CHAPTER 6

ALTERNATIVE FUNDING ARRANGEMENTS FOR DISABILITY SERVICES

6.1 This chapter will examine alternative funding arrangements for disability services. In particular, it will examine individualised funding and insurance models.

Individualised funding

6.2 With the deinstitutionalisation movement of the 1960s, people with a disability were encouraged to live independently. However, 'professionals still provided top-down support and people with a disability still had little power and influence'. This was followed by moves towards individualised planning and involved interdisciplinary coordination, accountability, integration and consumer participation. This came to be criticised as it retained the pivotal role of the professional, had a bureaucratic style for life planning and emphasised quality program delivery over quality lifestyles. There followed a move to 'person-centred-planning' which focussed on the person and their wishes and aspirations.[1]

6.3 Some witnesses argued that the current system of the provision of disability services is based on the financial support of service providers by government rather than financial support of users of disability services to purchase services. The Australian Federation of Disability Organisations (AFDO) commented that the current service delivery models:

- are inflexible and unnecessarily restrictive in what is defined as a legitimate support service;
- do not allow people with disability to take risks, make mistakes or simply to change their minds;
- physically restrict people through the lack of portability of funding; and
- take decision making power away from people with disability and put it in the hands of service providers or carers.[2]

6.4 Many witnesses supported the increased use of individualised funding to people with disability to enable them to purchase and control the services they require. Individualised funding can be undertaken in a wide range of ways including direct payments, indirect payments, and funding held by trusts. What all these types of

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[1] Laragy C, 'Individualised funding in disability services' in T Eardley and B Bradbury eds, *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001*, SPRC Report 1/02, Social Policy Research Centre, University of New South Wales, Sydney, pp 263-278.

[2] *Submission* 90, p.13 (AFDO).

individualised funding have in common is the principle that the funding is put under the control of the individual. It enables the recipient to decide which services they require, how they will be delivered and when they will be delivered, that is the individual's needs shape the service system, rather than the service system shaping the life of the person with a disability. The implementation of individualised funding in other countries has been through service brokers, personal agents, fiscal intermediaries and vouchering mechanisms. These assist with budgeting, selecting services, managing payments and accountability.[3]

6.5 Some supporters argued that direct payments allow a person with a disability to purchase their supports according to their needs and lifestyle requirements. The services purchased could include personal support, domestic services and social services. For example the NSW Council for Intellectual Disability thought that a system of self managed funds including Direct Payments is likely to lead to the most effective outcomes for people with disabilities and be more flexible to adapt to people's changing needs.[4]

6.6 Similarly Queensland Advocacy Inc (QAI) commented that 'direct payments elevate a person with a disability from a welfare and service recipient to a potential employer and purchaser of community based services'. Direct payments would provide personal control to purchase only those support services that are convenient and appropriate for their personal needs and support their personal goals and requirements. This would also enhance self-determination and overcome the problems people with a disability face when moving between and within jurisdictions.[5]

6.7 Supporters of this arrangement argued that there were significant financial benefits in this method of funding disability service:

- Administrative costs would be lessened.
- Increased competition would lead to lower costs for the provision of some services: some governments place emphasis on specialist disability support services for the provision of tasks which may be more economically delivered by mainstream services for example, house cleaning; This would 'open up' an otherwise closed market and provide employment opportunities within communities.[6]

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[3] Laragy C, 'Individualised funding in disability services' in T Eardley and B Bradbury eds, *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001,* SPRC Report 1/02, Social Policy Research Centre, University of New South Wales, Sydney p.264.

[4] *Submission* 46, p.6 (NSW Council for Intellectual Disability).

[5] *Submission* 26, p.2 (QAI).

[6] *Submission* 26, p.1 (QAI).

Implementing a direct payment system

6.8 QAI suggested that the mechanisms already exist to deliver direct payments to people with a disability:

- Many people with disability and their families are currently in the Centrelink system either through Disability Support Pension, Carer's Payment or Carer's Allowance and can be easily added if they are not.
- Some service provision can be allocated a Medicare Benefit number that allows people to purchase support services through the Medicare system.
- Currently any person with a disability cannot access support services without a formal diagnosis from an appropriate medical specialist. Medical specialists could also assess the levels of support needed in the process of diagnosis which in turn indicates level of funding for a person’s need. A central national data base that recorded this information would provide ease of coordination, as well as providing a more accurate picture of disability nationally for current and future needs.[7]

6.9 Other witnesses noted that the Commonwealth has already started a move to individual funding with the Case Based Funding program for employment support.[8]

6.10 Disability Advocacy and Complaints Service of SA pointed to a model espoused by People Power which called for the consolidation of all existing Commonwealth and State disability funding programs (with the exception of respite care) in a person-based funding entitlement (the Disability Funding Entitlement). The Entitlement would be allocated to the nominated agent (a community organisation, a health fund, a consumer co-operative, a for-profit financial agent, a GP or lawyer) or family member. Disability Agents would be permitted to contract with providers and practitioners in developing price and service quality arrangements and would be free to develop packages of care, innovations in care planning and information management, home-care supports, accommodation options and arrangements, and employment services for their people. People with a disability would be free to select their preferred agent, and to transfer from one to another annually.

6.11 The Disability Funding Entitlement would be adjusted for factors such as age, sex, disability and health status, and life-cycle-stage in order to ensure that agents will compete to attract the support of people with all kinds and severities of disability. Every child or adult who is diagnosed with a disability is eligible for the Disability Funding Entitlement from the time of diagnosis until death or until the disability has ceased to disable.

6.12 It was also suggested that a Respite Entitlement be established. The Respite Entitlement would be assigned directly to family carers or their agents as a respite

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[7] *Submission* 26, p.3 (QAI).

[8] *Submission* 50, p.11 (National Council on Intellectual Disability).

service voucher, adjusted with a severity-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 carer.

6.13 Other elements of the proposed system included an independent Disability Support Information Service to provide comparative online price and service quality data on Disability Agents, disability services, respite services, accommodation services, health services and practitioners and a Supported Accommodation Authority to research, design, purchase, and build innovative supported accommodation options.[9]

Accountability

6.14 One aspect to be considered in any individualised funding arrangement is the extent and form of accountability that will be required from people with a disability in relation to the use of public funding. AFDO commented that 'like the CSTDA, accountability by people with disability should be outcome focussed, in line with the goal of improving the quality of life of people with disability and enabling them to enjoy full citizenship'.[10]

Limitations of individualised funding

6.15 While individualised funding was supported by many, some shortcomings have been identified:

- individualised funding systems are not simple and can be more complex for individuals and their families to navigate;
- people with disability should be able to choose the level of self-sufficiency they need and are comfortable with, from traditional agency based services to self-management;
- individualising funding does not by itself lead to a person having increased control over their life or to a better quality of life – brokers can simply replace case managers as controlling forces and deciding how funds are spent;
- the removal of professional and service staff can lead to people with disability becoming increasingly isolated and more vulnerable to exploitation by family members and carers; and
- governments tend to abrogate their responsibility for individual support and service development once payments are devolved.

6.16 AFDO also noted that research has also identified the risk that people with disability, their carers and families, who are often already under immense pressure, can be asked to take on even greater responsibility under individualised funding

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[9] *Submission* 68, p.23 (Disability Advocacy and Complaints Service of SA).

[10] *Submission* 90, p.13 (AFDO).

models. Not only do they become directly responsible for the results of poor decision making, research suggests that apparent cost savings and efficiencies in the model may be gained at the literal expense of individuals and families, who absorb the cost of managerial tasks that were once undertaken by others.[11]

6.17 Both Canada and the United Kingdom have adopted individualised funding arrangements.

Vouchers

6.18 Vouchers were also raised as an alternative funding arrangement for disability services. Like individualised funding, arguments in support of a voucher system for disability services highlight that people with disabilities should be empowered to choose their services and where funding will go. This would encourage competition and better services from disability services providers. The providers with better quality disability services would attract more clients and other providers would have to reform. However, there were concerns raised about the practicality of a voucher system. NCOSS commented:

> …a voucher is useless if there are no services available to be delivered to the person in need and the services are not flexible enough to meet the person's needs. I fear for people in rural, regional and remote New South Wales, where everyone is walking around with a voucher but there are no services. Vouchers are just a different way of rationing limited resources. There are a lot of benefits in terms of the individualised stuff—and I know that a lot of people argue in terms of self-determination, and that is certainly attractive—but at the end of the day if it is still the same pie it will just get sliced a different way.[12]

6.19 Similarly Mr Craig Rowley of Multiple Sclerosis Society of Queensland commented:

> Just commenting on the voucher system, the DSQ lifestyle packages are, in effect, a voucher system. People are allocated a certain amount of money which is fixed and then they go to service providers and choose the provider they like, and if they do not like them down the track they can change provider. That is all in theory. In practice, it is much tougher. The problem with the system is an assumption that that person has the capability to do that. The reality is that people with a disability, particularly a severe disability, are by definition functioning at a much lower capability than other people in the community. It is only people with very stable disabilities, perhaps people with paraplegia, who can use those systems very effectively.[13]

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[11] *Submission* 90, p.13 (AFDO).

[12] *Committee Hansard* 3.10.06 p.38 (NCOSS).

[13] *Committee Hansard* 17.11.06, p.60 (MS Society of Qld).

6.20 Moving to a system based on individualised funding arrangements could lead to efficiencies and improvements in the provision of programs and services by increasing competition in service provision and reducing administrative costs, however the introduction of such a system poses some challenges for people with disabilities, their families and carers (and also for governments). Individualised funding systems can become more complex to navigate, and decision support tools and services would need to be provided. Ideally, people with disabilities should be able to choose the level of self-sufficiency they are comfortable with, and the introduction of such a system should not result in people with disabilities, their families and carers being put under more stress and required to absorb the costs of additional managerial tasks.

Insurance options

6.21 Several countries have instigated insurance systems for long term care. For example, in Germany, public long term care insurance commenced in 1995 and is comprehensive and mandatory, covering about 88 per cent of the population. Premiums are paid by employees and employers. There are uniform eligibility and benefit criteria and covers both institutional and home based care. Family caregivers receive cash payments. In 2000, Japan overhauled an ad hoc system for funding care provision. This tax-funded system pays a flat rate 90 per cent of costs of all care homes and home care. The remainder comes from a private 'co-payment' regardless of means. Unlike Germany, Japan does not offer public support for family care, which was previously the dominant form of long-term care, because the Government wants to relieve what is sometimes an excessive burden on families, and especially on women, by changing the prevailing culture. The reform has succeeded in increasing the amount of formal home care services.

6.22 Both of these systems have succeeded in establishing a coherent and transparent funding system. Neither has resolved fully the issue of how to pay for mounting demand, and both governments are curbing costs by adjusting the terms of their schemes.[14]

6.23 In New Zealand, a nationalised, no-fault disability service system has operated since 1974. The New Zealand system, irrespective of fault, provides ongoing support services to those acquiring permanent personal injury.[15]

6.24 In Australia, some people with disability are funded through transport insurance and workers compensation mechanisms. It was suggested that these schemes could be extended to include catastrophic injury more generally. Witnesses pointed to the Victorian Transport Accident Commission Scheme which is a no-fault insurance system for people who are injured in a traffic accident. People with

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[14] Joseph Rowntree Foundation, *Paying for Long Term Care: Moving forward*, www.jrf.org.uk/knowledge/findings/foundations/0186.asp

[15] *Submission 44*, p.26 (Ms R West).

disability have access to the services and supports that they actually need. By contrast, 'it is very unlikely that somebody who is noncompensable will be able to feel comfortable that they have what they need and that might not be taken away from them again at some point'.[16]

6.25 YPINHNA commented:

> …we believe that something like a social insurance levy, similar to the Medicare levy in intent and scope, is needed for long-term care and support. It is clear that younger people who need to access such a scheme are a small proportion of the overall demand…So if one of these levies were put in place you would have time to build capacity before people age and before the rise in disability that accompanies age.[17]

6.26 Ms Raelene West favoured a system modelled on the New Zealand system but inclusive of a capped common law system and commented that such a system would serve to provide an effective model for a nationalised no-fault disability services support scheme. This scheme could incorporate the various funding sources (motor vehicle, workcover, Veteran's Affairs) into a pool of funding and provide funding for services on a parallel pathway as generic services. A common law component could then still be maintained for acquired injuries within this framework.[18]

6.27 Some State and Territories have insurance options for catastrophic injury caused by motor vehicle accidents or work-related injury. The Victorian Government commented that a more general catastrophic injury scheme would alleviate some of the cost burden to States and Territories of responding to people with acquired disability. A catastrophic injury scheme could also include acute inpatient care, rehabilitation, specialist and expert medical care, pharmaceuticals, and disability support. The Victorian Government supported a national approach to the development of a catastrophic injury compensation scheme but if this was not developed 'Victoria will proceed with exploring options for a catastrophic injury compensation scheme locally'.[19]

Accommodation and care options

6.28 The Committee received evidence about parent initiatives to finance accommodation options for their children. The Disability Advocacy and Complaints Service of South Australia commented that a group of parents, in partnership with government, had developed a model of accommodation in a regional centre. DACSSA commented that 'these partnerships may indicate a future trend where the government uses resources provided by parents to ensure the future accommodation needs of their

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[16] *Committee Hansard* 28.09.06, p.27 (BIA).

[17] *Committee Hansard* 28.9.06, p.5 (YPINHNA).

[18] *Submission* 44, p.26 (Ms R West).

[19] *Submission* 99, p.15 (Victorian Government).

children with disabilities'. However, DACSSA warned that although parents may fund the accommodation, there must be adequate care packages for long term viability.[20]

6.29 In 2005 the Commonwealth announced changes to make it easier for parents of children with severe disability to make private financial provisions for their children's future care and accommodation needs by enabling parents to put up to $500,000 into a trust without being affected by the means test.[21]

Recommendation 25

6.30 That a review of alternative funding arrangements be undertaken through the research and development program of the next CSTDA which specifically considers, amongst other elements:

- **the likely costs and benefits of individualised funding;**
- **the issues encountered in the introduction of alternative funding overseas;**
- **provisions and alternatives to allow people with disabilities to choose the level of self-sufficiency with which they are comfortable;**
- **the provision of decision support tools and services to assist people with disabilities, their families and carers.**

That the findings of the review be reported to the relevant Ministerial Council.

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[20] *Submission* 68, p.17 (DACSSA).

[21] *Submission* 96, p.17 (Australian Government).