven, provider-centred model of funding across the human services that is the source and driver of the current fragmentation in care and support. It is this paradigm that enables the Issues Paper to pose a question such as:

> *‘How could the capacity for people to move between services — both intra and interstate — be made easier?”*

The assumption underlying this question is that services are funded independently of the people they are intended for. This is the root of the current malaise. If a new system is centred around Individual Budgets, and managed through Person-Controlled Information and Management Tools, in which allocations from various programs and jurisdictions are consolidated in a single working account, then this question becomes redundant.

Question 9 How much is needed?

13. 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 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.**

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.

In other fields subject to an investigation by the Productivity Commission, 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 this Inquiry, these areas have curiously been exempt from examination, even thought the first Issues Paper produced by the Commission speculates at length on how much additional funding is required to meet unmet need.

Question 10 Financing options

14. This section in the Issues Paper opens with the curious statement that

> Informal carers provide much of the current support for people with disability, contrary to the goal of pooling the costs of support and care more widely among the community.

Informal carers in familial settings will always provide the bulk of support for people with disabilities. We do not accept that our goal should be to pool the costs of support and care across the community, rather, our goal should be to provide more support for informal carers so that their role is sustainable and does not incur unreasonable personal and financial disadvantage to the families concerned. This goal is both more realistic, and more in tune with the stated desires of people with disabilities and their families.

Question 11 Workforce issues

15. It is the experience of most people with disabilities and their families who have achieved the right to select and appoint their own support staff, that workers drawn from outside the disability sector, with no disability training, who do not think in terms of ‘disability’ are invariably preferred as personal support staff. This suggests that a ‘de-industrialisation’ of disability staffing is needed, so that support roles more closely resemble community-based neighbour and peer relationships rather than industry relationships. The Issues Paper, however, points in the opposite direction.

The ‘workforce issues’ listed in this section of the Issues Paper are questions that concern disability service providers rather than people with disabilities and their families.

Question 12 Governance issues

16. We contend that the worst governance structure for a new system of disability support and care would be a monopoly insurer along the lines of the Transport Accident Compensation scheme in Victoria. Disgruntled ‘clients’ in the TAC cannot ‘exit’ this scheme and take their business elsewhere. They are locked into a monopoly organisation, which is located outside the formal mechanisms of democracy and is therefore not accountable politically for its actions. As a result, legal action is frequently the only option available when a dispute between a person with a disability and the monopoly insurer arises.