

Literature Review: Person-centred Approaches to Disability Service Provision

November 2010

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Introduction

Over the past decade ‘person-centred’ approaches to disability service delivery have gained momentum in international contexts, particularly in North America, and the United Kingdom. These approaches emphasise choice for people with disability and/or their carers in identifying, negotiating, and purchasing necessary support services, and in ‘driving’ disability system changes.

Recent policy direction in Australia’s Federal and State Governments have affirmed these approaches. The introduction of the Disability Act (2006) in Victoria has instituted a shift away from population focused and funded service delivery to an emphasis on individualised funding models. The Federal Government has commissioned the Productivity Commission to develop proposals for a new ‘National Disability Insurance Scheme’ (NDIS), and their recommendations are largely based on person-centred and individualised funding models.

Reflecting and responding to this policy direction, Melbourne Citymission has been developing individualised funding/person-centred approaches in key services in the Disability and Children’s Services division. For this reason it was seen as timely for the organisation to more clearly articulate our own position on person-centred approaches, starting with a review of the key evidence that informs these approaches. By examining the implications of these approaches for diverse populations living with a disability, Melbourne Citymission expects to be better equipped to advocate for and deliver high quality services for these populations and to inform policy development.

A key first step in the formulation of any policy is to review existing literature and research. This report was commissioned by Melbourne Citymission and we congratulate Maggie Kirkman, PhD, from the University of Melbourne, for providing us with this comprehensive literature review. Maggie has provided a useful analysis of the main streams of investigation that have been published in person-centred practice, and we expect this will contribute significantly to the ongoing introduction of policy and practices that benefit people with a disability and their families into the future.



Rev Ric Holland, CEO
Melbourne Citymission

Background to the Project

This document has been designed to inform Melbourne Citymission's position on individualised funding/person-centred approaches in key services in the Disability and Children's Services division. Melbourne Citymission's expectation is that, by examining the implications of these approaches for diverse populations living with a disability, Melbourne Citymission will be better equipped to advocate for evidence-informed policy and high quality service delivery for these populations. A position paper will be developed by the Melbourne Citymission RSPU in collaboration with the Children's and Disability Service Division.

The brief called for a selective review of the literature as a foundation document for the position paper.

Aim and Key Research Questions

The aim of the foundation document was to identify, document, and critically analyse the key ideas or discourses underpinning person-centred approaches to disability service provision. Key questions to address were:

1. What is the history of person-centred approaches in international and national contexts?
(A brief outline of scope, goals, and scale.)
2. What are the key ideas underpinning these approaches?
3. What are implications of these ideas for individuals, populations, and services?

Method

Consultations

An initial meeting was held with Anne Pate, Shelley Mallett, and Maggie Kirkman to discuss the project brief and agree to process, funding, and intellectual property. Early in the project, a consultation was held with Anne Pate, Maggie Kirkman, and senior managers in Melbourne Citymission Children and Disability Services division at Melbourne Citymission to inform the work. Anne Pate reviewed a draft document prepared by Maggie Kirkman. A revised version of the document was discussed at a meeting convened by Anne Pate with Maggie Kirkman and the General Manager and relevant senior managers in Melbourne Citymission Children and Disability Services division at Melbourne Citymission, after which Anne Pate and Maggie Kirkman agreed on a final version of the document.

Literature Review

The literature review was conducted and the report written by Dr Maggie Kirkman.

The first step in identifying relevant publications was to search six data bases (Web of Science, Scopus, Medline, CINAHL Plus, PsychINFO, and PubMed) using the following search terms: individualised + funding + disability; self-directed + support + disability; direct payments + disability.

From the large number of items produced by the searches, relevance was decided initially by title, then by abstract, then by reading whole papers.

To ensure that pertinent work not identified in academic data bases was found, searches were also conducted using Google Scholar and by visiting web sites recommended by Melbourne Citymission

staff. Useful papers were identified from Melbourne Citymission's collection and from suggestions made by staff. The reference lists of relevant papers, reports, and books yielded further items. While the review was in progress, frequent searches were made of the contents lists of appropriate journals.

Ultimately, 80 documents were selected for inclusion in the review.

All items were read and noted to identify salient contributions to answering the research questions. Papers of particular relevance were re-read to enable comparisons to be made, especially where there were conflicting views or contrasting evidence. Although all papers identified as important contributed to the construction of the report and are listed at the end of this document, not all are specifically cited.

Outline of the Document

The report is presented in four sections: 1. A brief history of person-centred approaches ("Background"); 2. An outline of the main person-centred approaches; 3. Introduction to the key ideas underpinning person-centred approaches; and 4. Implications of these ideas for individuals, populations, and services.

1. PERSON-CENTRED APPROACHES: BACKGROUND

Disability

An appreciation of person-centred approaches to disability requires a sense of what is understood by 'disability'. According to the Australian Productivity Commission (2010), there is no single definition. Contemporary definitions of disability tend to incorporate interaction between the person and features of the society in which she or he lives; this approach to defining disability is represented in the United Nations Convention on the Rights of People with Disabilities (adopted by the UN in 2006 and ratified by Australia in 2008) and the World Health Organisation. This understanding of the person in the social context comprehends the barriers to daily life and well-being that might be raised by social attitudes, policies, or the physical environment. Such an approach is compatible with both the social model of disability and the capabilities framework, sometimes seen in opposition but persuasively argued as complementary (Burchardt, 2004). Both the social model and the capabilities framework differ from the individual approach, allied to the medical model, which emphasises personal impairment and tends to focus on curative or rehabilitative strategies to adapt individuals to their context rather than attempting to adapt the context to support the individual (Burchardt, 2004). In relation to these definitions and theories, developments in disability care and support have been described as a move from a deficit model to a support-based model (Guscia, Harries, Kirby, Nettelbeck, & Taplin, 2006). On a more pragmatic level, the Australian Institute of Health and Welfare (2007) and the Australian Bureau of Statistics (2009) define disability as a limitation, restriction, or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. The Productivity Commission (2010) identifies the main personal sources of disability for those needing constant or regular support as physical conditions, mental illness, congenital anomalies, and intellectual disability.

The number of people with a disability will vary according to the definition. The Productivity Commission (2010) presents a range of such statistics, among which is that the Disability Investment Group estimated that, in 2009, Australia had about 580,000 people aged under 65 years with severe or profound disability, based on the AIHW Burden of Disease data. An idea of what this might mean to organisations like Melbourne Citymission is found in the following list of some of the support needs of people with a disability (from Productivity Commission, 2010, box 2, page 8). There are in Australia:

- 40,000 people with constant support needs: people in establishments other than nursing homes or people who cannot be left alone for one hour;
- 104,000 people with frequent support needs. These need assistance with at least one core activity at least three times a day and/or cannot be left alone for more than a few hours; and
- 32,000 people with regular support needs, who need assistance with at least one core activity once or twice a day.

Furthermore, the Productivity Commission drew on Commonwealth data to report that there were just over 245,000 people using specialist disability services under the Commonwealth State and Territory Disability Agreement in 2007-2008, and about 180,000 people aged less than 65 years who used Home and Community Care for services such as nursing care, allied health, and the provision of aids and equipment. Some people use both sources of services.

According to the Productivity Commission (2010), the types of services required by people with a disability as part of an adequate care and support system are usually grouped into personal care services, respite and accommodation services, community access, community support, income support, employment, transport, aids and appliances, and home modification, as well as a range

of other services such as counselling and mentoring. These are among the services to be provided under a system of individualised funding, although advocates of person-centred approaches include assistance with anything that will contribute to improving quality of life for a person with a disability. The Productivity Commission identified a high level of unmet need for services in Australia, reporting the most recent AIHW data that, in 2005, 23,800 people with disabilities aged under 65 did not receive the accommodation and respite they needed, 3,700 had unmet need for community access (support services to enable people to live in a non-institutional setting), and 1,700 people did not have access to disability employment services. The Productivity Commission pointed out that these data “will not capture many unmet needs by people with disability or their families—delays in access to appropriate aids and appliances, lack of flexibility in service provision and insufficient power for people seeking services” (Productivity Commission, 2010, p. 33). The assessment of individual support needs is not uniform in Australia (Guscia et al., 2006), which further complicates planning for organisations like Melbourne Citymission.

It has been argued that there is inadequate conceptualisation of the person with an intellectual disability (DiRita, Parmenter, & Stancliffe, 2008) which will also preclude optimal provision of services.

Person-Centred Approaches and Individualised Funding

Person-centred approaches to the care of people with a disability are designed to ensure self-determination and community participation. (These and other key ideas are developed in a later section.) Individualised funding is one mechanism for enabling such flexibility; it means that money to support a person is allocated directly to the person instead of to a service agency (e.g., Laragy, 2004; Lord & Hutchison, 2003). This process is also called direct funding, self-directed support, consumer-directed support, and cash-for-care (e.g. Cumella, 2008; Laragy, 2004; Rummery, 2009). The goal of providing funds directly to the person who needs services is to enable them to determine what services they need; their needs will thus shape the service system (Laragy, 2002). Worldwide, person-centred approaches and the associated individualised funding model still constitute a minority of methods for providing care to people with a disability (Fisher et al., 2010).

History of Person-Centred Approaches

Among the most useful documents for summarising the history of person-centred approaches, especially those that use individualised funding, are Cumella (2008), Lord and Hutchison (2003), Rummery (2009), and papers by authors whose work is particularly relevant to Australia (DiRita et al., 2008; Laragy, 2004, 2009).

Laragy (2002, 2004) draws on other authors to summarise the background to person-centred approaches to disability and individualised funding over the last five or six decades. After the Second World War, people with disabilities were treated as victims. Until the 1960s the medical model of disability dominated; decisions were made by doctors on behalf of patients, many of whom lived in institutions. The movement to deinstitutionalisation dominated the 1960s; independent living was the goal, but various professions retained the power to make decisions for people with disabilities. In the 1970s, ‘normalisation’ was the buzzword, with an emphasis on assisting people with disabilities to live as members of the community through ‘individualised planning’, but professionals still tended to make most of the decisions. It was criticised as emphasising quality program delivery rather than quality of life. Person-centred planning emerged at around same time; the focus was on the individual but it was still a professional who was focusing on and making decisions for the person with a disability. The most recent person-centred approach (often called ‘self-determination’) is that which gave rise to individualised funding, with the goal of enabling the person with a disability to determine what she or he needs rather than accepting what professionals think is required.

Behind most of the changes in approaches to the care and support of people with disabilities is an increased awareness of the rights of the person with a disability (e.g., Bigby, 2007; Ellis, 2005; Laragy, 2002). The United Nations Declaration of Rights of Disabled Persons (1975) is the foundation document which has guided legislation around the world. People with disabilities and their advocates constitute a disability movement that campaigned for an end to segregation as essential to the rights of people with a disability (e.g., Clapton, 2009). As institutions closed in Western countries and community living became the ideal, the campaign extended to advocating control over personal assistance, identified as fundamental to independent living (e.g., Boyle, 2008; Burchardt, 2004). Momentum increased after the International Year for Disabled Persons in 1981 (Clapton, 2009). Since then, there has been the 2006 United Nations Convention on the Rights of Persons with Disabilities which, among other things, requires governments to provide services that enable people with disabilities to exercise their rights (see Cumella, 2008). (There are differences of opinion within the rights movement, with civil and human rights set against social rights; this is discussed by Ellis, 2005, who argues that these rights are complementary and mutually strengthening. Ellis is also a good source of information on the rights movement.)

According to Burchardt (2004), the social model of disability arose from the disability movement whereas the capabilities framework was developed by economists and political philosophers, especially Amartya Sen and Martha Nussbaum, to conceptualise social, economic, and environmental barriers to equality. This parallel philosophical and advocacy history (which is outside the scope of this report) has added to the complexity of the current understanding of the move to person-centred approaches and individualised funding. Those seeking details are referred to Burchardt (2004) and Clapton (2009).

This century has seen the language of human rights replaced by the new discourse of consumerism (Cumella, 2008), in which people define themselves by what they can purchase in a market economy. Person-centred approaches to providing care and services for people with disabilities, especially in the aspect of individualised funding, are clearly consistent with consumerism, which in turn is linked with neo-liberalism, economic rationalism, and managerialism, to which more detailed reference will be made in subsequent sections. It can be inferred from Rummery (2009), among others, that the increasing advocacy for person-centred approaches arises from many powerful, intersecting historical movements, not all of which have at their heart the needs and rights of people with a disability. A recent, pragmatic impetus, according to Rummery (2009), is the increased demand for welfare services, especially from people with a disability, and the reduced availability of unpaid carers. A market solution and what some have called the commodification of care (Rummery, 2009) suits current political and economic orthodoxy as well as meshing with the desires of people with a disability and their carers.

Person-Centred Approaches Internationally

Over the past decade, person-centred approaches to disability service delivery have gained momentum internationally, particularly in Canada and the UK. A detailed history of programs is beyond the scope of this report. There are informative documents for Canada (Lord & Hutchison, 2003), the UK (Carmichael & Brown, 2002; Hudson & Henwood, 2008; Laragy, 2009; D. Leece & Leece, 2006; J. Leece, 2004; Priestley et al., 2007), Netherlands (Buntinx, 2008; J. Leece, 2004; Rummery, 2009), Sweden (Laragy, 2009) and other Scandinavian countries (Fisher et al., 2010), the US (Cloutier, Hagner, Malloy, & Cotton, 2006; Lord & Hutchison, 2003; Rummery, 2009), and New Zealand (Fisher et al., 2010, Appendix D). According to the Australian Productivity Commission (2010), some of the most advanced models of person-centred funding are to be found in the UK and Germany, and person-centred funding is an important aspect of disability services in many states in the US. Hatton and co-authors (2008) give information about the background and context of In Control, the UK charity founded

in 2003 specifically to promote personal budgets for people with learning difficulties, which was set up by a group including the Department of Health (see Hudson & Henwood, 2008, for a less partial perspective). Organisations to support the use of person-centred approaches have also been established in Europe, Canada, and the US (Laragy, 2002).

In Ontario, Canada, individualised funding for people with developmental disabilities began in 1982 in a program called Special Services at Home (SSAH), which gave families the option of administering their own disability supports (Lord & Hutchison, 2008).

In the UK, the *Community Care (Direct Payments) Act* (1996) gave people with all types of disabilities the right to direct payments depending on a needs assessment; direct payments have existed in the UK since April 1997 (Hudson & Henwood, 2008). Local authorities were enabled to make cash payments to disabled people aged 18 to 64 instead of directly providing services (Blyth & Gardner, 2007; Priestley et al., 2007). Because the scheme was designed to replace formal rather than informal care and support (Rummery, 2009), it was not permitted to use the direct payments to pay family members. Initially, direct payments could be used only to employ support workers, but greater flexibility has subsequently been introduced. Payments can now also be made to people over 65, to carers of disabled children under 18, and to young people in transition (aged 16-17) (Blyth & Gardner, 2007; Hudson & Henwood, 2008). More recently, there has been legislative commitment to extending the scope of direct payments to people “without capacity” who had been excluded (Hudson & Henwood, 2008). Legislative change means that direct payments are no longer available only at the discretion of the local authority but are a mandated responsibility that local authorities must offer to eligible service users (Blyth & Gardner, 2007). Nevertheless, there have been slower implementation and acceptance of direct payments than desired or expected by government and organisations advocating for people with disabilities (Blyth & Gardner, 2007; Hudson & Henwood, 2008). According to Priestley and co-authors (2007) among others, not all disabled people were aware of direct payments; furthermore, professionals tended to have limited views of capacity and entitlement, especially as they concerned people with intellectual disabilities. Local welfare politics also played a role in restricting implementation (Priestley et al., 2007). In particular, Hudson and Henwood (2008) associate the local variation in take-up of direct payments with the early activism of user-led advocacy groups, especially for those with physical disabilities, so that areas in which there was activism and early implementation have continued to attract support and encourage usage. The take-up continues to be largely by people with physical rather than intellectual disabilities.

The UK white paper *Valuing People*, distributed in 2002 by the then Labour government to outline policy for people with an intellectual disability (“learning disability”), emphasises person-centred planning, direct payments, and employment. It has been criticised as based on contradictory ideologies which contribute to the difficulties in evaluating policy implementation and outcomes (Burton & Kagan, 2006) (although there are disputes over the specific nature of these contradictions: Cumella, 2008). Burton identifies the impetus for *Valuing People* not only as philosophies of disability (such as normalisation and social role valorisation) and the influence of advocacy organisations in the UK (such as Mencap and People First), but also the increasing privatisation of service provision. The contribution of economic philosophies and interests further complicates the understanding of person-centred approaches to care and service provision for people with a disability. Burton and Kagan (2006) describe it as a mix of humane philosophy and the market model (see also Leece, 2004). An additional component of the *Valuing People* policy document is the role played by the transformation of services through the growth of professional and technical knowledge and skills, in which non-medical work with people with a disability is seen less as charitable and more as professional care (Burton & Kagan, 2006). *Valuing People* is identified with New Public Management, a consumer- and market-focused approach to reforming the public service, which is embedded in the rise of New Labour in the UK as

well as in US politics (Cumella, 2008). Person-centred approaches to disability services thus arise from a tangled history of philosophical, ideological, economic, and political changes in the UK and around the world. In the UK, there is also wide local variation in history and implementation (Priestley et al., 2007) which Priestley and co-authors attribute to local and regional cultural and political differences.

Decentralised policy and entrenched 'small government' means that there is considerable variation in US services for people with disabilities. However, 'consumer choice' programs have suited the political and economic climate and people with disabilities have been enabled to hire their own care workers through schemes such as the 'Cash and Counseling Demonstration' pilots in Arkansas, Florida, and New Jersey (Rummery, 2009). The Robert Wood Johnson Foundation funded the first demonstration project in the US on 'self-determination funding' at Monadnock Developmental Services, New Hampshire, in 1996 (Lord & Hutchison, 2003; Turnbull & Turnbull, 2006). Whereas in the UK the move to more person-centred approaches was instigated by disability rights organisations, in the US, organisations for older people were more influential (Rummery, 2009).

Among other countries with varieties of person-centred approaches in the disability field are the Netherlands (from the 1990s), Italy (in limited form, over the last 10 years), and Austria (limited, from the 1990s) (Rummery, 2009).

Person-Centred Approaches in Australia

Useful discussion of the history of person-centred approaches in Australia can be found in DiRita and co-authors (2008) and Laragy (2002, 2004), although the latter emphasises programs for young people.

The first large-scale individualised funding program in Australia began in 1988 in Western Australia (Laragy, 2009; Lord & Hutchison, 2003). The WA Local Area Coordination (LAC) program was established to support people with an intellectual disability and later expanded to include other disabilities. It has been admired and emulated elsewhere in the world (Clapton, 2009; Lord & Hutchison, 2003; Martin, 2009). An occasional paper from the federal Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Effectiveness of individual funding approaches for disability support*, states that Victoria introduced individual funding about 10 years later, beginning with the Futures for Young Adults Program (Fisher et al., 2010).

Laragy (2004) described individualised funding in Australia as lagging behind the programs in other countries and being more limited in its application; this still appears to be the case, although the approach is evidently beginning to be more widely accepted, if not yet adopted. Productivity Commission hearings have recently (June and July 2010) been held with the aim of developing a national disability scheme (Productivity Commission, 2010). It is planned that the scheme will be limited to people with severe or profound disabilities, excluding ageing. According to the Productivity Commission, "There is a widespread view that the current system to support people with disability and their families is deeply flawed and will increasingly be unable to meet people's needs" (Productivity Commission, 2010, p. 2). The Commission identifies a strong national movement to person-centred approaches.

Policy Context in Australia

Australia's current policy context is most clearly identified in the Productivity Commission Issues Paper *Disability care and support* (Productivity Commission, 2010), which gives background to a call for reform. It claims on page 2 that "Many people think that disability services are often in crisis mode, with very inadequate provision of services", and that there is also a strong view that good service is

a “lottery” dependent on where people live and how their disability was acquired. The inquiry was sparked, according to the Commission, by “mounting concerns about these systemic and enduring inadequacies”. The Commission has been asked to “examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme” that, among other things, “takes account of the desired and potential outcomes for each person over a lifetime, with a focus on early intervention; provides for a range of coordinated support options—accommodation, aids and appliances, respite, transport, day programs and community participation; assists the person with the disability to make decisions about their support; provides for people to participate in education, training and employment where possible” (Productivity Commission, 2010, p. 3). Key questions for the Commission’s inquiry include “how a new scheme could encourage the full participation by people with disability and their carers in the community and work” and “how to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)”. Given the criticisms of the apparent location lottery, another key question was stated as “what to do in rural and remote areas where it is harder to get services” (Productivity Commission, 2010, p. 8).

It is noted in the Commission’s issues paper that disability services have traditionally been understood as part of the welfare system; people with disabilities have thus been seen as “passive recipients of government-funded services” (Productivity Commission, 2010, p. 22). However, the Commission reports growing impetus towards “a shift to provide people with disabilities and their carers with more control”, including “so-called ‘individualised funding’ or ‘consumer-directed’ care” whereby “people receive an annual funding entitlement that they can spend on the services they want or can exercise greater control over the services they receive” (Productivity Commission, 2010, pp. 22-23). The Productivity Commission identifies the “overarching goal” of new disability policies in state and federal governments throughout Australia as “to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights” (Productivity Commission, 2010, p. 9). The policy context in Australia therefore seems to be one of reassessing old policy in favour of more person-centred approaches, including individualised funding, a view confirmed by the FaHCSIA report (Fisher et al., 2010). The desired approach outlined by the Productivity Commission echoes the emphasis of the 2002 UK white paper *Valuing People* on person-centred planning, direct payments, and employment.

In Victoria, the *Intellectually Disabled Persons Services Act 1986* acknowledged the rights of people with an intellectual disability (the first piece of legislation in Australia to do so: Bigby, 2007); this was extended a few years later to people with various disabilities in state and commonwealth acts (Laragy, 2002). The individual needs of people with disabilities have been emphasised in government policy from the 1990s (Laragy, 2002). Over the last few years, the Disability Service Division of the Victorian Department of Human Services has instituted a shift away from population-focused and population-funded service delivery to individualised funding models, especially with the launch of the Victorian State Disability Plan (2002-2012). The *Quality Framework for Disability Services in Victoria* (DHS, 2007) establishes outcome criteria identifying what is considered to be important to people with a disability as citizens. Disability advocacy groups have been among those lobbying for person-centred approaches and individualised funding (e.g. National Disability Services Victoria, 2008).

Bigby and Knox (2009) quote Section 52 of the *Victorian Disability Act, 2006*, which states that “Planning should (a) be individualised; (b) be directed by the person with a disability; (c) where relevant, consider and respect the role of family and other persons who are significant in the life of the person with a disability”; they add that similar legislative provisions are found in other Australian states. This is a clear statement of a person-centred approach.

2. MAIN PERSON-CENTRED APPROACHES

The main person-centred approaches have been variously categorised and described. An occasional paper from the federal Department of Families, Housing, Community Services and Indigenous Affairs (Fisher et al., 2010), *Effectiveness of individual funding approaches for disability support*, identifies individualised funding as varying according to who holds the funds, the degree of portability, and the types and sources of support it can be used to buy. In examining the gendered implications of “cash-for-care” schemes in six countries, Rummery (2009) organises them into three categories: highly formalised; some scrutiny, with local discretion and variability; and limited state governance. Rummery’s headings are used here to organise some of the available data about international programs, followed by Australian approaches organised around the FaHCSIA information. Despite evidence of the burgeoning popularity of person-centred planning, there is limited formal evaluation of programs from which to draw conclusions about efficacy (Cumella, 2008; Fisher et al., 2010; Hatton et al., 2008; Mansell & Beadle-Brown, 2006).

The literature deals with a range of communities with a disability to which person-centred approaches apply: children (e.g. Blyth & Gardner, 2007), school-leavers (e.g. Laragy, 2002, 2004), people with a disability who are ageing (e.g. Bigby & Knox, 2009; Boyle, 2008), people with specific disabilities (e.g. intellectual: Bigby & Knox, 2009; Wolff, 2009; physical: Houston, 2004; mental health: Cloutier et al., 2006; Spandler & Vick, 2006; Taylor, 2008). The target community obviously affects the goals, scope, and evaluation (among other things) of the program; this report can present only an overview which will not be able to do justice to all the permutations.

International: Highly formalised approaches

According to Rummery (2009), highly formalised approaches are found in the Netherlands and France, which her analysis identifies as the most gender equitable as well as offering the most favourable outcomes for older people and those with a disability.

Laragy (2009) investigated individualised funding in Sweden and the UK. Sweden appears from this account to fit Rummery’s category of highly formalised provision of individualised care. In Sweden, according to Laragy, there is a variety of management options providing different levels of control for people with a disability. Only 3% of people take full control and directly employ their own staff; these are predominantly people with a physical disability. At the other end of the scale, 60% of people transfer their funds to the local authority which then provides rostered support workers. A trustee, often the person’s mother, is legally appointed when people are judged unable to make independent decisions.

The Netherlands introduced a personal care allowance scheme in 1991 and extended it in 1995 to become part of the national long-term care insurance scheme in which recipients could choose to receive direct payments rather than services (Rummery, 2009). Their monthly allowance is individually calculated and can be used to purchase services on the open market or from an informal carer. The type, level, and provider of care are chosen by recipients who are responsible for administering the funds and accountable to the government (Fisher et al., 2010). Rummery (2009, p. 637) described the system as “relatively strictly regulated” in ways that protect directly-employed care workers including making it impossible to pay workers on the black market. Because it permits payment to family members for care, the scheme enables a flexible combination of formal and informal care that recipients welcome, as they welcome their greater sense of control over the care they receive. There are some political concerns over the potential for demand for the generous funding to rise, but Rummery

cites evidence that the direct funding is less costly than the provision of state-funded services. An explicit goal of the scheme was to reduce state costs, including moving away from expensive residential services.

The scheme described by Rummery (2009) in France is of insurance-based health and social care payments that operate in a cultural tradition of family-based care. However, her information relates to aged care and does not mention people with a disability. She does state that, in addition to an apparently universal “neo-liberal drive to reduce state involvement and expenditure on social care”, the French cash-for-care scheme was also designed “to protect the employment rights and status of formal care workers” (Rummery, 2009, p. 641) who are, in France as around the world, overwhelmingly women. France and the Netherlands both route carer payments through recognised agencies.

France and the Netherlands can thus both be seen to go some way towards addressing gender inequalities as well as the needs and rights of people with a disability and, of course, political moves to reduce state financial liability. Rummery also points out that the regulation that protects vulnerable members of society also enables state power to scrutinise and police intimate relationships and reduces personal control over how they are managed. Nevertheless, Rummery concludes that

“what is good for gender equality and equity is good for other groups of society too, and that a benign-but-powerful welfare state has an important role to play in protecting the citizenship rights of women, disabled people and older people”. (Rummery, 2009, p. 646)

International: Approaches with moderate scrutiny

Rummery (2009) identifies the UK and the US as exemplifying cash-for-care approaches with a moderate degree of scrutiny and uneven implementation. According to her, both the scrutiny and restrictions on paying family members act as some protection against abuse both of recipients and their employees, but the high degree of discretion and variability can have adverse impacts on women.

The UK has a national regulatory system for the distribution and use of individualised funding for people with disabilities. (Detailed information on the way that funds are distributed in the UK can be found in Prideaux, Roulstone, Harris, & Barnes, 2009.) Laragy (2009) presents data from the UK indicating that, in 2007, 54,000 people in England (which has the highest uptake in the UK) were using direct payments and 1,000 were using individual budgets. A needs assessment is undertaken to establish the level of funding; recipients decide the level, type, and provider of the services and assume responsibility for administration (Fisher et al., 2010). The UK organisation founded specifically to promote individualised funding, In Control, allows funds to be spent on anything except illegal activities or gambling (Department of Health, 2007; Duffy, 2005; Hatton et al., 2008). Nevertheless, there is evidence that funds in the UK are almost exclusively used for personal care rather than services such as education or employment support (Riddell, 2008). There is no formal assistance in recruitment and little formal employment protection for care workers directly employed by recipients of care (Rummery, 2009), which can lead to concerns for their welfare (Spandler, 2004). For historical reasons, implementation varies by country and local area, with diversity in eligibility criteria and access. Recent policy has been developed to extend access and encourage take-up, especially in under-served areas (Hudson & Henwood, 2008).

Although Rummery included the UK in the moderately-regulated category because of the local variability, she acknowledges that, in some respects, it is as open to scrutiny as the Dutch scheme with both the potential to protect users and to limit user control over caring relationships. Laragy (2009) reports a meta-analysis conducted by the English Social Care Institute for Excellence of data from

individualised funding projects which concluded that they have been successful in enhancing choice, autonomy, empowerment, outcomes, and satisfaction. No evidence was found of fraud or abuse of vulnerable people; there was inconclusive evidence about cost efficiencies, quality assurance, and equity. In Control's informal evaluation, reported by Hatton and Waters (Hatton et al., 2008), found that few people thought that their circumstances had worsened in any measured domain through individualised funding and most thought it had improved in the domains of Relationships, Quality of Life, Community, Choice and Control, and Dignity. The authors concluded that support may be more successful when family and friends are involved in decisions rather than just social workers. Another research project conducted in one north-west of England authority investigated the effects on children with intellectual disabilities and their carers (mostly families) of receiving direct payments (Blyth & Gardner, 2007). It found that parents described direct payments as improving the quality of their family life because they could afford to buy care that enabled them, for example, to spend time with the non-disabled siblings. Parents said that they needed not a social worker but support at home that allowed them to lead an ordinary family life, and that it was easier for them to coordinate their own care. The researchers concluded that mothers became managers rather than recipients, which gave them a sense of welcome control (Blyth & Gardner, 2007). At the same time, they acknowledge that recipients who lack confidence and skills could actually be disempowered by the shift to direct payments. There is evidence from the UK that most users of individualised funding are articulate, well-educated, younger adults with physical disabilities (Riddell, 2008; Spandler, 2004), despite the stated intention to encompass people with a wide range of disabilities, including intellectual. It has been argued that undue emphasis is placed on choice in person-centred planning to the exclusion of other legal and civil rights and that, in any case, only a minority of those eligible for person-centred planning in the UK has achieved enhanced choice (Cumella, 2008).

In the US, policy decentralisation means that there is a variety of what are known as consumer-directed programs of social care (Fisher et al., 2010; Rummery, 2009). People with disabilities (and the aged) can hire their own care workers through schemes such as the 'Cash and Counseling Demonstration' pilots in Arkansas, Florida, and New Jersey and the 'New Hampshire Self-Determination Project'. In practice, people tend to employ workers with whom they have a relationship, including previously-employed workers and family members; the wide variability leaves room for inequity (Rummery, 2009). These services are means-tested and most funded through Medicaid, the limited medical insurance program for low-income earners, and healthcare foundations. The New Hampshire project emphasises the development of administrative practices that enable self-determination (Cloutier et al., 2006; Fisher et al., 2010). In Illinois, the 'Home Based Support Services Program' provides individualised budgets for adults with intellectual disabilities living at home and their parents. The program aims to provide services that remove pressure from informal carers and encourage community participation, thereby preventing out-of-home placement (Fisher et al., 2010). Unfortunately, the program experienced cuts and changes that limited continued achievement of its original goals (Caldwell, 2007).

One US (Washington DC) investigation found that, when families caring for a member with a disability were very involved in decision-making, they experienced high levels of satisfaction (Neely-Barnes, Graff, Marcenko, & Weber, 2008). However, when families had more control over how money was spent, they received fewer services than those who had less control over money, despite feeling satisfied with the process. Researchers explained the results in relation to empowerment theory, in which people who feel in control can experience satisfaction even if measurable benefits have been reduced. This is an important lens through which to interpret evaluations that report solely on "satisfaction" or similar measures. These researchers also pointed out the problems confronting people with a disability without family members able to contribute to decision-making, including those with older families who are accustomed to having decisions made on their behalf (Neely-Barnes et al., 2008).

Both the UK and the US have governance schemes to scrutinise the level and quality of care received, so even the US is not part of a completely unregulated market.

International: Approaches with limited state governance

Austria and Italy are presented as examples of approaches that are explicitly unregulated (Rummery, 2009). Both countries have a traditional gendered system of family and labour, with minimal formal care services.

In Austria, a long-term care allowance was introduced in 1993. It is not means-tested and is a benefit paid directly to the person with a disability (or an aged person). Rummery reports that it is used predominantly to buy care from individuals or organisations or to reimburse family members for their time spent caring. Lack of regulation means that the allowance has often been used to employ informal or immigrant labour, thus reinforcing low-paid and insecure segments of the labour force, especially women.

The Italian system also has a non-means-tested benefit available to people with a disability (and the aged) who are certified as 'dependent'. Considerable regional variation in implementation arises from decentralisation of state provision of services. According to Rummery (2009), no restrictions are placed on the use of the benefit which is not adjusted according to need. As in Austria, it is most often used to employ care workers who tend to be paid low wages 'off the books'. There are also some local means-tested allowances, with variations in eligibility and access. These are used primarily to pay family members to supplement the family income or to provide care, or to employ other care-givers.

Rummery assesses these highly unregulated systems as not only providing inadequately needs-responsive care but also supporting an insecure and underpaid segment of the labour force and reinforcing gendered divisions of labour. When allowances can be paid to the family of the disabled person without specifying limits on their use, Rummery also reports evidence that it tends to promote intergenerational dependency, such as between intellectually disabled adults and their parents, and exposes vulnerable people (disabled people and carers) to exploitation.

International: Summary outcomes

Rummery (2009) summarises individualised payments in 'cash-for-care' schemes as popular and potentially beneficial but with attendant risks. She identifies two main incentives to policy, a topic that is developed in the next section on key ideas. The first is political pressure from users to promote autonomy and choice. The second she identifies as the neo-liberal concern to reduce costs. She cites evidence that costs have been reduced, sometimes through greater efficiency, sometimes by shifting responsibility to families or non-government organisations. Others caution that it is difficult to identify the true costs when comparing direct payments with traditional approaches to service provision (Stainton, Boyce, & Phillips, 2009). Rummery (2009) also cites evidence that the schemes are popular with users because they are perceived to offer more choice and control, to acknowledge the citizenship of people with disabilities, and to promote well-being. She notes particularly that individualised payments can enable varieties of support to be purchased, leading both to increased community participation and to a reduction in the 'burden of gratitude' arising from being a recipient of voluntary care or care from people employed by an organisation. Rummery also draws together reports that individualised funding implicitly acknowledges and encompasses complex relationships that disallow simple binary distinctions. For example, people can be simultaneously employers and carers and exercise their rights and duties as citizens in many ways. The intricate ramifications of power in employer-employee relationships resulting from direct payments in the UK is investigated

and discussed by Leece (2010). However, when problems and burdens are ameliorated through adequate schemes, it is argued that well-being is promoted for people with a disability, their families, and their carers.

The risks and problems identified in these international schemes, according to Rummery (2009), go beyond the individual person or family to the social fabric. (Leece, 2004, presents a similar argument.) For example, when the scheme includes means of regulating the employment of carers, as in France, the Netherlands, the UK, and the US, it can polarise the market, “creating ever-increasing gaps between paid workers with structured career paths working in the non-profit and statutory sectors, and family or casual labour carers without the benefit of such regulation and protection” (Rummery, 2009, p. 639). The division is gendered, it is argued, with men more likely to occupy the former category and women the latter. It is paradoxical that the unregulated schemes in Italy and Austria, designed to replace or commodify informal care, are identified as having gendered benefits, by freeing unpaid family carers to join the paid workforce and by acknowledging the value of care by paying previously volunteer carers. In the traditionally gendered countries, volunteer carers are likely to be women who will benefit from the chance to earn an income.

Australian programs

The FaHCSIA occasional paper presents a valuable discussion and evaluation of various programs and approaches in Australia (Fisher et al., 2010). As part of the project, the investigators from the Social Policy Research Centre at the University of New South Wales selected 10 case studies from New South Wales, Queensland, Victoria, and Western Australia to represent a range of disabilities, disability support, and individualised funding. Their categorisations are used here to give a brief overview of Australian person-centred programs. The categories relate to the degree of autonomy of individual consumers/clients and involvement of providers: individual packages held by a provider, individual budgets held by the person to spend through a provider, and direct payment to the person to spend in an open market. A quarter of funding through the Commonwealth State Territory Disability Agreement is offered as individualised funding. With the exception of Western Australia, which has the longest history of person-centred approaches, Australia tends to use portable individual funding packages held by a service provider. The FaHCSIA paper presents data revealing that most people with disabilities in Australia receive only informal care from family and friends. In contrast to international programs, the employment of family members under Australian person-centred programs is discouraged and often disallowed (Laragy, 2009).

Although there is wide diversity among those who receive individualised funding, data from the Commonwealth State Territory Disability Agreement National Minimum Data Set and the survey conducted by the Social Policy Research Centre reveal that there is an identifiable majority profile. Recipients tend to be non-Indigenous, men, with low support needs, of an age (20-59) to be in the work force, having one disability only, and lacking an informal care network (Fisher et al., 2010). The average amount available for each package in the programs investigated by the authors of the FaHCSIA report was \$28,500, with a range of \$700 to \$250,000 (Fisher et al., 2010).

This section presents an overview only, because details are clearly described and discussed in the FaHCSIA paper, to which those requiring more information are referred.

Australia: Individual packages held by a provider

When an individual budget is held by a service provider, the person with a disability can choose the provider, change providers, and decide how the budget should be spent, within the limits of the program. There are various types of budget, including holistic support packages; the budget may include an allocation to the provider to cover administrative and management costs (Fisher et al., 2010). According to the FaHCSIA paper, managing funding through a single service provider often restricts support to one kind, such as accommodation support, which can make it hard to achieve a comprehensive variety of personal goals. There are also frequent limitations imposed by inadequate funding. Laragy (2002) reported that payments from government to services were processed around annual service agreements and that computer technology was designed for bulk payments and not individual flexibility; this may be a criticism that no longer applies.

Western Australia has both the oldest and the most comprehensive range of individualised funding approaches, including when funding is held by providers. All funding in WA is now individualised, except some respite and therapy (Fisher et al., 2010). WA is described in the direct funding category, below.

Individualised funding began in Victoria with packages held by a service provider. Funding can now also be administered through a financial intermediary; it is planned to have a third option of direct funding to the person with a disability (Fisher et al., 2010). The state government's Disability Services Individual Support Packages are designed to help people with all kinds of disabilities and across the age spectrum to meet their own goals and exercise choice in finding appropriate support to achieve them (Fisher et al., 2010). Choice is limited to the categories of support defined by the Department of Human Services: residential care, personal and in-home support, health and professional services, skill development, leisure support, aids and equipment, transport, and case management (Fisher et al., 2010). Policy officials told the authors of the FaHCSIA paper that it requires more than a funding mechanism to achieve control and flexibility: there must also be viable providers and the development of consumer skills in making informed decisions (Fisher et al., 2010). In accordance with this view, Victoria uses the language of self-directed approaches rather than individualised funding in order to redirect the emphasis away from funding (Fisher et al., 2010). There is evidence that the self-directed approach is effective in helping people to move into a wider range of appropriate housing than was previously available as well as addressing other needs (Fisher et al., 2010). Among the range of projects in Victoria, there is criticism that a few have failed to include consultation with a young person with a disability or adequate involvement of the person's family, where appropriate (Laragy, 2009). Laragy (2009) comments that flexibility is the key to being truly person-centred and achieving individual goals. Victoria is currently developing a resource allocation tool to assist in the process of assessment and the allocation of funds (Fisher et al., 2010). Most packages appear to be used for attendant care (Fisher et al., 2010).

In the Australian Capital Territory, individualised funding is primarily through Individual Support Packages, which are held by a service provider and are portable; consumers and their families participate in choosing how the money should be spent, within guidelines (Fisher et al., 2010). Any person with a disability can apply for a package. There is an emphasis on encouraging community participation. Recipients and their families have access to independent advice in making decisions. There are variations in the types of package; details are in the FaHCSIA paper (Fisher et al., 2010). Reports to the authors of the FaHCSIA paper indicate mixed responses from recipients and their families, with satisfaction for straightforward arrangements with a single support service and provider; others would prefer greater flexibility and financial independence, without having the provider as financial intermediary (Fisher et al., 2010). Choice is inevitably limited by the small service sector in the ACT.

In the Northern Territory, problems of geography, history, and population distribution contribute to difficulties in providing services for people with disabilities. Without a robust block-funded system, the FaHCSIA white paper reports that individualised funding is used “to fill the gaps in service provision” (Fisher et al., 2010, p.15). The approach was launched in 2000 with a Local Area Coordination system, but this was replaced by a system of Disability Case Coordinators and Case Managers. The preference is for funds to be distributed by service providers; a suitable provider is approached after a Department of Health and Community Services needs assessment and budget development. Although the ideal is for packages to be portable, the limited availability of providers and services means that choice may be extremely limited or impossible. The NT gives priority to accommodation support and respite care because of the high demand for and low availability of each. Community access has a lower priority (Fisher et al., 2010).

The main approach in Queensland is for individual packages held by a service provider (Fisher et al., 2010), although the state also has varied funding models that include block funding, targeted funding, individual funding, and hybrid funding, which is the most recently developed. A critical account of the development of individualised funding which locates it in its political and economic history is given by Spall, McDonald, and Zetlin (2005). They identify individualised funding as positioned to serve the goal of the quasi-market model and thus to reduce government costs. They conducted a demographically-representative qualitative investigation of people with a range of disabilities throughout Queensland and present evidence to show that people with disabilities were not well served, at least before 2005, in part because of the limited options for choice in services (or even the presence of any services at all) in such a large and sparsely populated state. They concede that those with packages did reasonably well, but reported that most people with disabilities had not been able to secure packages, referring to AIHW data on unmet need as well as their own data.

In South Australia, portable individualised funding packages are held by a service provider; individualised funding is common but not, however, available across all service types (Fisher et al., 2010). People with disabilities register with the Disability Services Provider Panel which meets to determine need and an appropriate budget. Recipients are consulted about their preferences for a service provider. SA relies on brokerage, about which more is written below.

Tasmania, too, has predominantly individualised funding packages held by a service provider (Fisher et al., 2010). A maximum of 34 hours per week is negotiated among the recipient, the provider, and the Department of Health and Human Services. The package is portable. Because the basis of calculation is hours of service provided and there is no standard hourly rate among providers, the cost of the package is variable. A reform movement aims to standardise costs so that competition relies not in reducing cost but on providing better service. According to the FaHCSIA paper, the main service provided in Tasmania comprises group homes for people with intellectual disabilities (Fisher et al., 2010).

Australia: Individual budget held by the person to spend through providers

In this model, the person holds her or his own individual budget or package which they must spend through approved providers. A financial intermediary may manage the funding or package on behalf of the person with a disability. There has been concern expressed that limiting potential providers in this way restricts the possibility for innovation and even viability as well as suppressing any potential response to market demand (Laragy, 2002).

A Victorian program called the ‘Direct Payments Pilot Project’ ran from January 2006 to June 2007 to enable people with disabilities and their families to buy services (which did not include the

employment of personal assistants or support workers) through recognised providers (Fisher et al., 2010). Evaluation of the pilot, reported in the FaHCSIA document, found that users felt that they had greater flexibility to achieve their goals, which could also be more varied than before (Fisher et al., 2010). In the same evaluation, service providers expressed concern about whether organisations could remain viable because of the unpredictability and instability of portable funding; this applies not only to moves between disability service providers but to moves to outside services such as gyms.

In Western Australia, a project named 'My Place' provides accommodation to meet the needs of the disabled person based on personal choice; a service coordinator works with the person to find the best option (Fisher et al., 2010).

Tasmania is conducting trials of funding paid directly to people with disabilities; they must enter a contract with a non-government organisation, to which they pay an administrative fee, and can then choose their own support workers (who are paid by the NGO) and have more control over how funds are spent. The pilot is judged to be "working well", although officials stressed the importance of recipients having a good relationship with the NGO and being aware of fair employment practices (Fisher et al., 2010, p. 21).

Australia: Direct payment to the person to spend in an open market

The best-known and longest direct payment funding model was established in Western Australia: the Local Area Coordination program. A central feature of this program is that coordinators work in a defined local area and can thus be expected to build relationships with their clients and be familiar with local resources (Fisher et al., 2010; Laragy, 2009; Lord & Hutchison, 2003). Money allocated to individuals can be used flexibly to buy personal support, household help, goods, or leisure activities. According to the FaHCSIA paper, about 1500 people with disabilities now receive direct payments totalling about \$10 million; changes over the years are also recorded in the FaHCSIA paper (Fisher et al., 2010). Direct payment amounts include the very small (single grants of \$50), flexible small packages of about \$5000, and larger packages up to \$100,000. A review in 2003 found that some recipients and families had to manage complex, substantial packages, which posed a risk because of the very great responsibility required (Fisher et al., 2010). A shared management model is now available so that the burden is shared (to varying degrees) with a service provider. The LAC approach is well suited to the rural areas that constitute most of WA; case management dominates in more urban states, although there are critics of the case management approach (e.g., Lord & Hutchison, 2003).

Although the ACT predominantly uses individual packages held by a provider, they also have 'Quality of Life' grants, a one-off direct payment (usually less than \$5000) to be spent on the open market (Fisher et al., 2010). The grants are designed to assist in participation in community activities or to have access to community resources. Given the limited range of providers accessible in or from the ACT, these grants expand the options for recipients who can look beyond disability providers for what they need.

In New South Wales, the 'Attendant Care Program Direct Funding Pilot' was conducted by the Department of Ageing, Disability and Home Care in 2007, as an alternative to the existing Attendant Care Program. These programs provide support to people with physical disabilities to live in the community. The pilot provided funds directly to 10 clients to buy personal care services, including the employment of support workers; the clients were responsible for administering the finances and reporting to the Department (Fisher et al., 2010; Laragy, 2009). According to the FaHCSIA paper, participants in the pilot program found that it improved their well-being and community participation. The positive evaluation is apparently influencing the government to assess how aspects of the pilot can be incorporated in the Attendant Care Program (Fisher et al., 2010).

In the Northern Territory, fewer than half of the individualised funding packages are paid directly to the person who can use the quarterly allocation to buy services on the open market (Fisher et al., 2010). Each person must provide an acquittal form justifying each purchase. This funding is often used for respite care, which can be bought from formal or informal services, the latter most often neighbours or friends. People with an intellectual disability are eligible for these packages, which might be directed to the family, carer, or guardian. Because of concerns about accountability and appropriate expenditure when funds are paid directly to the person, officials tend to prefer packages to be paid to a service provider to hold for each individual (Fisher et al., 2010). According to the FaHCSIA paper, there has been no formal evaluation of the direct payment system although officials interviewed thought that recipients were very satisfied and would be reluctant to change to another system.

In Queensland, about 10 people, predominantly with physical disabilities, receive funding directly to be spent on the open market (Fisher et al., 2010). A few families with a member who has an intellectual disability have become incorporated as service providers in order to receive funds directly. In rural and remote areas, according to officials, consumers have found direct funding to be effective (Fisher et al., 2010). According to Laragy (2009), Queensland now discourages direct funding.

Australia: Summary

Person-centred approaches are described, on the whole, in relation to funding mechanisms. Australian jurisdictions aim to offer a continuum of individualised funding approaches (Fisher et al., 2010) with a range of strategies for distributing funds (Laragy, 2002). On the basis mostly of anecdotal evaluation, it appears that many people with disabilities and their families, service providers, and policy officials think that individualised funding facilitates personal choice and control in service provision; this is endorsed by formal evaluations (such as those reported by Fisher et al., 2010; Laragy, 2009; Productivity Commission, 2010). A Victorian evaluation found well-being among people with disabilities using individualised funding to be consistent with the Australian population norm and the Victorian norm for people with disabilities, with higher scores for some domains including personal relationships and community connectedness (Fisher et al., 2010). There is variation in satisfaction and achievement of goals depending on the type of funding and the degree of flexibility that it allows, with flexible access to a wide range of formal and informal services the most popular with recipients.

The type of disability also influences outcome, with greater limitations on expressing choice for people with intellectual disabilities, although family members, friends, and informal carers can assist (Fisher et al., 2010). One study of older people with an intellectual disability in Victoria and Queensland concluded that person-centred planning still had not reached them (Bigby & Knox, 2009). Funding packages are usually too small to enable independent living for people with significant intellectual disability (Fisher et al., 2010; Laragy, 2009). The Victorian evaluation cited in the previous paragraph found that the well-being scores of people with intellectual disabilities receiving individualised funding, although higher than the norm for people with intellectual disabilities in some domains, were lower in personal relationships, community connectedness, and future security (Fisher et al., 2010). Nevertheless, families commented that they appreciated the opportunity to share responsibilities in decision-making about and management of service provision, which contributed to greater family well-being, although they remained concerned about the future provision of services when they were not available to assist with individualised funding (Fisher et al., 2010). Some people with disabilities who received direct payments told the authors of the FaHCSIA report that they had insufficient administrative support (Fisher et al., 2010). Earlier concerns about the rarity of individualised funding programs for people with intellectual disabilities (e.g., Laragy, 2009) appear to be diminishing with increased attention being paid to including all disabilities in programs.

There is anecdotal evidence that some sections of Australian society are less well served than others. For example, it was reported that Indigenous Australians in Queensland may think that it is pointless to try to apply for individualised funding packages (Spall et al., 2005).

The impossibility of transferring individualised packages from one state to another limits the opportunities for people with a disability to move around Australia (Fisher et al., 2010). As the Productivity Commission (2010) points out, people with disabilities and their carers come under state and federal responsibility for different aspects of service. The federal government's major role in non-aged disability is to provide employment services and income support through programs such as the Mobility Allowance, Carer Allowance, and Disability Support Pension (DSP). However, because the states have responsibility for rehabilitation and other disability services, the DSP is not coordinated with these services, which restricts the likelihood that people on the DSP will move to a job.

Authors of the FaHCSIA paper reported that some officials were particularly concerned about avoiding excessive administration but equally adamant that a good system of consistent data-collection is vital to ensure appropriate access and support across all regions (Fisher et al., 2010). This conclusion is consistent with Rummery's (2009) finding that a mix of flexibility and strong governance is essential for equitable management of funds.

Person-centred approaches and individualised funding can be of benefit to people employed to provide care and support but there are also inherent and potential disadvantages. Safeguards need to be developed and maintained to ensure that employment practices minimise exploitation of both the worker and the recipient of care. As the FaHCSIA paper makes evident, direct employment of support workers by the person with a disability, while common practice internationally, is a minority practice in Australia, partly because the main form of individualised funding is when funds are held by the service provider, which employs the support workers (Fisher et al., 2010). The schemes in Queensland, Northern Territory, New South Wales, and Western Australia in which people with a disability employ their own care workers appear, on the whole, to attract satisfied workers who stay with the one employer for a reasonably long time and appreciate above-award conditions (Fisher et al., 2010). However, in Western Australia, where friends and neighbours can be paid as care workers with the goal of not obliterating the informal care network, there have been reports that some workers do not have conditions up to the required standards, despite the close monitoring of Local Area Coordinators. The problem is claimed to arise when recipients are trying to purchase as many hours of care as possible with severely limited funding (Fisher et al., 2010). Even when conditions are good and benefits of individualised approaches are recognised, a longitudinal qualitative study of 12 families revealed that carers can feel isolated and unsupported when they have greater control and responsibility (Ottmann, Laragy, & Haddon, 2009). There are also concerns about the appropriate development of skills when untrained people are employed without an association with an agency; furthermore, individualised funding was not found to be associated with increased availability of trained support workers (Fisher et al., 2010). Despite this, the FaHCSIA report found no comments from the service providers interviewed by the authors expressing concern about their ability to protect the rights and conditions of workers employed under individualised funding packages (Fisher et al., 2010).

It was concluded that, on the whole, individualised funding did not add to government departments' administrative costs, although there were some greater expenses in the transition to a new system (Fisher et al., 2010). It is hard to know what this means when the claim is made that funding is often insufficient. This suggests that the funding formula is set according to what the funding body is prepared to spend rather than to what is required. Under these circumstances, it is not surprising that expenditure has not risen.

Brokerage

One aspect of some person-centred approaches and individualised funding is the involvement of a broker or similar intermediary, a role that can be taken by a person or an organisation and assumes many forms with a variety of duties. Senker (Hatton et al., 2008) argues that a good, independent broker can ensure that person-centred approaches are needs-led and not service-led; he repeats the opinion stated elsewhere in In Control's documents that families, not social workers, should become the new experts in the support needs of the person with a disability and that various systems of "support brokerage" should guide them. Social workers, according to him, are too enmeshed in the need to ration resources. (The de-professionalisation implicit in the sidelining of social workers is discussed in the next section.) According to Senker, who used to be a support broker, brokerage relates to a set of tasks and functions, which he outlines, rather than to a role. This is a large and complex topic to which this report can not do justice; readers are referred to other sources of information (Hatton et al., 2008; Hudson & Henwood, 2008; Laragy, 2002; Lord & Hutchison, 2003).

Assessment and 'Banding'

It has been argued that assessment is the key to person-centred programs (Lyon, 2005). True individualisation may be more complex than most systems can manage. Many programs, therefore, employ some kind of categorisation or 'banding', such as grouping people into low, medium, or high need for care before allocating funds (e.g., Hudson & Henwood, 2008). This has aroused concern that assessing people with disabilities and putting them into bands or categories of need not only undermines individualisation but makes it easy to ignore some needs altogether; it has led to the emphasis, for example, on physical assistance needed in schools at the expense of other needs and goals (Laragy, 2002). On the other hand, it has been argued that more complex categorisation, drawing together several factors into six levels, enables people to be told from the outset how much money they have been allocated and encourages them to use it efficiently and to take into account their own skills and interests when developing their care plan (Duffy, 2005). Duffy, who was at the time Director of the UK's In Control, claimed that this was a more genuinely individualised approach while acknowledging the challenge of allocating funds when needs are rarely static. A UK report that discusses the need for assessment that is personalised and designed to prevent harm or deterioration rather than to manage crises is informative on this topic (Hudson & Henwood, 2008). It is also claimed that the slow take-up in the UK is partly because of confusion over assessment and eligibility (Taylor, 2008).

In Australia, there are few validated measures for assessing support, and none that is generally accepted (Guscia et al., 2006). The topic is discussed by Guscia and co-authors (2006), who report on the construct and criterion validities of an instrument (already found to be reliable) called the Service Need Assessment Profile (SNAP), which they recommend. Establishing appropriate levels of funding and allocating money for person-centred programs continues to be the subject of discussion and debate.

Person-Centred Approaches

Overall, there seems to be satisfaction with person-centred approaches and individualised funding from people with disabilities and their families, despite little evidence to enable assessment of specific goals. Rummery identified a desirable balance of strong policy and governance with adequate choice and control by individuals in order to promote the best interests of people with a disability:

"It is clear that marketized solutions involving the commodification of care can offer gains in social citizenship for users and carers if the state is prepared to have a strong influence over the governance of such solutions while still enabling both groups to exercise choice and control:

it is also clear that marketized solutions involving the commodification of care can offer potentially worrying effects on the social citizenship of users and carers if the market is left unchecked.” (Rummary, 2009, p. 646)

There are few publicly-available evaluations of person-centred programs; even fewer would qualify as rigorous or scientifically acceptable. This is partly because most programs are recent and apply to relatively few people (Bigby & Knox, 2009). As will be evident in the following section on ideas and discourses underpinning the move to person-centred approaches, strongly-held beliefs, desires, ideologies, and political discourses impelled the move rather than evidence. Advocates of a social program that is to them self-evidently just or desirable do not require evidence of specific benefits of the program before advocating it; often the benefits they seek are hard to count or measure (such as dignity, citizenship), and the gradual, piecemeal nature of large-scale change can make before-and-after assessments difficult to capture. When governments seek change, the process of implementation may leave little time and inadequate staff for evaluation; policy changes along the way also muddy the process. These seem to be appropriate explanations for the limited evaluations of person-centred approaches. Perhaps, as these approaches become more established and widespread, more—and more rigorous—evaluations will be reported.

3. PERSON-CENTRED APPROACHES: KEY IDEAS

Two main discourses have been identified as fundamental to person-centred approaches to disability service provision: social justice and a market philosophy (Leece, 2004; Pearson, 2000; Rummery, 2009). Social justice is the most prominent framework within which reform of disability services is discussed, in Australia (Bigby & Knox, 2009; Productivity Commission, 2010) as elsewhere. Disability advocacy has for some decades been based on the idea of independent living and a social concept of disability (Pearson, 2000). The initial impetus was for people with disabilities to leave long-term stay institutions; now there is a more general emphasis on freedom, choice, and control over one's own life (Pearson, 2000; Stainton & Boyce, 2004).

Lord and Hutchison (2003) found that values and principles underscored the projects they investigated, and that the values were consistent with those espoused by disability advocacy groups. Although principles and values are different, most organisations did not distinguish them (Lord & Hutchison, 2003). The US organisations were explicitly guided by values and principles related to freedom, authority, support, and responsibility; in Canada, they were enhancing dignity, community integration, support networks, comprehensiveness, and continuity of supports; and in Western Australia, the values specified were access to information and choice, network building, person-centred planning, and community participation. All are consistent with a social justice discourse.

The philosophical underpinnings of person-centred approaches aligned with social justice are, in most cases, overt. For example, the UK's In Control claims that its campaign for individualised funding is "a disciplined attempt to generate a clear understanding of the moral foundation for social care and to gather support for it" (Hatton et al., 2008, p. 127). There are four related principles specified in the UK's *Valuing People*: rights, independence, choice, and inclusion (Burton & Kagan, 2006). These principles support 11 key objectives that specify idealistic yet practical goals: "maximising opportunities for disabled children; transition into adult life; enabling people to have more control over their own lives; supporting carers; good health; housing; fulfilling lives; moving into employment; quality; workforce training and planning; and partnership working" (Burton & Kagan, 2006, p. 301). Similarly, the UK guide to implementing person-centred policies, *Putting people first: Transforming adult social care. Self-directed support process* identifies the underlying principles as "treating people as individuals", "enabling and empowering", "allowing people to make their own informed choices", "recognising and separately assessing the distinctive needs of carers", and "fair and equitable" (Department of Health, 2007, Appendix A). The social justice discourse is implicit in these principles (which also specify that the emphasis on people with disabilities is not to be at the expense of carers).

The market philosophy is an internationally powerful political discourse. Although it rarely appears in advocacy documents, its influence on person-centred approaches to disability services is profound. In subsequent paragraphs, discussion of the market discourse follows discussion of the social justice discourse.

The Social Justice Discourse

Social justice for people with disabilities incorporates concepts of citizenship, autonomy, agency, community participation, and choice.

Citizenship

The promotion of active citizenship is given as the central reason for In Control's endorsement of individualised funding in the UK (Hatton et al., 2008, p. 9). Establishing full citizenship for people

with a disability, they argue, bestows the benefits of the implicit equality of all citizens. People with disabilities, their carers, and other advocates have been at the forefront of the move to recognise the full citizenship of people with disabilities, working to transform the way they are conceptualised from passive recipients of care to active citizens (Rummery, 2006). Other terms related to claims on citizenship are normalisation and social role valorisation (Burton & Kagan, 2006). Claims on citizenship often relate to the capacity of a person to contribute to society. Person-centred approaches and individualised funding are seen not only as playing a major role in this transformation but as a response to the fact that “People are entitled to the support they need to function as citizens” (Hatton et al., 2008, p. 127).

The citizenship debate is a complex balancing act because advocates must both draw attention to the comprehensive support needed by people with severe and profound disabilities whilst also claiming that even the most profoundly disabled people can take their places in society. The debate is linked to the valorisation of work and the disputed concept of care. The rhetoric of care, whether care is provided informally or by the state, has been rejected by disability advocacy organisations throughout the developed world as relegating people with disabilities to a socially inferior position as passive beneficiaries of the generosity of others (Rummery, 2009). Being in paid employment remains the defining criterion of active citizenship; there is a persistent fear of “bludgers” being a drain on the public purse (Prideaux et al., 2009). Among those so pejoratively categorised are welfare recipients such as people with disabilities. Claiming citizenship for all people with disabilities, then, entails complex revision of the meaning of citizenship and the nature of work. Person-centred approaches and individualised funding have been seen as “the first step towards a dynamic reconceptualisation of ‘work,’” appropriately reflecting “the activities and efforts of disabled people to overcome unwarranted and enforced dependence” (Prideaux et al., 2009, p. 565). Prideaux and co-authors (2009) are emphatic that tasks undertaken to manage one’s own individualised funding constitute work and not welfare dependence.

There is lively debate over the nature of personhood and humane ways in which every individual can be recognised as a person and a citizen while still protecting the vulnerable (e.g., Clapton, 2009; Harvey, Popowski, & Sullivan, 2008). People with intellectual disabilities severe enough to limit their rational thought have been protected under the law as acknowledged not to be responsible for their actions. However, this denial of their moral agency also denies personhood to a large category of people with disabilities (Clapton, 2009). Clapton (2009) points out that qualification for citizenship and the way in which people with intellectual disabilities are depicted are always dependent on the current political ideology. A useful discussion of political discourses about citizenship, society, and responsibility over the last few decades in the UK and how they relate to person-centred approaches to people with disabilities comes from a social worker (Scourfield, 2007).

Autonomy and Agency

Citizenship and personhood are interrelated concepts; in Western philosophy, personhood includes the concept of autonomy, which is claimed as a right for all people, including those with a disability (Boyle, 2008). Autonomy is a recognised subfield of philosophy, sociology, and other disciplines. In most documents relevant to person-centred approaches to disability service provision, however, it is taken simply to refer to taking control over and being responsible for one’s own life and actions, as it is in common speech. Other terms used in the documents, often interchangeably, are agency, which has a similar meaning of being active rather than passive in one’s daily life; independence; and self-determination.

The promotion of social justice by the disability movement arose from the premise that people should be not passive recipients of services but in control of the services they choose to receive (Pearson,

2000). Disability activists (at least in the UK) have endorsed autonomy as the most important goal of service provision to people with a disability (Ellis, 2005; Hatton et al., 2008). Individualised funding is one means of achieving autonomy, so that people with disabilities can decide for themselves what they need to improve well-being and ensure a good quality of life (Blyth & Gardner, 2007; Burton & Kagan, 2006; Laragy, 2002). According to *In Control*, the practice of co-production is also essential to self-determination; this means ensuring that people with disabilities are represented on committees and involved in all stages of decision-making, in the development and evaluation of policy as well as in their own lives (Hatton et al., 2008, ch. 6).

The concept of autonomy can be problematic for people with severe or profound intellectual disabilities who cannot be judged fully capable of making rational decisions; a proxy may need to be appointed to exercise autonomy on their behalf (Clapton, 2009). A useful discussion of a meaningful concept of autonomy for people with a severe intellectual disability concludes that it cannot be a normative concept; that is, it cannot be assessed in relation to what autonomy ought to be for the population at large nor in relation to common value judgements (Wilson, Clegg, & Hardy, 2008). It is complicated by evidence that professionals tend to see themselves as the vehicle through which autonomy is achieved for people with intellectual disabilities, and to identify it reductively with decision-making (Wilson et al., 2008).

Ellis (2005) discusses important distinctions between autonomy and independence in the context of a detailed consideration of human rights and social rights. In brief, autonomy entails being recognised as an individual with the right to control one's own life, whereas independence implies being able to care for oneself without assistance. Clearly, many disabled people might want to assert their autonomy while also being dependent on others. The concern is that the move to person-centred care that has grown in tandem with new public management (to be discussed in subsequent sections) entails encouraging independence: being able to do things for oneself. Those who cannot are identified as passive, dependent, and not autonomous. Direct payments are labelled as enabling autonomy but, according to Ellis (2005), are in fact used within new public management systems as a means of promoting independence.

The meaning of autonomy to older people with disabilities who have been dependent on others for providing services, whether they are institutionalised or in a private home, has also been analysed (Boyle, 2008). It was concluded that a high degree of perceived choice is a necessary part of operationalising autonomy, whether or not assistance is required to exercise that choice. Boyle (2008) acknowledges the difficulty in enabling autonomy in people with profound intellectual disabilities and that it may come down to offering the opportunity for little more than limited choices, but argues nevertheless that autonomy under these circumstances demands greater attention from academics and policy makers. Boyle (2008) draws on the work of others in reporting the debate about the ethics of autonomy versus the ethics of care or the concept of interdependency, and what this debate might mean for people with disabilities who may prefer to exercise their autonomy in employing personal assistance rather than being dependent on the feminist notion of care and kindness. It is a complex debate with a long history, in which the emphasis changes depending on the focus of the current injustice being challenged: women or people with disabilities, to take two examples.

Authors of *A report on In Control's second phase: Evaluation and learning 2005-2007* (Hatton et al., 2008) strongly endorse the need for autonomy, choice, and control for even the most disabled person, intellectually or otherwise. They advocate individualised funding and reject any qualifications or reservations, such as that success depends on maintaining family support, or that it is effective only for those wanting to live as independent adults or those with more expensive packages. Their assertions of general applicability are supported by very limited evidence. *In Control's* advocacy is grounded in

a philosophy of disability rights in which evidence appears to be of less significance than justice. The ideology of In Control is recognised and applauded; their evangelical zeal, however, has also attracted criticism (Hudson & Henwood, 2008).

Community Participation

An autonomous citizen with equality of opportunity is part of the community; inclusion has been identified as a prerequisite for citizenship in a humane society (Clapton, 2009). Social inclusion is thus an essential component of person-centred approaches to people with a disability. It is evident in the disability literature that recognising people with disabilities as full citizens entails acknowledging the need to support them to be enabled to participate in the community (more locally) and in society (generally). Carl Poll, from In Control, has a chapter devoted to the significance of community in person-centred approaches to disability care, describing work with community as the most challenging of the “Six Keys to Citizenship” (Hatton et al., 2008, ch. 5). (The other keys are self-determination, direction, money, home, and support.) According to Poll, community development is aligned with equal citizenship and social justice, which are the “real goals of the new system” (Hatton et al., 2008, p. 96). Lord and Hutchison (2003) found community participation to be a principle espoused by all the projects they reviewed. Practical limitations to this goal are also acknowledged (Laragy, 2004).

Community engagement contributes to the holistic quality of life of all citizens. Improving overall quality of life is identified as a major goal of most person-centred approaches to disability services, encompassing not only the choice of where and how to live and community involvement, but also employment and leisure activities, both of which usually require social inclusion (Lord & Hutchison, 2003). When people with disabilities are assisted to participate in the community, it is not just for respite care but to give them pleasure and diversion, including activities such as entertainment, holidays, and attendance at sports events (Blyth & Gardner, 2007; Hatton et al., 2008, ch. 5). Building community capacity and networks is intrinsic to the reform of service provision to people with a disability (Hudson & Henwood, 2008).

Lord and Hutchison (2003) discerned in the programs they evaluated an identified need for both formal and informal support for people with disabilities, with two broad trends: that strong community networks improved health and contributed to the inclusion of people with disabilities, and that informal supports could mitigate limitations to formal disability support. In other words, the community fills the gaps left by service inadequacies. They also point out that emphasis on funding without working on community relations would falsely suggest that money alone would solve the problems in the system (Lord & Hutchison, 2003). However, Lord and Hutchison are confident that engagement with the community builds the capacity not only of people with a disability and their families but also of the community.

Choice

The notion of choice is associated with citizenship, autonomy, and community participation, in contrast to being controlled, suppressed, and hidden away. It is sometimes linked to the term “empowerment”. The right to make choices as a way of enacting control over one’s life is claimed for everyone, regardless of how they are categorised or labelled in relation to their ability or disability (Hatton et al., 2008). The statement from In Control that “Self-directed support is a process of empowering citizens” (Hatton et al., 2008, p. 111) speaks directly to its philosophical underpinnings and the assertion of autonomy and choice.

There have been criticisms, however, that choice has been elevated to a status above all else (Burton & Kagan, 2006), without any consideration of whether a person with profound intellectual disability is

capable of choice or even whether there are options from which to choose. The ideals of choice and autonomy themselves have been problematised:

“Choice and independence are powerful concepts but there is more to ‘self-determination’ and, indeed, ‘self-actualization’ than simply ‘going it alone’. Dependency and interdependency are part of all of our lives, for some more than others. This needs to be acknowledged or there is a real danger that only those who are enterprising and can manage their own affairs will have earned the badge of citizenship”. (Scourfield, 2007, 120)

These comments will be illuminated in what follows, because the concept of choice is the point at which the social justice discourse collides with the market discourse. Once you have people with disabilities recognised as full citizens with the right to determine how their lives are to be lived; once policies have been developed to find ways of supporting people with disabilities to exercise their rights; and once person-centred approaches to the provision of services include individualised payments that can be spent according to the choices made by people with a disability and their carers: once these things have occurred, you have people with disabilities participating in the market economy as consumers.

The Market Discourse

Consumerism, Neo-Liberalism, and Economic Rationalism

The contemporary understanding in most industrialised countries of what it is to be a citizen encompasses being a consumer in the market economy (Clapton, 2009). Neo-liberalism is the ideology in which the market is the prime regulatory instrument in the public domain, where the preferences of consumers rather than policies and programs govern production and distribution, and which changes citizens into consumers (Reinders, 2008). It is not surprising, then, that the dominant ideology in the disability movement has been described as positioned within the philosophy of consumer choice (Reinders, 2008). The goal of enhancing people’s authority over their own lives, especially people with an intellectual disability, has been operationalised in neo-liberalism as increasing people’s ability to buy the services they want on the open market (Burton & Kagan, 2006; Reinders, 2008). Service provision thus becomes consumer-focused (Productivity Commission, 2010). Individualised funding has been credited with redefining people with disabilities as consumers—contributors to society—rather than welfare recipients. Demands for rights have brought about the shift; achieving them brings responsibilities as a full member of society, including responsibility for money and the employment of others, whether or not that responsibility is assumed by a proxy such as a parent or carer.

According to Cumella (2008), admitting people with disabilities into the consumer society is one approach to ‘normalisation’. However, consumerism is a passive form of citizenship, in contrast with actively engaging with the democratic processes of organising society, and inherently inegalitarian: the consumer hierarchy has at the top those with the most to spend (Cumella, 2008). There is concern that the market does not serve people with disabilities well, not only because their disability may restrict their capacity to deal with it, but also because the market is not kind to low-income groups, and people with a disability tend to constitute a low-income group (Reinders, 2008). It is also argued that choice in the market system is illusory (Cumella, 2008; Reinders, 2008), largely because of the shortage of effective services for people with disabilities. Their particular consumer demand is not valuable enough to inspire the market.

The emphasis on choice may actually reduce the prospects of people with a disability attaining respect from and equality of opportunity with the non-disabled population, because granting “choice” removes responsibility from governments to provide public services and make environmental and policy

changes that increase access for people with disabilities (Cumella, 2008). Consumerism can thus be seen as a direct challenge to the ideals of human rights and comprehensive social inclusion (Cumella, 2008).

Furthermore, rationalist economic models can cater only for the average and must try to bring “deviations” into line (DiRita et al., 2008). It suits the logic of market service provision to shape the person to fit what is available rather than to adapt the services to people’s needs. According to Australian researchers DiRita, Parmenter, and Stancliffe (2008), it is the managerialist approach to providing person-centred services for people with disabilities that has produced a utilitarian emphasis on servicing the average, which is the opposite of the stated goal of being person-centred and effectively weakens or even nullifies the impetus to reform. They concluded that the utilitarian social response of economic rationalism has “transformed inclusion into assimilation” (DiRita et al., 2008, p. 623) by assimilating people with disabilities into the system of service provision rather than adapting the system so that they can be fully included.

De Rita and co-authors (2008) concede that disability services have improved over the past few decades but argue that economic considerations, not the needs and desires of people with disabilities, dominate the system. They acknowledge the need for compromise in the gap between the ideal and the limitations of reality, but regret that “this compromise has been determined through ER [economic rationalism] and managerialism in a way that has prioritised economic considerations over the moral equality of individuals” (DiRita et al., 2008, p. 623). Under economic rationalism, organisations have secure funding only if pre-specified outcomes are achieved through economic efficiency (DiRita et al., 2008); there is no accommodation for services that are justly expensive. The average outcome is measured, disregarding individual differences; this is presented as equity (everyone gets the same) (DiRita et al., 2008). Organisational viability in such a restrictive system makes it difficult to meet the needs of people outside the average. Service provision is based on what is available, not what is possible or needed. Standardisation of outcomes may be good for quality assurance but it makes services inflexible.

Person-centred plans are expensive to provide (Cumella, 2008). Undue focus on the financial aspects, it has been claimed, has tended to pervert the goals of individualised funding (Lord & Hutchison, 2003). Explicit statements about the need to reduce the cost of service provision are part of the guiding principles of many person-centred programs around the world (Lord & Hutchison, 2003). Indeed, the UK bill to extend direct payments was rejected in 1990 by the Conservative government because it claimed the program would not be cost-efficient and it would be too difficult to oversee the expenditure of public funds. It was only after an investigation initiated by the British Council of Disabled People demonstrated that direct payments could be cheaper that legislation was passed (Pearson, 2000).

Some projects elsewhere were designed not only to increase self-determination and community participation but also explicitly to decrease costs. One example is the New Hampshire Self-Determination Project, which specified that it aimed to “identify and utilise new forms of community support” in order to fulfil both goals (Lord & Hutchison, 2003, p. 77). The community, therefore, would take responsibility for providing services to people with a disability. Cost-shifting, it could be argued, would be easier to implement and evaluate than the well-being of people with disabilities. One result of the intention to reduce expenditure on social care provision at all levels of government has been the deliberate development of a mixed economy, in which private providers play a significant role (Burton & Kagan, 2006; Leece, 2004).

In Australia, economic rationalism and neo-liberalism have, perhaps surprisingly, seen an increase in social expenditure rather than a decline; however, some disadvantaged groups, including people with

a disability, have been treated punitively while other groups flourished (Mendes, 2009). It is argued that, in the Howard years, conceptions of welfare were built on narrow notions of individualism and self-reliance, avoiding discussion of collective responsibility. The emphasis on the frameworks and values of the free market was designed to increase participation in the workforce and reduce welfare payments (Mendes, 2009).

Australia, in common with other countries, wants not only to support people with disabilities but to reduce costs to counter the escalation in unmet need (Laragy, 2009). The Productivity Commission (2010) endorsed the need to distribute among a wider group of people the cost burden borne by people with a disability and their families, thus reversing the argument about reducing the cost to government, although with the same effect: transferring the cost to the private sector. They suggest a form of social insurance, while acknowledging the small chance that private insurance markets would function equitably in supporting people with a disability. The Commission's discussion of this matter established that the government positions itself within the rights and justice discourse of person-centred care, but holds equally salient the need to reduce the increasing cost of supporting people with a disability.

Even when public funding plays a major role in service provision, the market model is retained. The term "quasi-market" describes publicly funded services in which, to approximate market behaviour, the role of agencies purchasing services is distinguished from that of agencies providing services (Spall et al., 2005). Reinders (2008, p. 567) gives as an example of a quasi-market health care in Europe, in which "the provision of services is looked at as if it were governed by the law of supply and demand, even though the state retains overall control on the distribution of these services". Efficiency is a major goal of the quasi-market model; it can be used to stimulate price competition and is argued variously to be of benefit to consumers and purely cost-cutting (Spall et al., 2005). As Spall and co-authors (2005) note, the goals of enhancing choice and reducing expenditure appear to be in conflict. However, in the economic rationalist model, it is the market that enables choice and diversity in service provision. As we see in our parliamentary spectacles of debate and question time, this is a matter of ideological conviction, resistant to logical persuasion and supported by disputed evidence on both sides of the argument.

Duffy and Waters from *In Control* (Hatton et al., 2008) assert that self-directed support costs no more than the previous system, although they present inadequate financial data to support their assertions. They claim that the new system is more efficient, that efficiency does not equal funding cuts, and that the old system was over-managed. However, others have established that, under new public management, person-centred approaches are even more heavily managed. (This theme is developed in the next section.) Duffy and Waters appear to imply that the new system has no administrative costs. In addition to claiming that the new system is more efficient and cheaper, however, they state that there is as yet no discernible effect of self-directed funding. They also accept that there is likely to be greater demand on the new system than the old, but once again say that efficiencies will make it cheaper. Unfortunately, advocacy appears to have led them to make premature claims embedded in a confused argument. It may also have blinded them to the threats from economic rationalism and the neo-liberal market economy.

Rather than identifying as a triumph of social justice the transformation of the person with a disability into a consumer, Cumella (2008) links consumerism with a decline in concern for human rights, where fellow citizens are threats and potential terrorists, against whom limits on freedom and rights are justified. Consumerism, therefore, is the portal through which advocates of social justice for people with disabilities find themselves passing in company with those for whom maintenance of the market economy necessitates restrictive and exclusionary policies of management and control.

New Public Management and Managerialism

New public management is a component of the market discourse that has important ramifications for person-centred approaches to service provision for people with disabilities. The rise in consumerism and the popularity of new public management have occurred in tandem (Cumella, 2008). New public management is aligned with economic rationalism, in which the core task of government is market management (Cumella, 2008). In the culture of managerialism, society is viewed as “a market with competing interests, not a community with a common goal” (Reinders, 2008, p. 567).

New public management, practised in Western countries, is a strategy to impose on the public sector managerial techniques from private enterprise (Reinders, 2008). Its operating logic is purely managerial. New public management is about economic and managerial efficiency, about improving consumer choice through increasing the diversity of providers, about developing market systems to support these increasing options, and about setting targets and implementing monitoring by governments (Cumella, 2008). Value for money is emphasised; transparency and accountability are more important than professional judgement; and administration, especially documenting their activities, dominates professionals’ time (Reinders, 2008). Under new public management, the public sector is seen as inefficient, expensive, and of poor quality; the solution is understood to be the development of markets and quasi-markets. It has been widely applied to the public service in the UK, US, and Australia.

Cumella (2008) has identified the common elements of new public management. Those relevant to change in the disability service sector include criticism of large public sector service-delivery agencies, which are depicted as hierarchical, inflexible, and driven primarily by the interests of their staff; and a commitment to consumer choice among competing providers, which may be publicly owned, private, or charitable. It is assumed, in the new public management approach, that competition among agencies will stimulate more cost-effective and consumer-oriented services, in a market-focused environment. One role of new public management is to distance itself from direct provision of services; the goal is for the market to sustain itself rather than to rely on public grants (DiRita et al., 2008).

Under new public management, business processes, not the stated ideals of valuing individuals, dominate the work of service organisations funded by governments (DiRita et al., 2008). Regulation and compliance take precedence over any idea of quality service delivery. Its application to disability services can be seen in cost-control, performance measurement, financial accountability, quality control through output indicators, and reduced numbers and consequent reduced flexibility of staff (Reinders, 2008). The managerialist compromise of adapting service provision to the services available means disregarding the real level of need among people with a disability (DiRita et al., 2008). The emphasis on compliance militates against innovation and tends to entrench current levels and types of service provision rather than extend the possibilities.

Cumella (2008) cites intense criticism of public service reforms initiated under new public management, particularly the diversion of substantial capital and revenue streams from public finance to private enterprise. An expensive new bureaucracy of inspection and audit agencies has risen to monitor the decentralised provision of services. Nevertheless, as a dominant ideology, new public management is difficult to challenge.

Economic rationalism in Australia has produced an emphasis on cost-benefit analysis which has encouraged the rise of managerialism and new public management in Australian disability services (Clapton, 2008, 2009). As we have seen in Australia over the past few years, the result has been that

provider agencies compete for contracts that specify targets and require frequent reporting on quality protocols in exchange for time-limited contracts. The introduction of person-centred approaches and individualised funding further dilutes any connection between governments and service providers, apart from monitoring the achievement of targets. Queensland researchers contend that 'reform' of service delivery to people with disabilities is predominantly the result of adopting the principles of new public management, and present a political history to illustrate its origins (Spall et al., 2005). However, despite the market and economic origins of the reforms, the authors concede that there were also policy ambitions to improve conditions for people with disabilities.

Managerialism and Deprofessionalisation

Strictly speaking, deprofessionalisation is not a key idea behind person-centred approaches to disability service provision. It is, however, inextricably entangled with the market discourse, especially managerialism. As such, it has ramifications for the meaning and implementation of service reform and needs to be acknowledged before the implications of person-centred approaches can be considered.

A literature review of neo-liberal managerialism found that it presented a profound challenge to professionalism, both in undermining respect for professional knowledge and in the necessity for the compliance of professionals with the managerial system (Reinders, 2008). Reinders (2008) gives three explanations for the transformation of the social and health care sectors into parts of the service economy: neo-liberalism, new public management, and managerialism. Of the three interconnected explanations, it is managerialism that is credited with undermining professionalism, because the self-regulation and self-controlled expertise of professional bodies are challenged as incompatible with the public management accountability espoused by neo-liberal managerialism. Furthermore, professionals no longer have the authority of their expertise but must respond to the demands of their clients:

“Clients and patients are encouraged to determine for themselves what they want from providers, rather than seeking professional advice about what they need. Neoliberalism does not recognise ‘need’, because it aims at transforming ‘need’ into ‘choice’. People are not to be told what they need, but they are to be served with what they demand.” (Reinders, 2008, p. 565)

Promotion of respect for the citizenship and personhood of people with disabilities is evident in the previous quotation, as is the new administrative and managerial bureaucracy. The two have developed simultaneously and the effect of the second on the first is profound. The logic of relationships between professionals and clients in the field has come to be dominated by the logic of management (Buntinx, 2008). Traditionally, professional bodies were designed to keep most people out while admitting the few (“experts”). The professions used to have their own standards, bodies of knowledge, and mechanisms for admission, but claims to professional expertise are now doubted because their opinions have come to be seen as benefiting the professionals themselves rather than their service users (Reinders, 2008). Professional practices have been colonised by managerial discourse, which holds that managers can apply their skill to any area and that professionals cannot reasonably be exclusive. In disability services, a manager can do the work now required of a social worker. The role of professionals is unclear in this model, except as administrators (Reinders, 2008).

According to Ellis (2005), consumerism and new public management have transformed the idea of professionalism and the confidence of professionals in their role. Professionals now deal with consumers, not clients for whom they take responsibility within the traditional context of beneficence; their familiar role is no longer legitimate. New managers are required, not social workers or welfare workers. Front-line social work now involves less human interaction and is “a linear sequence of calculations about the negative consequences of not intervening to prevent harm” (Ellis, 2005, p. 696).

Professional autonomy cannot be maintained in an economic rationalist world in which professionals must be accountable to managers, their clients, client advocacy groups, public administrators, service providers, insurance agencies and many other individuals and groups. Ironically, because of its role in undermining the authority of the professions, management has itself become a profession, perhaps the most powerful one (Reinders, 2008).

Among the most alarming implications of individualised funding, according to Reinders (2008), is that specialist expertise can be considered a hindrance to the achievement of efficiency. Professionals are there to deliver primary processes: the services that improve people's health, their social skills, or their ability to govern their own lives. Managers focus on the secondary processes of keeping everything running efficiently. Professionals may be left to feel that their work takes second place to or gets in the way of the demands of management. In relation to individualised funding, it may mean that the processes of accountability and transparency dominate the original intention of using individualised funding as one tool for the achievement of citizenship, choice, and participation for people with a disability.

Reinders (2008) does not claim that managerialism is imposed on resisting professionals. Rather, in Orwellian or Foucauldian terms, compliance is internalised. Puzzled, stressed, unconfident professionals strive to fulfil the demands made on them and to perform as best they can. The only other option is to leave. Professionals are now made to do the work that was once done for them by administrators who enabled them to implement their expertise.

Ellis's (2005) particular concern is that the recognition and implementation of a human rights agenda is more likely to be enshrined within a professional code of practice than in a managerial culture, and that the dominance of managerialism marginalises the rights agenda. However, Ellis discusses her research with social workers in which she found that they tend to accept that human rights accrue because one is human, but that the majority maintained a conception of conditional social rights, in which each citizen must minimise dependency by taking all possible responsibility for her or his own welfare. That this view meshes so well with neo-liberalism and new public management can be understood as a significant means whereby it became so hard for the social work profession to disentangle itself from the managerial approach to care for people with a disability.

Problems and Paradoxes in Key Ideas Informing Person-Centred Approaches

In their analysis of the UK government's intellectual disability policy paper *Valuing People*, Burton and Kagan (2006) reveal inherent contradictions: the ideological position and policy framework set out in the document simultaneously challenge and endorse social processes that create inequalities and oppression. Although the analysis concerns New Labour in the UK, Burton and Kagan neatly encapsulate the paradoxes and contradictions permeating person-centred approaches to supporting people with a disability in general. The *Valuing People* document describes policy designed to reduce the systemic disadvantage of people with an intellectual disability and increase their inclusion in community life, but it also positions itself within the market discourse and managerialism that serve to marginalise them. Burton and Kagan (2006, p. 300) identify "an uneasy amalgam of the progressive and the neoliberal, the romantic and the practical" which not only makes the policy difficult to evaluate but also ensures that it is difficult to implement consistently. This succinctly summarises the uneasy blend of economic rationalism and idealistic advocacy for the full citizenship of people with disabilities, when noble goals can be subverted by market interests.

Some concerns are already evident in the preceding discussion of key ideas, but a few problems and paradoxes deserve emphasis. These relate to the effect of the two discourses on the person with a

disability, effects on people and agencies providing services to people with a disability, the shifting of responsibility for providing services, and the disappointments of idealism.

One contradiction arising from person-centred approaches and the desirability of choice for people with disabilities is that they may come to be seen as 'negative consumers', failing the standards of the market society and thus unworthy of public support, to be transferred once again to faith-based and charitable agencies as their responsibility (Cumella, 2008). Advocacy of full citizenship for people with disabilities and their consequent involvement in the community has coincided with the economic rationalist "fragmentation of the welfare state in Australia", forcing people on to community resources (DiRita et al., 2008, p. 614). This is, of course, consistent with the goal of greater community participation by people with a disability, but the need for community members to carry out 'charitable' work places the person with a disability at a disadvantage, constructed as a passive recipient of services rather than a participating citizen.

Prideaux and co-authors (2009) discuss the dichotomy in the conceptualisation of people with a disability under individualised funding schemes, in that, on the one hand, they are seen as employers when it comes to accountability and management procedures while, on the other hand, they are seen as receiving government funding to which they are entitled only because they are categorised as eligible welfare dependents. The latter implies passivity which is inconsistent with the goal of autonomy. When people with disabilities are managed within economic rationalism, they are assessed as part of a cost-benefit analysis as contributors to society. When they are found to be unable to contribute as expected, they become part of the cost rather than the benefit, no longer considered moral equals, and thus vulnerable to discrimination (DiRita et al., 2008):

"Although the influence of Normalisation, Social Role Valorisation and the Social Model of Disability have contributed to changes in how choice and community presence has been conceived, the dependency on service patterns and processes suggests there has not been any real change to the moral status of individuals in regard to agency. Simply providing opportunities and rights is restrictive when programme specifications and capacity are symbolic of the compromise between the desirable and the achievable." (DiRita et al., 2008, p. 623)

According to DiRita and co-authors (2008), the rhetoric of choice is construed within the logic of utilitarianism. The goal then becomes to raise the average status of people with disabilities, thus reducing the gap between the generic person with a disability and the average of society as a whole. This runs counter to the central goal of person-centred care because its emphasis is on a class of person, not individual people. Formulating service provision to people with a disability as an economic matter, as it is within economic rationalism, has encouraged the construction of a generic person as the target of service provision (DiRita et al., 2008). The goal of maximising utility obscures any emphasis on the requirement to understand the needs and hopes of each person. Any apparent consideration of the individual is concentrated within the idea of individual choice in a competitive marketplace. Economic rationalism cannot accommodate the person unable to operate independently as a consumer in the market.

Person-centred planning has been promoted as a tool for change, designed to recognise the individual and respond to her or his specific needs and desires. However, rather than catering for all kinds and degrees of disability, person-centred approaches may actually exclude the most disabled (Cumella, 2008). People with profound physical or intellectual disabilities are difficult to accommodate as full citizens when the market dominates the conception of the social and political system. According to Burton and Kagan (2006), person-centred planning has had the effect of isolating people, almost in a Thatcherist context of the non-existence of society. In other words, person-centred can mean "You're on your own", without the support offered by a communal sense of responsibility for society's

weaker members. Burton and Kagan (2006) argue for a model of collective responsibility, participative governance, and critical systems methods. Their suggestions for implementation are specific to the British system, but the heart of what they endorse is that participation by the user and the community should occur at all systemic levels, not just at the level of consumer choice. They cite other commentators in stating that the dominant rights model applied to disability prioritises market choice “at the expense of rights to health and well-being, education, political, civic and cultural participation” (Burton & Kagan, 2006, p. 309).

According to Burton and Kagan (2006), there is in *Valuing People* a Utopian vision of a new life for people with a disability, in which they live independently in a pleasant neighbourhood, making choices from a wide range of options, supported by their own staff, with many friends who are mostly not disabled. They see the Utopian vision as valuable in destabilising stereotypes and helping us to see beyond the disability to the person. The Utopian vision however, omits any reference to the need for profoundly intellectually disabled people to have access to medical and health specialists, to which the concept of choice is largely redundant. Visions of friendly communities in which people with disabilities participate fully can best accommodate people with relatively mild disabilities and fail to take account of the needs of the more severely disabled, especially those with profound intellectual disabilities. Therefore, the humane philosophy of inclusion, independence, and choice has the paradoxical effect of further excluding those citizens who most need support. Burton and Kagan (2006) claim that this adoption of the least disabled to represent all disabled people, and with it the denial of all that the concept of ‘disability’ entails, limits any sense that greater investment and expenditure may be required from governments.

A problematic outcome of the collision of social justice and the market economy is that seeking autonomy and control can have the effect of shifting responsibility back on to families and communities, rather than seeing it as a collective or state responsibility (Clapton, 2009). Person-centred programs, with their emphasis on individualisation, have been identified as part of the political-ideological move to shift public responsibilities on to the individual (Scourfield, 2007). Ellis (2005) points out that both governments and disability movements work with an individualistic approach to freedom and rights. Disability advocates urge attention to individual needs and desires; governments place responsibility on individuals to limit the burden of their demands on resources. The emphasis on human rights, therefore, has the paradoxical effect of shifting responsibility for the care of society’s most vulnerable members from the state to the vulnerable people themselves or their families.

Once private citizens become responsible for spending public funds, the accountability and reporting required turns them into managers. They must assume the functions, responsibilities, and risks formerly accepted by the State (Scourfield, 2007). Being able to choose one’s own services can be liberating but it can also be a burden which is more than some people with disabilities are equipped to bear, and risks leaving them unsupported when there is no public organisation whose job it is to identify and respond to need. If people who lack the confidence and skills to manage their own funding and employ their own support teams are disadvantaged by person-centred approaches and direct funding, the cycle may then be set to start again: these are the people for whom professionals such as social workers may feel responsible, thinking that it is appropriate to manage care on their behalf (Blyth & Gardner, 2007). Is this paternalism? Does it set in train the possibility of dual systems and the problems of streaming people with disabilities into one system or another? Answers to these questions lie at the heart of what is desirable and possible in person-centred approaches to disability service provision.

Scourfield (2007) is sceptical of the emancipatory power of what is known in the UK as direct payments; he concludes that too much is being asked of even the most enterprising citizen in this transfer of responsibility. Some functions, Scourfield (2007, p. 117) argues, are more appropriately

managed by public bodies: functions such as “ensuring the efficient and equitable use of resources through the strategic planning, commissioning and regulation of services”; the development of staff training “both to ensure that care standards are maintained and that vulnerable people are protected against abuse”; and “commitment to anti-discriminatory practice” and equal-opportunity employment. It is difficult to disagree with Scourfield that “It is hard to see how individuals who have been given both the option and also the responsibility to sort out their own provision can reproduce or, indeed, fit in with these functions” (Scourfield, 2007, p. 117). Scourfield does not deny that some people with disabilities report benefits from direct payments and other aspects of individualised approaches. Nevertheless, his concern is that social justice cannot be assured when individuals are placed in circumstances in which they must compete with each other for limited resources. He is also concerned about what will happen when ad hoc innovation replaces strategic planning and when “the quality of service someone receives is less to do with what needs they have and more to do with their entrepreneurial competence” (Scourfield, 2007, 120).

It has been pointed out that individualised funding has ramifications for the whole care sector and not just among those people with disabilities who choose to use it (Lyon, 2005). The Productivity Commission (2010, p. 12) identifies what it calls “trade-offs” in goals as governments try to satisfy competing obligations, affecting service providers, for example: “more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, potentially leading to less coordination and greater costs.” There is concern that shifting attention to individual disabled people, who also take on much of the burden of management and administration, can undermine the infrastructure of support services (Burton & Kagan, 2006). This could have the effect of diminishing rather than increasing the availability of stable services from which to choose.

Furthermore, the sense of independence and autonomy achieved through individualised and direct funding can come at a cost to those who are employed in such schemes, who tend to constitute a poorly-paid and non-unionised labour force (Burton & Kagan, 2006). The absence of adequate regulation can deny training and undermine safety as well as being outside pension schemes (Burton & Kagan, 2006; Leece, 2004; Rummery, 2009). Without a holistic view of social equity, attempts to improve the quality of life of one segment of society (people with a disability) can introduce inequalities and disadvantage into another segment of society (informal care workers employed by a disabled person directly or through a casual staffing agency).

In his recent memoir, *Hitch 22* (2010), Christopher Hitchens quoted Oscar Wilde saying that, “A map of the world that did not show Utopia would not be worth consulting.” This speaks to the idealism and optimism that prompted advocates to fight for the rights of people with disabilities and to promote person-centred programs and individualised funding. However, Hitchens went on to say, “I used to adore that phrase, but now reflect more upon the shipwrecks and prison islands to which the quest has led.” Shipwrecks and prison islands may be a bit extreme as metaphors for the problems encountered by person-centred approaches, but Hitchens’ reservation may stand as a caution to take heed of other agendas that may become attached to the quest for Utopia. There is not a clear conflict between ideals and money (to put it crudely); disability advocates are part of a consumer community in marketised economies, and neo-liberal policy makers subscribe to the rights perspective. Paradoxes can be found in the same person, who may position herself simultaneously within contradictory discourses.

Principles and values are crucial in trying to bring about a better world. However, those who strive to improve the lives of people with a disability may need not only to consider how to implement their goals with limited budgets but also to be aware of the goals of dominant ideologies within which they must operate. It is evident that the discourses of social justice and of the market economy simultaneously operate in tandem and aim for incompatible results.

4. PERSON-CENTRED APPROACHES: IMPLICATIONS OF KEY IDEAS

The conundrum of how to integrate all people with disabilities into the community and improve each person's quality of life when social justice is confronted by the market economy amounts to a 'wicked' problem (Australian Public Services Commission, 2007; see also Bigby, 2007). Challenges arise from inherent paradoxes and contradictions, but also from the creation of new problems with each solution. Furthermore, definitions of such a socially complex problem will vary according to which stakeholder is describing it.

A new, national, person-centred disability care and support scheme is likely to be proposed, designed "to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights" (Productivity Commission, 2010, p. 9). The implications of developing person-centred approaches under the influence of discourses both of social justice and a market economy are evident, to some extent, in the previous section. In this section, key implications are summarised as they affect individuals, populations, and services. The implications include some unanswered questions.

On the assumption that Melbourne Citymission aims first to promote the best interests of people with disabilities and second to remain a viable organisation, this section accepts social justice as the discourse within which Melbourne Citymission would choose to position itself and the market discourse, associated with economic rationalism and managerialism, as the dominant discourse within which it must operate. Although, in what follows, attempts are made to categorise the implications, wicked problems such as how to develop effective person-centred approaches to disability service provision tend to cross boundaries; they also cannot be solved in a traditional analytic, linear way (APSC, 2007).

Implications for Individuals of Person-Centred Approaches

Person-centred approaches guided by a commitment to social justice should enable each person with a disability to receive the necessary assistance to be an active citizen, to take control over her or his own life, to participate in community life, and to experience well-being. However, equity in person-centred approaches is difficult when there may be limited "equity" in the degree of disability, capacity for independence, or available family support: people are not equally well placed to take advantage of autonomy. Furthermore, in a world dominated by consumerism, economic rationalism, and managerialism, it has been claimed that economic considerations tend to be given priority over social justice in the pragmatics of disability service delivery (DiRita et al., 2008).

The Isolated Individual

Person-centred approaches and individualised funding are understood as means by which people with disabilities can be helped to achieve more meaningful and fulfilling lives, preferably on their own terms. However, Harvey and co-authors (2008) point out that the concept of the individual in social policy discourse is likely to entail an atomistic, rational thinker. At the same time, by definition, the individual model of care or service delivery does not embrace a collective model of responsibility or support (Spall et al., 2005). It could be understood as parallel to the individual workplace agreement model of employment contrasting with unionised collective bargaining. It is possible, therefore, for individuals to be isolated under this system, especially if group programs are rejected as not fitting the individualised model.

Each person, regardless of disability, needs to be part of a community. To ensure that people are not isolated, the concept of “individualised” should position the person with a disability in a web of supportive relationships designed to support his or her unique needs and abilities (Harvey et al., 2008). Support can come from the community at large, but there is also benefit in having a web of people with disabilities, where possible and appropriate, to share knowledge and experiences and to provide peer support.

Dependence, Independence, Autonomy

In considering individualised funding as an aspect of person-centred approaches, the Productivity Commission (2010) includes on its list of risks that of “dependency”:

“Individualised funding arrangements in which families effectively pay themselves for attendant care or use the money to purchase ordinary goods and services would mean that funding would become like ordinary income. That might create dependency by carers on the support system and undermine the goal of achieving independence for the person with a disability.” (Productivity Commission, 2010, p. 23-24)

Whether it is undesirable or not for people with disabilities and their carers to depend on an income like the majority of the community is a moot point. One may ask, on what else should they depend?

Independence is not advisable, probably not even possible, for many people with disabilities. If they are to include people with the widest possible range of disabilities and severity, person-centred approaches, it is argued, need to emphasise autonomy rather than aim for independence (Ellis, 2005). Individuals may need to have a proxy appointed to help with or undertake decision-making. A system can be truly person-centred only if it enables the widest possible choice. It was recently found that, in Sweden, only 3% of people with a disability chose to manage their own funding when other options were available (Laragy, 2009). Dependence, independence, and autonomy are complex notions for everyone, not just for people with a disability. An important implication for people with a disability of the discursive threads underpinning person-centred approaches is how to enable autonomy while accepting various degrees of dependence and support.

Choices and Decisions

Choice, a central component of person-centred approaches, is limited by capacity and availability of options. The Productivity Commission (2010, p. 23) includes as a risk “whether all people with disabilities or carers have the capability of making well-based choices”. The Commission’s concern is that people might not make the kind of choice that others consider to be in their best interests. The broader implication is whose decisions should be given priority.

However, decisions are being made at many levels before the person with a disability has any opportunity to exercise choice, and these decisions are made under the influence of a market ideology. They include how person-centred services are conceptualised, funded, and implemented. Each decision shapes the choices available to a person with a disability. A person in a wheelchair may dream of a large, well-adapted house when others higher up the system have decided that only about \$5000 to \$10,000 is available for her. At each decision point, implications for individuals will vary according to the level of contribution permitted to be made by people with disabilities and their advocates.

Interpersonal Relationships

Interpersonal relationships, already challenged by the effects of a disability, may be put under further strain by some of the demands of a person-centred approach to disability services. The Productivity

Commission (2010, p. 23), for example, identifies as a risk that “tensions over the use of individualised funding may sometimes arise between informal carers and people with disabilities (for example, over the need for respite services for the carer)”. There are further concerns that people with disabilities may be more subject to the preferences of their parents or carers once they are no longer protected by a professional such as a case manager (Laragy, 2002).

Implications for Populations of Person-Centred Approaches

Social justice requires that all people, no matter what their disability, its severity, or their circumstances, are given the assistance and support required to experience well-being, to exercise choice, and to participate in community life. However, the market is not kind to low-income groups and unsatisfactory consumers, which has implications for people with disabilities and their carers.

Rummery, for example, expressed concern that

“the introduction of a marketized, consumerist mechanism such as cash-for-care schemes into an area that was previously the domain of either the private, familial sphere or the public, statutory sphere is likely to create and exacerbate social divisions already apparent between different social groups.” (Rummery, 2009, pp. 642-643)

According to Rummery, there is evidence of limited inclusion in such schemes of older people, ethnic minorities, and adults with intellectual disabilities.

Ageing Population

Australia’s population is ageing. An ageing population of people with disabilities, their families, and their carers more broadly might have difficulty adapting to a new system; resistance to change commonly increases with age. It has already been established that some older families are uncomfortable with individualised funding (Neely-Barnes et al., 2008) and require additional oversight and assistance, not “independence”.

People with the Most Severe Disabilities

The more able service users and those with strong support networks are most likely to benefit from individualised funding (Rabiee, Moran, & Glendinning, 2009). Laragy (2009) reports concerns expressed in the literature that the most vulnerable may be left unsupported in a market economy, marginalised even further because they are not the route to a profit and, lacking a case manager, without an effective advocate to challenge inadequate resources and support. It is troubling that a scheme designed to bring dignity, autonomy, and choice, and to recognise the equal citizenship of people with disabilities, could contribute to further inequity by disadvantaging the most profoundly disabled, the socially isolated, and the poorly-educated (Rummery, 2009). However, Laragy (2009) concluded from her investigations in Australia and overseas that it is not the case that people with an intellectual disability will be disadvantaged in a market economy. She suggests an important safeguard against risk: the involvement of a broad range of people in the planning and oversight of service delivery, with specific attention paid to the vulnerabilities of each person concerned.

There are some who argue that categorisation rather than individualisation will best protect people with the most severe disabilities. For example, one US examination of the market approach to the provision of disability services concluded that other mechanisms for service distribution should be considered (Swenson, 2008). Swenson’s main suggestion is more specific categorisation of people by needs and type of service required, to enable targeted planning, delivery, and evaluation.

As an example of new problems that can arise from attempting to solve an old one, people with the most severe disabilities are at risk of being marginalised by the otherwise laudable goal of categorising as work the tasks performed by users of individualised funding schemes, such as recruitment, management, accounting, supervision, and interpersonal negotiation (e.g., Prideaux et al., 2009). The aim of such categorisation is to contribute to reconstructing the provision of disability services and the meaning of “work” (consistent with a feminist assessment that does not include only paid employment as work). However, it seems to exclude those people whose disability is so severe as to limit or prevent active participation in the management of services. Are there to be two or more categorisations of disability such that some are left behind in “welfare” and only some are understood to be full citizens? When implementing person-centred approaches in a market economy, a conscious effort will need to be made to ensure that all kinds and degrees of disability are included.

People in Rural and Remote Areas

Ensuring appropriate person-centred care in rural and remote areas is extremely difficult when there are so few options available. Indigenous people living in rural and remote areas are especially vulnerable, but they are likely also to be at a disadvantage in urban areas. The Productivity Commission (2010, p. 18) said that, in assessing eligibility for the proposed new national scheme, factors taken into account will need to include places where “local support and resources are low (some country areas) or where general disadvantage is combined with disability (some Indigenous communities)”.

Carers

It seems at times that approaches to person-centred care, especially individualised funding, are premised on the educated, middle class family that might know its way around the system. People managing their own packages need to be intelligent and diligent or to have an articulate, dedicated carer. It is expensive to hire one’s own support worker and a daunting task without the support of an organisation that provides substitutes when the worker is ill, pays on-costs, and deals with all the other unexpected ramifications of being an employer. Some authors and researchers are concerned that many parents and other family members do not feel “equipped to negotiate with service providers about costs and services” and are “reluctant to negotiate a competitive, commercialized service system” (Laragy, 2004, p. 527). This not only implies a discriminatory system but also entails a heavy burden on people with disabilities and their families.

One concern with the commodification of care, when people with a disability are enabled to employ people who would previously have been caring informally or people who do not operate within the formal systems of service providers, is that roles can be ill-defined and boundaries blurred (Leece, 2004). In her research on carers of people with a disability, Leece (2004) found that commodified care might lead to warm relationships that benefit both parties, but it can also lead to workers who, feeling like family, are open to exploitation through “boundless obligations” (Leece, 2004). Being encouraged to feel like family, she argued, benefits the employer rather than the employee because it is hard to refuse assistance during what should be time off duty (Leece, 2004). Nevertheless, Leece (2004) concluded that workers who had a harmonious relationship with their employer described it as warm, and were happy to take lower wages and work longer hours. A longitudinal, qualitative study of 12 families using consumer-directed care in Australia (Ottmann et al., 2009) found that there are benefits for people with disabilities and their carers. However, it was also concluded that carers may experience feelings of increasing isolation and lack of support. The authors argue for the establishment of safeguards to avoid the isolation of carers.

Implications for employees are presented in this section as well as implications for carers. This is a recognition both of the blurred boundaries and also that a family member may be a carer who assists with employing a support worker.

Workers Employed Under Person-Centred Schemes

Workers within cash-for-care schemes, it is argued, are at risk and this risk is gendered; such schemes are

“likely to lead to a widening gulf between carers working in regulated, professionalized and protected formal care employment and those working in private, unregulated employment, whether this be for a family member, a direct employer or through the grey/black labour market. They are likely to further disenfranchise low-skilled, poorly paid women.” (Rummery, 2009, p. 644)

Rummery is particularly concerned that the economic policy objective of limiting costs means that users and their families must absorb all the risks, including filling any gaps in service provision and managing everything to do with employing care workers. This has adverse implications for people with a disability, their families and carers, and employees. Given that the level of payment is likely not to cover all expenses, people who are employed on these schemes, whether they are “agency workers, privately employed workers or previously unpaid family members”,

“are having to work long hours for low pay with often little employment protection or direct scrutiny of their labour, and are therefore vulnerable to exploitation, abuse, and being trapped into low-paid work with little prospect of improving their skills or career development.” (Rummery, 2009, p. 645)

Families or individuals may not know about and hence not pay penalty rates, work cover contributions, insurance, or other hidden costs of employment. Exploitation is a problem, whether or not it is intentional. Families may not employ staff with adequate training to care for someone with high needs, which has ramifications for the person receiving care as well as for the employee. It is evident that adequate regulations are necessary to protect the wages and conditions of workers employed by people with disabilities, and that training of the workforce is essential for the safety of both workers and clients (Burton & Kagan, 2006; Leece, 2004; Rummery, 2009).

Implications for Services of Person-Centred Approaches

Prioritising social justice for people with a disability means that services direct their activities and their professional development to enabling the fulfilment of relevant goals for the full spectrum of people with a disability. This is already fundamental to the profession of social work and to service organisations like Melbourne Citymission with its mission of “Building inclusive communities”. The challenge in implementing new person-centred approaches arises with the need for working with consumerism, economic rationalism, managerialism, and deprofessionalisation. Compliance with business and accountability processes is demanding an increasing proportion of organisations’ time. Given the repeatedly-stated goal of reducing the cost of service provision, services are likely to have to achieve their goals with limited and possibly unpredictable funding. Blyth and Gardner see a paradox in the move to person-centred approaches in that

“the desire to increase control and choice for service users via direct payments could threaten a developing public sector committed to collectively developing best practice, choice and standards in the provision of support.” (Blyth & Gardner, 2007, p. 244)

Diverse Clients

The extremely diverse kinds and severities of disability experienced by clients of services has implications for the service organisations as well as for the individual people concerned. The

literature incorporated in this review assumes (sometimes without stating it) an extensive variety of service requirements, from someone who needs to be encouraged to join community sports or find a companion to escort her to the football each week, through someone who needs a few thousand dollars to run a community activity in which disabled people can be included, all the way to a person dependent on 24-hour expert care. Without adequate and predictable funding, it will be difficult for services to cater for all and to respond to individuals rather than provide categories of care.

Diversity encompasses more than disability, of course. In common with the rest of the community, people with disabilities have varied cultural backgrounds, sexual orientations, interests, affiliations, and many other meaningful components of individual and social identity. These are all part of the challenge of implementing person-centred approaches in a culturally sensitive manner, relating not only to national cultural differences (Laragy, 2009) but also to the other intersecting cultures within which meaning is constructed. How flexible will new person-centred approaches be? Is there any risk of having a supposedly personal service plan imposed on an unwilling recipient?

It has been argued that individualised funding schemes could act as a “powerful counterweight” to the new public management performance governance approach by redistributing power and resources to where they are most needed; it is with this understanding that they have been enthusiastically supported by groups representing people with disabilities (Ellis, 2005). However, Ellis (2005, p. 700) argues that, to bring this about and ensure that all people with disabilities are included, “there will need to be a concomitant expansion in the grassroots organisational infrastructure required to recruit, employ and train staff and manage budgets” and the comprehensive representation of people with disabilities at all planning stages: that is, co-production (see also Hatton et al., 2008). Limiting factors include the availability of voluntary organisations to carry out the wide range of tasks, as well as the challenges for traditional organisations in adapting to the uncertain demands of a radically restructured system.

Communication and Information

Large-scale transformations in service provision such as those proposed for person-centred approaches can cause organisational havoc if those who must implement policy are uncertain about roles and requirements. As changes are made to legislation and policy, service agencies need clear, timely, up-to-date information that they find helpful and that they can communicate effectively to their clients. The need for a communication chain mediated by services should be built in to policy so that all information can flow within response deadlines without causing anxiety and confusion. Communication will need to take many forms, including written documents, websites, and personal training, taking place all along the chain from policy-makers through agencies to clients and the community at large. Just as service agencies need to be aware of and understand what is required of them, so clients need both services and information about their existence (Laragy, 2004, 2009). According to Laragy (2009, p. 9), “service designs need to build in information and support services that are readily available, even if costs are involved”.

Community Support

“In the areas of welfare, health, crime, employment, education and the environment it is clear that achieving significant progress requires the active involvement and cooperation of citizens. Agencies may have more impact on key policy outcomes by using their limited resources to engage, involve and change the behaviour of users and other parties, than by concentrating on traditional policy tools and service delivery.” (APSC, 2007, p. 31)

Extensive, coordinated, committed, and (mostly) voluntary community support is a hallmark of person-centred approaches to disability care, in keeping with its status as a wicked problem. A community of citizens needs to be persuaded to understand and endorse person-centred approaches as well as to behave in ways that enable the full participation of people with disabilities. The support available to each person with a disability is dependent on and will vary according to the style, capacity, size, stability, socio-economic status, and interests (among other things) of his or her community. This has implications for services, which will need to facilitate community networks in both formal and informal settings. Services are also likely to have an important role in ensuring community connectedness among people with a disability by establishing and maintaining user-support groups. Work mobilising a voluntary web of supporters will take commitment and innovation and will not be cost-free.

Workforce

Implementing social justice in the market economy has implications for all those employed by service agencies, including social workers, welfare workers, and home care providers. It is suggested that professionals will need conceptual clarity about any new person-centred approach and that specialist staffing, training, and information resources are required for adequate implementation (Manthorpe et al., 2009; Priestley et al., 2007; Rabiee et al., 2009). According to the Productivity Commission, the new specialities and skills required to implement new person-centred approaches must be developed in the midst of a diminishing workforce:

“The bulk of support for disability is informally provided by predominantly (female) family members. Formal disability services are delivered by a range of practitioners from the health and community sector. There is already a shortage of workers in this area. An ageing workforce and increasing competition for the same services by other sectors, such as aged care, will add to these shortfalls. Efforts are underway to attract new workers, including by improving wages, working conditions, training and career paths. However, increasing a workforce’s capacity is typically a slow process. ... [T]he skills of the workforce will need to change over time to accommodate new and better ways of delivering services and supporting people with disabilities.” (Productivity Commission, 2010, pp. 38-39)

It is also possible that, under a new system, high mobility, working without supervision, non-standard hours, and increasing casualisation will be expected.

Organisational Structure

According to Rabiee, as just one example, “Individual Budgets require changes in the routine practices and organizational culture of adult social care services, from a needs- or service-led approach to an individualized and outcomes-focused approach” (Rabiee et al., 2009, p. 932). The literature suggests that some restructuring will be required for all aspects of new person-centred approaches being implemented in a market economy, not just individualised funding. Changes may incorporate the use of brokers or other intermediaries. The comprehensive organisational transformation may bring with it a sense of insecurity among staff for their own jobs and the continuity of the service (Manthorpe et al., 2009).

A person-centred approach is likely to require more time planning and processing for each individual client, compounded as they choose to move between agencies and to use agencies for different purposes. Greater inter-agency cooperation will be necessary. Different, more complex accounting processes will be required by new funding arrangements. Given new public management, it seems reasonable to expect increasing administrative and reporting demands which might also affect organisation and staffing. All of this costs money.

Laragy (2004) described an organisational paradox after reviewing seven services (transition programs for young people with disabilities) in Australia. Although there was increased service responsiveness as a result of participation in decision-making by young people and their families, the increasing bureaucratic demands put pressure on staff time and services, which decreased flexibility and the ability to provide an individual focus.

Professional Roles and Culture

Wicked problems tend to require behaviour change, including commitment from many people (APSC, 2007); this is obviously the case in reforming both professional and client practice to bring about full person-centred approaches to disability services. Behaviour change and commitment are acknowledged to be among the most difficult aspects of tackling a wicked problem (APSC, 2007). Laragy, for example, summed up other authors in writing that it is “very difficult for services and service systems to make radical changes as there is a tendency for them to remain the same and for professionals to retain control” (Laragy, 2004, p. 527).

Tensions have been noted in reconciling professional practice with person-centred approaches, especially individualised budgets. Although the concepts of individual care and empowerment are consistent with social work ideals, the challenges to expert knowledge, the commodification of social care work, and the potential inequity inherent in a new, poorly regulated, casual workforce do not sit well with many social workers (Ellis, 2007). This tension and other conflicts and paradoxes arising from the intersection of social justice and the market ideology are likely to continue to present difficulties to professionals in the field: “The inherent tensions of direct payments policy find expression in a lack of operational clarity at each level of implementation” (Ellis, 2007, p. 407).

Professional roles and confidence are being challenged by managerialism. Furthermore, it has been said that professionals whose code of ethics requires them to acknowledge the autonomy of their clients and to treat them sensitively now work in a managerial environment of accountability that encourages them to treat people with suspicion and mistrust (Wilson et al., 2008). This has profound implications for services.

Varied responses were found among social workers in the UK who were asked to be part of pilot schemes in which individualised funding was introduced (Manthorpe et al., 2009). Some were concerned that the new paradigm might make all previous social work practice seem worthless, some participants were unsure of what was expected of them and saw training as further undermining their professional experience, while others welcomed it as the epitome of social work. Training, therefore, needs to acknowledge the interpretation and understanding of the people involved. In this UK evaluation, limited funding was allocated for training, although the authors stressed that training should be coordinated for staff and the service users, and that staff may benefit from developing professional networks to work through the demands and challenges of the new system. It was also noted that the optimal timing of training—before the new system began or soon after—was difficult to establish and that the effects on social workers of full transformation to person-centred approaches and individualised funding are yet to be assessed (Manthorpe et al., 2009).

Viability of Services

Individualised funding as part of person-centred approaches implies the end of government block-funding of service providers, who confront uncertainty about their future viability (Productivity Commission, 2010). It is likely that non-specialised providers of services will respond to the market opportunity, as they have already done in Victoria with the tendering of services in a wide range of previously specialised areas. A new opportunity might be the provision of assistance in making decisions and intermediary services or brokerage (Productivity Commission, 2010).

Not-for-profit organisations are likely to face competition from increasing numbers of for-profit organisations, which was a process encouraged by the previous Liberal government and not thus far discouraged by the current Labor government. This will affect standards, consistency, and quality; the aim will be to deliver the minimum required by the funder in order to increase profit, a process consistent with economic rationalism. Profit-seeking agencies will deliver services at a cost equal to what the Department gives them minus profit, which may not be enough to serve individuals adequately.

The Productivity Commission (2010, p. 23) includes as a risk of the proposed service reforms “the viability of service providers, which may need a certain critical mass of demand to survive.” Those who endorse the market philosophy will see this as an appropriate outcome for an organisation that was not able to meet the demands of the market.

From another perspective, there is a chance that, by transferring responsibility for much of the management and administration to people with disabilities or their proxies, the infrastructure of support services could be undermined (Burton & Kagan, 2006). If service agencies cannot survive the market, the major risk—and one that undermines the whole social justice agenda—is that there will be fewer options for individuals, not more.

Comprehensive Implications of Person-Centred Approaches

There are implications of introducing person-centred approaches to disability service provision that cannot be isolated to individuals, populations, or services. Recognition of the citizenship of people with disabilities, adaptation of the social and physical environment to enable people with disabilities to exercise their rights as citizens, and inclusion of people with disabilities in community activities are obligations borne by society as a whole. Policy makers and opinion leaders need to work at developing and maintaining supportive public opinions and attitudes. Commitment to change is required at all levels: from policy makers, funders, service providers, families and carers, recipients, advocates, and the community.

Policy Development

For a successful person-centred approach to disability service provision there needs to be committed government planning and a strong policy framework that is adequately resourced (e.g., Bigby, 2007; Laragy, 2004; Lord & Hutchison, 2003; Rummery, 2009). A market unchecked by effective policy can have adverse effects on people with a disability and their carers (Rummery, 2009).

A vital component of policy must be adequate and equitable accountability at all levels, from the funder to the recipient, linked to values and principles (Lord & Hutchison, 2003).

Funding

Although Victoria de-emphasises funding by using the language of self-directed approaches rather than of individualised funding (Fisher et al., 2010), it is evident that adequate funding is at the heart of achieving good person-centred approaches. When Laragy assessed transition programs for young people in Australia, she found generally that resources were inadequate, and concluded that “While adequate funding does not ensure choice and self-determination, the lack of funds does restrict opportunities” (Laragy, 2004, p. 527). Other researchers and commentators share this view (e.g., Cumella, 2008; DiRita et al., 2008; Spall et al., 2005). Given that one of the reasons identified for introducing individualised funding is to reduce costs, this has implications for policy-makers, governments, services, and individuals.

The Productivity Commission acknowledges the costs involved in the proposed scheme and argues that “any new financing approach must principally involve new revenue from the community as a whole (taxes, insurance premiums and voluntary community contributions, such as more volunteering)” (Productivity Commission, 2010, pp. 34-35). Calling on further contributions from the community as a whole may collide with the problem of transforming community attitudes and engendering commitment to the needs of people with disabilities. When people are highly dependent, it is expensive to provide adequate care; there can be a perception in the community that this is not an appropriate use of “our” money and consequent resistance to the commitment of funds.

Obligation for Providing Services

One characteristic of a wicked problem is that it does not sit conveniently within the responsibility of a single organisation (APSC, 2007). With person-centred approaches, the devolution of responsibility to individuals, families, and communities entails a risk that no organisation will take ultimate responsibility for providing disability services. Collaborative strategies are recommended in dealing with wicked problems, to be preferred over authoritative or competitive strategies (APSC, 2007). The need for developing networks and for collaboration among service providers and across all aspects

of the service-delivery chain is also a consistent theme in the literature on person-centred disability service provision. A sense of collective responsibility and shared obligation for providing services will be an essential component of successful person-centred service provision.

Responsibility for Decisions

According to the Productivity Commission (2010, p. 24), “even where individualised funding (and personalised care) might be the dominant basis for decision-making in a new scheme, inevitably service providers and governments will continue to play a major role (determining who is eligible, funding rules, promoting innovation, quality assurance and so on).” The new scheme will bring with it, therefore, problematic considerations about how decisions are to be made at all levels, and who is to make them. Not least among these decisions will be developing a system for resource allocation (Rabiee et al., 2009).

Evaluation

Success in person-centred approaches to disability care is difficult to measure because it is personally defined (Laragy, 2004). Nevertheless, evaluation needs to be built in to the design and implementation of a new program. Lord and Hutchison (2003) concluded from their review of services in the US, Canada, and Australia that a “learn as you go philosophy” gave the best chance of success. In other words, all those participating in a person-centred approach need to be ready to try new ways of doing things, to evaluate the process and outcomes constantly, and to make changes as necessary.

5. CONCLUSION

A discussion paper distributed by the Australian Public Service Commission (2007) summarises the task of tackling wicked problems as follows:

“Wicked problems are characterised by social complexity—they cross the boundaries of APS agencies, they cross jurisdictional boundaries, stakeholders (and experts) often disagree about the exact nature and causes of the problems and, not surprisingly, they disagree about the best way to tackle them. A key part of the solution to many wicked problems involves achieving sustained behavioural change. It has become increasingly clear that a disengaged and passive public can be a key barrier, and is a factor in the policy failures around some of Australia’s longstanding wicked problems. In the areas of welfare, health, crime, employment, education and the environment, significant progress requires the active involvement and cooperation of citizens.” (APSC, 2007, p. 35)

Although the document is directed at the Australian Public Service, the approaches it suggests apply more broadly, and seem to be exquisitely applicable to the wicked problem of fully developing person-centred approaches to disability services. Among its recommendations are the following:

“Tackling wicked problems is an evolving art but one which seems to at least require:

- *holistic, not partial or linear thinking.* ...
- *innovative and flexible approaches.* ...
- *the ability to work across agency boundaries.* ...
- *increasing understanding and stimulating a debate on the application of the accountability framework.* ...
- *effectively engaging stakeholders and citizens in understanding the problem and identifying possible solutions.* ...
- *additional core skills.* ... communication, big picture thinking and influencing skills and the ability to work cooperatively. ... A multi-disciplinary team approach is a practical way to garner all the required skills and knowledge for tackling wicked problems.
- *a better understanding of behavioural change by policy makers.* ...
- *a comprehensive focus and/or strategy.* Successfully addressing wicked policy problems usually involves a range of coordinated and interrelated responses given their multi-causal nature and that they generally require sustained effort and/or resources to make headway.
- *tolerating uncertainty and accepting the need for a long-term focus.* ...” (APSC, 2007, pp. 35-36)

There is a compelling need to ensure social justice for all citizens, including people with disabilities, their families, and those who work with them. Services confront a significant challenge in endeavouring to implement the social justice agenda in a strong market environment.

BIBLIOGRAPHY

- Australian Bureau of Statistics. (2009). *Survey of Disability, Ageing and Carers* (Cat. no. 4430.0). Canberra: Australian Bureau of Statistics.
- Australian Institute of Health and Welfare. (2007). *Current and Future Demand for Specialist Disability Services*. Canberra: AIHW.
- Australian Public Services Commission. (2007). *Tackling wicked problems*. Canberra: AGPS.
- Batavia, A.I. (1998). Prospects for a national personal assistance services program: enhancing choice for people with disabilities. *American Rehabilitation*, 24(4), 2-8.
- Berkowitz, E.D. (1999). Supporting disability: an historical perspective. *American Rehabilitation*, 25(1), 2-7.
- Bigby, C. (2007). The challenge of implementing state disability policy to achieve second generation rights for people with disabilities. *Just Policy*, 43, 68-75.
- Bigby, C., & Fyffe, C. (2009). An Overview of Issues in the Implementation of Individualised Funding. Paper presented at the *Achieving their own lives: The implementation of individualised funding for people with intellectual disability. Proceedings of the Third Annual Roundtable on Intellectual Disability Policy*, held on Friday 24 October, 2008, Bundoora: La Trobe University.
- Bigby, C., & Knox, M. (2009). "I want to see the queen": Experiences of service use by ageing people with an intellectual disability. *Australian Social Work*, 62, 216-231.
- Blyth, C., & Gardner, A. (2007). 'We're not asking for anything special': direct payments and the carers of disabled children. *Disability & Society*, 22, 235-249.
- Bostock, L., Gleeson, B., Mcpherson, A., & Pang, L. (2004). Contested housing landscapes? Social inclusion, deinstitutionalisation and housing policy in Australia. *Australian Journal of Social Issues*, 39(1), 41-62.
- Boyle, G. (2008). Autonomy in long-term care: a need, a right or a luxury? *Disability & Society*, 23, 299-310.
- Buntinx, W. (2008). The logic of relations and the logic of management. *Journal of Intellectual Disability Research*, 52, 588-597.
- Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. *Disability & Society*, 19, 735-751.
- Burton, M., & Kagan, C. (2006). Decoding *Valuing People*. *Disability & Society*, 21, 299-313.
- Caldwell, J. (2007). Experiences of families with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society*, 22, 549-562.
- Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 47, 352-367.
- Carmichael, A., & Brown, L. (2002). The future challenge for direct payments. *Disability and Society*, 17, 797-808.

- Clapton, J. (2008). 'Care': Moral concept or merely an organisational suffix? *Journal of Intellectual Disability Research*, 52, 573-580.
- Clapton, J. (2009). Inclusion; illusion or confusion. Paper presented at the *Achieving their own lives: the implementation of individualised funding for people with intellectual disability*, Proceedings of the third annual roundtable on intellectual disability policy, held on Friday 24 October, 2008, Melbourne.
- Cloutier, H., Hagner, D., Malloy, J., & Cotton, P. (2006). Choice and control over resources: New Hampshire's individual career account demonstration projects. *Journal of Rehabilitation*, 72(2), 4-11.
- Cumella, S. (2008). New public management and public services for people with an intellectual disability: A review of the implementation of Valuing People in England. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 178-186.
- Danagher, N. (2003). From the margins to the mainstream. *Learning Disability Practice*, 6(1), 18-20.
- Department of Health. (2007). *Putting people first: Transforming adult social care. Self-directed support process*. London: Department of Health.
- Department of Human Services (2007) *Quality Framework for Disability Services*. http://www.dhs.vic.gov.au/disability/improving_supports/quality_framework_for_disability_services
- DiRita, P.A., Parmenter, T.R., & Stancliffe, R.J. (2008). Utility, economic rationalism and the circumscription of agency. *Journal of Intellectual Disability Research*, 52, 618-625.
- Duffy, S. (2005). Individual Budgets: Transforming the allocation of resources for care. *Journal of Integrated Care*, 13(1), 1-11.
- Ellis, K. (2005). Disability rights in practice: the relationship between human rights and social rights in contemporary social care. *Disability & Society*, 20, 691-704.
- Ellis, K. (2007). Direct payments and social work practice: The significance of 'street-level bureaucracy' in determining eligibility. *Br J Soc Work*, 37, 405-422.
- Fisher, K. R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., et al. (2010). *Effectiveness of individual funding approaches for disability support* (Occasional Paper No. 29). Canberra: Australian Government: Department of Families, Housing, Community Services and Indigenous Affairs.
- Flanagan, S.A., Green, P.S., & Eustis, N. (1998). You can do It: State initiatives broaden access to consumer-directed personal assistance services through the use of intermediary service organizations. *American Rehabilitation*, 24(2/3), 21-26.
- Guscia, R., Harries, J., Kirby, N., Nettelbeck, T., & Taplin, J. (2006). Construct and criterion validities of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability*, 31, 148-155.
- Harvey, O., Popowski, T., & Sullivan, C. (2008). Individuation and feminism--A Commentary on Gilbert Simondon's 'The Genesis of the Individual'. *Australian Feminist Studies*, 23(55), 101-112.
- Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., et al. (2008). *A report on In Control's second*

phase: *Evaluation and learning 2005-2007*. London: In Control.

Houston, S. (2004). The centrality of impairment in the empowerment of people with severe physical impairments. Independent living and the threat of incarceration: a human right. *Disability & Society*, 19, 307-321.

Hudson, B., & Henwood, M. (2008). *Prevention, personalisation and prioritisation in social care: Squaring the circle?* A report commissioned by CSCI for the review of eligibility criteria. London: Commission for Social Care Inspection.

Kröger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy*, 29, 398-420.

Laragy, C. (2002). Individualised funding in disability services. Paper presented at the *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001*, University of New South Wales, Sydney.

Laragy, C. (2004). Self-determination within Australian school transition programmes for students with a disability. *Disability & Society*, 19, 519-530.

Laragy, C. (2009). Does individualised funding offer new opportunities or unacceptable risks? Australian case studies of people with an intellectual disability. Paper presented at the *Achieving their own lives: The implementation of individualised funding for people with intellectual disability. Proceedings of the Third Annual Roundtable on Intellectual Disability Policy*. Friday 24 October, 2008, La Trobe University

Leece, D., & Leece, J. (2006). Direct payments: Creating a two-tiered system in social care? *Br J Soc Work*, 36, 1379-1393.

Leece, J. (2004). Money talks, but what does it say? Direct payments and the commodification of care. *Practice*, 16, 211-221.

Leece, J. (2007). Direct payments and user-controlled support: The challenges for social care commissioning. *Practice: Social Work in Action*, 19, 185-198.

Leece, J. (2010). Paying the piper and calling the tune: Power and the direct payment relationship. *Br J Soc Work*, 40(1), 188-206.

Lord, J., & Hutchison, P. (2003). Individualised support and funding: building blocks for capacity building and inclusion. *Disability & Society*, 18(1), 71-86.

Lord, J., & Hutchison, P. (2008). Individualized funding in Ontario: Report of a provincial study. *Journal on Developmental Disabilities*, 14(2), 44-53.

Lyon, J. (2005). A systems approach to direct payments: a response to 'Friend or foe? Towards a critical assessment of direct payments'. *Critical Social Policy*, 25, 240-252.

Mansell, J., & Beadle-Brown, J. (2006). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17, 1-9.

Manthorpe, J., Jacobs, S., Rapaport, J., Challis, D., Netten, A., Glendinning, C., et al. (2009). Training for change: Early days of Individual Budgets and the implications for social work and care management practice--A qualitative study of the views of trainers. *Br J Soc Work*, 39, 1291-1305.

- Manthorpe, J., Stevens, M., Rapaport, J., Harris, J., Jacobs, S., Challis, D., et al. (2009). Safeguarding and system change: Early perceptions of the implications for adult protection services of the English Individual Budgets pilots--A qualitative study. *Br J Soc Work*, 39, 1465-1480.
- Martin, C. (2009). Commissioning services for people with learning disabilities in Scotland: linking evidence and practice. *British Journal of Learning Disabilities*, 37(1), 28-33.
- Melbourne Citymission. (2009). *The need for a formalised consumer participation approach at Children's and Disability Services: Background paper*. Melbourne: Melbourne Citymission.
- Mendes, P. (2009). Retrenching or renovating the Australian welfare state: the paradox of the Howard government's neo-liberalism. *International Journal of Social Welfare*, 18(1), 102-110.
- National Disability Services Victoria. (2008). *Annual Report 2007-8*, Melbourne
- Neely-Barnes, S., Graff, J.C., Marcenko, M., & Weber, L. (2008). Family decision making: benefits to persons with developmental disabilities and their family members. *Intellectual and Developmental Disabilities*, 46, 93-105.
- Ottmann, G., Laragy, C., & Damonze, G. (2009). Consumer participation in designing community based consumer-directed disability care: Lessons from a participatory action research-inspired project. *Systemic Practice and Action Research*, 22(1), 31-44.
- Ottmann, G., Laragy, C., & Haddon, M. (2009). Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. *Health & Social Care in the Community*, 17, 466-475.
- Pearson, C. (2000). Money talks? Competing discourses in the implementation of direct payments. *Critical Social Policy*, 20, 459-477.
- Prideaux, S., Roulstone, A., Harris, J., & Barnes, C. (2009). Disabled people and self-directed support schemes: reconceptualising work and welfare in the 21st century. *Disability & Society*, 24, 557-569
- Priestley, M., Jolly, D., Pearson, C., Ridell, S., Barnes, C., & Mercer, G. (2007). Direct payments and disabled people in the UK: Supply, demand and devolution. *Br J Soc Work*, 37, 1189-1204.
- Productivity Commission. (2010). *Disability care and support: Issues paper*. Canberra: Australian Government.
- Rabiee, P., Moran, N., & Glendinning, C. (2009). Individual budgets: Lessons from early users' experiences. *Br J Soc Work*, 39, 918-935.
- Reinders, H. (2008). The transformation of human services. *Journal of Intellectual Disability Research*, 52, 564-572.
- Renshaw, C. (2008). Do self-assessment and self-directed support undermine traditional social work with disabled people? *Disability & Society*, 23, 283-286.
- Riddell, S. (2008). Chapter 4. Direct payments and disabled children and young people: the service of

- the future? *Journal of Research in Special Educational Needs*, 8(3), 174-181.
- Rummery, K. (2006). Disabled citizens and social exclusion: the role of direct payments. *Policy & Politics*, 34, 633-650.
- Rummery, K. (2009). A comparative discussion of the gendered implications of cash-for-care schemes: Markets, independence and social citizenship in crisis? *Social Policy & Administration*, 43, 634-648.
- Scourfield, P. (2007). Social care and the modern citizen: Client, consumer, service user, manager and entrepreneur. *Br J Soc Work*, 37(1), 107-122.
- Spall, P., McDonald, C., & Zetlin, D. (2005). Fixing the system? The experience of service users of the quasi-market in disability services in Australia. *Health & Social Care in the Community*, 13(1), 56-63.
- Spandler, H. (2004). Friend or foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24(2), 187-209.
- Spandler, H., & Vick, N. (2006). Opportunities for independent living using direct payments in mental health. *Health & Social Care in the Community*, 14(2), 107-115.
- Stainton, T. (2002). Taking rights structurally: Disability, rights and social worker responses to direct payments. *Br J Soc Work*, 32, 751-763.
- Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *J Intellect Disabil.*, 9, 289-298.
- Stainton, T., & Boyce, S. (2004). 'I have got my life back': Users' experience of direct payments. *Disability & Society*, 19, 443-454.
- Stainton, T., Boyce, S., & Phillips, C.J. (2009). Independence pays: a cost and resource analysis of direct payments in two local authorities. *Disability & Society*, 24, 161-172.
- Swenson, S. (2008). Neoliberalism and human services: threat and innovation. *Journal of Intellectual Disability Research*, 52, 626-633.
- Taylor, N. (2008). Obstacles and dilemmas in the delivery of direct payments to service users with poor mental health. *Practice*, 20(1), 43-55.
- Tomlinson, C., & Scope, W. (2006). An individual budget in practice. *Journal of Integrated Care*, 14(1), 35-37.
- Turnbull, A.P., & Turnbull, R. (2006). Self-determination: Is a rose by any other name still a rose? *Research and Practice for Persons with Severe Disabilities*, 31(1), 1-6.
- West Sussex Adult Services. (2007). *Adults' Services Transformation Programme (ASTP): Blueprint*, version 0.7. West Sussex County Council.
- Wilson, N., Clegg, J., & Hardy, G. (2008). What informs and shapes ethical practice in Intellectual Disability services? *Journal of Intellectual Disability Research*, 52, 608-617.
- Wolff, J. (2009). Cognitive disability in a society of equals. *Metaphilosophy*, 40, 402-415.



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