



National Federation of Parents, Families and Carers

Submission No. 1286

(Inq into better support for carers)

Rec 24/9/08

Parliamentary Enquiry into Better Support for Carers

House of Representatives Standing Committee on Family, Community,
Housing and Youth

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 carers 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

1. Supports for carers are fragmented, difficult to access, and largely ineffectual for the large majority of families. This is because the service system in disability, chronic and mental illness, and aged care, is a provider-centred system, not a person and family-centred system. Services and information channels are built around providers. There is a closed funding and information loop between funders and providers, and carers are outside this loop.

Recommendation 1:

Piecemeal reform of separate components of the service system and supports for carers is ineffective and should not be attempted. A systemic, integrated restructuring of supports is necessary. The required system-change must encompass new support models, new funding models, and new forms of information channels.

2. The service system should be transformed from a provider-centred system to person and family-centred system, so that carers and the people they care for can devise a personalized web of services and supports around their unique situation.

This can only be achieved by a funding shift from providers to consumers through the establishment of a **Personal Budget** for people with disabilities, mental and chronic illnesses, and aged frailty, and their families, so that resources from various programs and governments can be aggregated in a single account. This budget can then be used in purchasing supports, services and interventions that suit the needs and priorities of each individual and their family.

This means funding should not go directly to providers, public and private sector practitioners, or local governments - but should go to *Personal Budgets* administered by the budget-holder or agent of the family's choice..

Recommendation 2:

*People with disabilities, mental and chronic illnesses, and aged frailty, and their families, should be recognised as the central unit of the service and funding system. A **Personal Budget** for each person/family should be established into which individualized funding from various programs, departments and jurisdictions should be directed and aggregated into a single account, administered by a budget-holder or agent of the consumer/family's choice.*

3. A 'per person unit cost' for all programs and services funded by the Commonwealth should be introduced, so that families and their agents may purchase a suite of units of service and support to fit the needs of their loved ones.

Recommendation 3:

All programs and services funded by the Commonwealth should introduce a 'per person unit cost' to enable individualised purchases of support from carers to fit their personalised situations.

4. Information about the medical, educational, social and care history of loved ones is locked up in the possession of disconnected practitioners and providers, in disparate filing cabinets and unconnected computer databases. Carers are not able to access or use a consolidated information system to direct an efficient system of care and support for their loved ones.

A legislative requirement should be introduced to require all service providers and practitioners to use a person-centred information system nominated by the consumer/carer - where a consumer/carer requests that it be used.

For persons under 18 years of age, the consent of their family should be required before service providers, institutions and practitioners may access the information in this system, or enter new information.

Recommendation 4:

The Commonwealth should legislate to require all service providers and practitioners to use a person-centred information system nominated by consumers/carers (where a consumer/carer requests that it be used) and that for people under 18 years of age the consent of their family should be required before service providers, institutions and practitioners may access the information in this system.

5. A *Respite Entitlement* should be introduced, assigned directly to carers in the form of a respite service voucher, adjusted with a difficulty-in-caring rating, giving 6 weeks of respite per year to all primary caregivers. The *Respite Entitlement* should be used to purchase in-home respite or facility-based respite according to the preference of the family.

Recommendation 5:

The Commonwealth should introduce a Respite Entitlement, assigned directly to carers in the form of a respite service voucher, adjusted with a difficulty-in-caring rating, giving 6 weeks of respite per year to all primary caregivers.

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