<table>
<thead>
<tr>
<th>SEARCH ENGINES</th>
<th>SEARCH TERMS USED (DESCRIPTORS)</th>
<th>SOURCE/CITATION</th>
<th>ABSTRACT, COUNTRY, and KEY WORDS</th>
</tr>
</thead>
</table>
Focuses on how individualized funding and support brokerage can contribute towards self-determination in people with developmental disabilities. Benefits offered by individualized funding structures; History of support brokerage; Overview of the work of independent support brokers. |
Author-Supplied Keywords:
consumer direction
family caregivers
home care
paid caregiving
personal assistance
satisfaction
This study describes consumers who hire friends, family members, or strangers as paid personal assistants and compares service satisfaction among the three groups. From surveying 511 consumers of self-directed home care services, the authors found that consumers who hire friends as workers are younger and more educated than consumers who hire family members. |
and strangers, and they are more impaired than consumers with strangers as workers. The friend cohort experiences more stability with their personal assistants than does the stranger cohort but not as much stability as the family cohort. On some dimensions of consumer satisfaction, friends as workers are perceived by consumers to be either the same as or better than strangers, but they also are perceived as either the same as or worse than family workers. Using friends as paid workers is an important resource. Researchers and policy makers should further explore this approach because the need for home-based personal assistance continues to increase.


**Country:** USA

**Author-Supplied Keywords:**
- career development
- customized employment
- gender equity
- intellectual and developmental disabilities
- self-determination
- self-directed planning
- self determination

Self-determination, choice, and preference have become important issues in vocational rehabilitation and have long been staples of social work practice. This article provides an
overview of a model, the self-determined career development model, which is designed to enable people with disabilities to self-direct planning that leads to employment. Specifically, this model is applied to young women with intellectual and developmental disabilities to obtain nontraditional employment through self-regulated, customized employment planning. This article examines issues pertaining to self-determination in the context of vocational guidance and planning, introduces the model and its use in secondary education and rehabilitation, and discusses the role of social workers in supporting consumer control and self-direction.

Focused on the reversal of the exclusion of people with learning disabilities under the Direct Payments Act of Great Britain. Efforts of the Dept. of Health to promote Direct Payments; Uncertainty over decision-making for learning disabled; Possibilities of individualized funding; Increase in third-party arrangements. |

Funding is a central tool for improving the quality and range of employment service options. While outcome-based funding models are more common in the Vocational Rehabilitation system, there is a need |
for funding structures in intellectual and developmental disabilities (IDD) service systems that signal a clear preference for high-quality, cost-effective integrated employment outcomes. In an environment of increasing fiscal demands and limitations, and expansion of self-directed services and individualized budgeting, state IDD systems must engage in rate-setting and funding discussions that are rooted in their priorities and long-term goals. This paper explores rate-setting methodologies, rate structures, and incentives for integrated employment, and the relationship between funding, policies, and priorities. A detailed analysis within five states yields lessons for other state IDD systems as they contend with evolving funding structures that respond to fiscal pressures and demands. Implications include the need for funding to be seamless, goal-focused, and connected to and consistent with larger systems strategies.

Country: USA
years. At the same time, challenges in the recruitment, retention, and training of direct support workers in the field have grown more acute. In this article, the authors investigate the status of the direct support workforce for people using self-directed supports in a Midwestern state, based on the results of a statewide survey of service users. Although additional research is needed, the results of this study suggest that people who use self-directed funding options are satisfied with their ability to direct staffing, though challenges remain. Among these challenges, the presence of higher than expected wages but lower than expected benefits provision compared with traditional services may have serious policy and staff retention ramifications that affect the long-term viability of self-directed funding options. In addition, staff training remains a challenge, with service users in this sample reporting low rates of training beyond a general skill set. Implications of these findings are discussed.

A central element in the shift to a “personalised” care system in the UK is the opportunity for disabled people to hold and manage budgets for the purchase of care and support, to replace local authority services. The delivery
mechanisms of ‘Direct Payments’ and ‘Individual Budgets’ have allowed many disabled people to control their care and support better, and have promoted their social inclusion. However, the particular contexts and issues for people with learning disabilities in holding personal funding have been little considered. The paper sets out the broad themes of the introduction of personalised care, and examines the limited use by people with learning disabilities of Direct Payments and the subsequent development of Individual Budgets.

The paper considers the challenges to the nature, spaces and relations of care commonly used by people with learning disabilities that personal budgets present, in particular for those with more severe disabilities. The paper concludes by suggesting ways in which people with learning disabilities can use personal budgets, whilst maintaining the collective relations and spaces of caring desired by many.

Background This paper reports the findings of a study of individual budgeting practices in state-financed developmental disabilities services in the United States. The study's purpose was to describe key process components and methodological variables integral to
<table>
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<td>consumer-controlled, individual budgeting formats employed in state-funded services.</td>
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**Method** The study was conducted in two phases: a national survey sent to state agency directors in all 50 states plus Washington DC, and an in-depth assessment of individual budgeting practices in nine selected states.

**Results** Data received from 84% of state developmental disabilities agencies contacted indicated considerable variability in the formats employed by states to: determine support needs of eligible individuals; equate needs to specific services; and set an amount of funding sufficient to pay for identified supports.

**Conclusions** No single individual budgeting method is universally accepted by all state agencies. State practices differ significantly from one jurisdiction to another, although most follow a developmental, statistical or mixed methodology.

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**Keywords:** Australia individual funding intellectual disabilities |
organizational change
program implementation

Although individual funding is increasingly being used around the globe as a mechanism to fund social care, its implementation is proving to be problematic and implementation strategies are not well developed. This paper proposes a framework for the successful introduction and implementation of individual funding programs based on the analysis of data collected in a qualitative case study conducted in an Australian not-for-profit disability agency over a 4-year period from 2003 to 2007. Data were gathered through participant observation and interviews with program participants and managers, and the findings were validated with those involved. Bronfenbrenner's ecological systems theory is used to analyze the findings from a micro, meso, exo, and macro perspective. The following factors were found to be important for successful implementation: the meaningful involvement of the person with disability in decision-making; adequate resources; access to information and appropriate supports; suitable activities being available; knowledge of policies and procedures; policies ensuring oversight and responsible accountability; employment conditions for workers being safeguarded; and
support for staff and managers to adjust to their new roles. Knowledge of effective implementation strategies is important for disability agencies and for governments promoting **individual funding** because this radically different funding arrangement requires new implementation strategies.

**Subject Terms:**  
Disabilities  
Communities  
Guardian & Ward  

The paradigm in disability supports is shifting away from institutional services and professional control towards self-determination and community involvement of people with disabilities. The assumption that the best way to provide disability supports is for government to give money to agencies or services, rather than directly to people with disabilities and their support networks, is being challenged. This article reports on findings and themes fruit: a Canadian study that investigated **individualised funding** projects from different parts of the world. Ten of fifteen of the most 'promising initiatives' were selected for more detailed study and analysis. Projects analysed were from Canada, the US, and Australia. Themes emerging from the study included the fact that values and
principles mattered, a policy framework provided coherence and equity, infrastructure supports for **individuals** were separate from service system, the facilitator-broker role differed from case management, allocation of **individualised** funds was designed to be equitable and accountable to the funder and person, and a 'learn as you go' philosophy maximised positive outcomes. This research project demonstrates that **individualised** support and **funding**, when embedded in the new paradigm of disability and community, builds capacity of **individuals**, families and communities.


**Key Words:**

Community disability services
Consumer-directed care
Participation
Policy development

User participation has been embraced worldwide as a means to provide better consumer outcomes in health and community care. However, methodologies to achieve effective consumer engagement at the programme design level have remained underexplored. The purpose of this study was to evaluate the impact of a Participatory Action Research (PAR)-inspired methodology used to develop a

**Country:** Australia

**Subject Terms:**

People with disabilities
Customer services
Consumers
Public welfare

A qualitative study involving semi-structured interviews with 31 people with disabilities and 32 carers in the state of Queensland, Australia, found that their experience of supportive service delivery had not improved despite reforms of the service delivery system driven by a version of the quasi-market model. Instead of delivering consumer-directed community care/individualised funding service model for people with disabilities. A retrospective analysis of case notes and internal reports for the first 6 years of an ongoing project were examined. The findings suggest that PAR methodologies need to take into account community development, group support, and capacity building as well as succession planning and risk management issues in order to facilitate the often lengthy policy and project development process. Drawing on these findings, this article discusses five lessons and their methodological implications for PAR in a health or social policy/programme design context.
increased consumer choice and improved efficiency in service delivery, service users experienced inadequate service supply, service cutbacks, and an increased emphasis on cost subsidisation and assessment processes. Additionally, few consumers felt that individualised funding arrangements had personally delivered the benefits which the quasi-market model and associated policy paradigm had indicated that they should receive. For many consumers, the notion of consumer ‘choice’ around service provision was fictitious and they felt that any efficiency gains were at the agency level, largely at the consumers’ cost. It is concluded that there appears to be no particular benefit to service users of quasi-market reforms, particularly in policy contexts where service delivery systems are historically under-funded.
consumers and improve the flexibility and quality of care. However, reports highlighting quality and risk concerns associated with CDC focusing on a longer time frame have been few. This paper presents the findings from a qualitative longitudinal evaluation of an Australian CDC programme. Focusing on the period between 2003 and 2008, it reports on the experiences of 12 families caring for a dependent family member. It is based on two external evaluations completed 6 and 36 months after enrolment, and one internal evaluation completed 48 months after enrolment. The findings were triangulated with internal memos, reports and minutes of meetings, as well as with the theoretical literature. The study demonstrates that CDC harbours considerable benefits for people with disabilities and their carers. However, the study also suggests that, over time, carers may experience an increased sense of isolation and lack of support as a result of their involvement in the CDC programme. The paper argues that the development of safeguards addressing these weaknesses is crucial for the sustainability of CDC programmes in contexts where risk cannot be simply transferred onto consumers.

Country: Australia

Subject Terms:
This paper examines the impact of direct payments on social isolation. We define what social isolation means, and then evaluate the role of direct payments in the provision of social services in the United Kingdom. Social isolation is a particular problem for older people. In Australia there are an increasing number of older residents who are isolated, but would benefit from having greater choice in terms of how they access and receive social services. Increased access to direct payments could help to reduce waiting lists for traditional social services and address gaps in service provision.


**Country:** England

**Keywords:**
- community care policy
- direct payments
- independent living
- individualised funding
- mental health

Mental health service users have yet to reap the benefits of greater choice, control and independent living, which
direct payments have facilitated in other groups of community care users, particularly people with physical disabilities. To redress this imbalance a national pilot to promote direct payments to people with mental health needs in five local authority sites across England was set up and evaluated. The evaluation used a multi-method approach incorporating both qualitative and quantitative data, including individual semi-structured interviews and group discussions with key stakeholders across the pilot sites. This article draws on findings from the pilot evaluation to provide a preliminary understanding of how applicable the independent living philosophy is to mental health and what opportunities direct payments offer for service users. When given the opportunity, service users were able to use direct payments creatively to meet a range of needs in ways which increased their choice, control and independence. This suggests that the benefits of greater independent living through direct payments may be realisable in mental health. However, a number of ways in which the principles of direct payments in mental health could be ‘downgraded’ were identified. The evaluation results indicate that a thorough understanding of the independent living philosophy needs to be developed in the context of mental health.

Although there is an increasing amount of literature on direct payments (DP), to date there have been few studies which have examined in any detail the costs and resources associated with them. This paper presents findings from a two year study conducted in two Welsh local authorities that jointly fund an Independent Living Support (ILS) scheme. The main study was not designed to provide definitive cost comparisons with conventional services, however, cost and resource implications of DP were considered and an analysis to determine comparative costs between DP and traditional services was undertaken. The study notes the difficulty in identifying the true cost of DP and reasonable comparators with traditional services. A set of four case studies are presented comparing actual costs of DP and in-house and independent sector services in the two local authorities studied. The comparison of costs and resources, which did not include significant costs
for traditional local authority services but included the cost of the DP support scheme, found that DP was cheaper than traditional in-house service provision and relatively cost neutral when compared with independent sector provision. User satisfaction, however, was significantly greater with DP than traditional service delivery methods. The paper also examines factors which can potentially influence the cost of DP. The study suggests that DP represent a substantial improvement over traditional arrangements from a cost-benefit perspective. There is strong evidence to suggest that greater 'opportunity cost' savings can be anticipated when DP schemes become more fully integrated into policy, practice and procedures.

|-------------------------------------|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country: Great Britain and England  | Subject Terms:  | Payment Children with disabilities Legislation Political science Research  

1997 saw the introduction of the Community Care (Direct Payments) Act in the UK. This piece of legislation introduced a mechanism that enabled local authorities to make cash payments to disabled people aged between 18 and 64 in lieu of directly provided services.
The years since 1997 have seen the introduction of additional legislation resulting in direct payments now being an option for many more groups of people, including the carers of disabled children. Following the changes in the legislation, government now wishes to see local authorities significantly increasing the numbers of families that receive direct payments. This paper will report on a research project carried out within one local authority in the north-west of England that has one of the largest numbers of carers of disabled children receiving direct payments in the UK. Using a variety of methods this paper explores how the local authority has made direct payments so widely available to carers and the effect that this has had on their own and their children's lives.


Subject Terms:
- mental health services
- payment
dementia
patients
focus groups
telephone surveys
professional employees

This article describes research carried out for the Central Research Unit of the Scottish Executive about Direct
Payments to mental health service users including people with dementia. Previous research had found that Direct Payments were not often, if at all, offered to mental health service users. Using focus groups, interviews and a telephone survey, Scottish Health Feedback explored the extent of implementation of Direct Payments across Scotland, and the views of mental health service users, carers and professionals about the idea of Direct Payments, the potential obstacles, and the support that would be needed. Awareness of Direct Payments was low, even among professionals. Many were hearing about this option for the first time through this research and a common reaction to the research questions was 'Direct what?' The study found that in order to make Direct Payments work for mental health service users, what was needed was 'person-centred' assessment, access to proper support, advice and training, and Direct Payment schemes that were flexible to allow for different arrangements and for transitions.


**Country:** Great Britain

**Keywords:**
- community care
- service development
- strategic planning
- user satisfaction
Spandler (2004) identifies the need to move from reactionary to progressive arguments about direct payments in the UK to enable progress towards a critical assessment of direct payments to users of care services. This reply advocates a strategic view of direct payments within the social care system, by looking at the context within which direct payments operate and system issues that affect the whole social care sector. The discussion advances the hypothesis that critical assessment of direct payments needs to recognize their impact on the whole social care sector and not just on those people who elect to receive them.

**Keywords:**  
Disability policy implementation  
direct payments  
devolution  
Direct payments have brought new opportunities for self-determination and independent living to disabled people in the UK, featuring prominently in government strategy and the 2006 White Paper, ‘Our Health, Our Care, Our Say’. However, ten years after direct payments legislation, take-up remains low and implementation varies |
greatly. Rates of take-up in England remain more than double those in other parts of the UK, raising questions about devolution and equity. This paper presents data from a national study to examine some of the mechanisms underlying uneven outcomes for disabled people in different parts of the United Kingdom, with particular reference to the politics of devolved governance. The analysis focuses on scope for interpretations of policy; resources for information and training; the impact of mandatory duties and targets; extensions to new user groups; and the role of support organizations and disability activism. The evidence suggests that local variations have been produced not only by ‘local’ factors, but also by different opportunity structures for policy development in England, Scotland, Wales and Northern Ireland. This raises questions about the impact of devolution on equity and opportunity for disabled people in the UK.


**Country:** Norway

**Subject Terms:**

payment
Personal assistance organised as **direct payments** is seen as an important means for securing user control and freeing disabled people from their reliance on welfare professionals and unpaid carers. The hypothesis put forward in the article is that just looking at whether personal assistance is organised as **direct payments** or as an **alternative service** represents an overly restricted approach to judge how the user’s preferences are taken care of. By comparing models of personal assistance in the US, the UK, Sweden and Norway it will show that several other factors influence user control. In the final part of the article the question is raised as to whether paternalism is always negative for welfare **service** users. Since the users constitute a broad group it might be questioned if the assumption of the **service** users as rational, well informed and competent to make the best choices is always valid.

**Key words**: South Asian communities  
This article explores the issue of cultural
In all, 24 service providers and professionals were interviewed. Data analysis showed that the suitability of direct payment schemes to ethnically defined needs may be eroded by cultural insensitivities, communication failures and dependency on a competitive care market. Improved training of staff, maximal employment of culturally matched support workers, schemes to address language barriers and focused outreach are recommended. INSET: Implications for practice.

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**Country:** UK

**Subject Terms:**
Home care services-Prospectivbe payment  
People with disabilities-Home care  
Medical care

This paper reports on a study of disabled people with receiving Direct Payments who were able to purchase assistance in ways that cross conventional boundaries between ‘health’ and ‘social’ services. Indeed, most of the Direct Payment recipients used the term ‘personal care’ to describe a range of help that extended right across this conventional divide. Nevertheless, most of the users reported purchasing help with aspects of health care through their Direct Payments,
including physiotherapy, management of incontinence, chiropody, changing dressings and sustaining tissue viability. They chose to purchase this help from their personal assistants (PAs) because statutory services were not available, had been withdrawn, or because they were able to retain greater independence and control over their lives compared with receiving conventional services. Many Direct Payment users wanted more opportunities to purchase a range of health-related services, although this also raised questions about training, supervision and the professionalisation of flexible personal assistance. The paper concludes that health purchasers may need to consider contributing to Direct Payments in acknowledgement of the health care which such schemes are currently providing.

**Subject Terms:**  
Learning disabled  
Mentally ill  
Local government  
Implementation of the 1996 Community Care (Direct Payments) Act from April 1997 has gradually gained momentum as more and more local authorities have begun to embrace the idea, and develop their own direct payment policies and |
support structures. However, whilst users have overwhelmingly welcomed this transition, there remains a stark divide between the implementation and promotion of policy in different parts of the UK. This has resulted in only marginal use of direct payments for a small number of disabled persons in Scotland. As legislation moves to widen access to direct payments in Scotland, this article draws on a series of interviews with policy makers in two local authorities and examines some of the key problems that, to date, have prevented many authorities from offering direct payments as a mainstream service option for disabled people.

|------------------------------------|----------------|------------------------------------------------------------------------------------------------------------------|
| Country: England                   |                | **Keywords:**
|                                    |                | consumerism
|                                    |                | cooperatives
|                                    |                | personal assistants
|                                    |                | self- determination
|                                    |                | user movement.
|                                    |                | **Direct payments** enable individuals to purchase their own care rather than have directly provided services. This article unpacks the complexities involved in the implementation of direct payments by addressing the need to reconcile the strong evidence of their benefits with emerging concerns about the wider consequences of their implementation. |
One practice that highlights the conflicts at the heart of direct payments is the employment of personal assistants. While directly employing personal assistants offers maximum benefit for recipients, it also produces the strongest concerns. Therefore, an understanding of the context of direct payments, specifically the practice of employing personal assistants, is used to explore these complexities in greater depth. The discussion concludes by arguing for a more critical awareness of the wider context in which direct payments are being developed in order to understand how this context can open up or limit opportunities for greater self-determination. It suggests a number of factors that need to be addressed to ensure that direct payments continue to be a progressive strategy. These include reconciling conflicting ideologies such as those advocating individual choice and/or collective provision; the need for political action to secure adequate resources; and the development of alternative strategies such as cooperatives to address the collective needs of direct payment recipients and workers.

Keywords: direct payments disability |
In 2003, the UK government placed a mandatory responsibility on local authorities to offer direct payments to eligible people. Given the extent to which the government is committed to extending the number of people using cash payments and research that shows the enormous benefits to users, then some areas of research into the take up are sadly neglected. For example, is it the case, as some literature suggests, that direct payments are by being disproportionately utilized by middle-class, affluent disabled people, effectively creating a two-tiered system in social care? The research in this paper provides some insight into this question by reporting a unique study to look at statistically significant differences in the financial situation of direct payment users compared with users of traditional services.

Since 1997, Local Authorities have had the discretionary power to pay cash directly to disabled adults up to the age of 65 and assessed as needing social service support. More recently, the scope of Direct Payments has been widened to include people aged over 65 years and will, under the Health and Social Care Act 2001, be extended to further groups including disabled people from 16 to 18 years of age and parent carers of young children with impairments. Direct Payments have the potential not only to impact radically upon an individual's quality of life but also to influence the 'community care' market economy and the way personal support services are purchased and delivered in the future. Recent figures from a survey undertaken by the Association of Directors of Social Services suggest that 80% of local authorities have already introduced a Direct Payments scheme and that over 3500 people are already in receipt of direct payments (Jones, 2000). This paper is based upon evidence from a user-controlled Best Value Review of
Direct Payments (BVD) in Wiltshire. It explores, from disabled people's perspective, the advantages and disadvantages of Direct Payments, and demonstrates the challenges still facing both service users and service providers.


**Country:** Great Britain  
**Keywords:**  
Financial  
Long-term care management  
Personal care

The article discusses the impact of direct payments system on patient care in Great Britain. It is noted that the direct payments system proposal is one of the provisions include in the Health Bill, which is already waiting for the approval from the House of Lords. Meanwhile, a consultant nurse at Ealing Primary Care Trust Linda Nazarko commented that the proposal can empower patients where they are given real choice.


**Country:** UK  
**Keywords:**  
direct payments  
employment  
independent living policy
This article critically explores and adds to research on the social benefits of self-directed support schemes for disabled people and their families. We argue that, although research to date has defined the benefits of such services within conventional 'cost-benefit' frameworks, this approach has failed to address the more significant challenge to traditional models of welfare and, particularly, the role of users of these schemes as employers. The article begins the process of repositioning understandings of welfare and work with reference to self-directed support services. In so doing we argue that future research and policy should be based on a more thorough analysis of the less acknowledged socio-economic costs and benefits of these developments for users, their families, personal assistants and local/national economies.


**Country:** UK

**Subject Terms:**
- POLITICAL action committees
- SOCIAL movements
- SOCIAL change
- LIFESTYLES
- POLITICAL activists
- POLITICAL participation

After years of activism by disabled
people's organizations, the Community Care (Direct Payments) Act 1996 made Direct Payment (DP) schemes a reality. Proponents of DP argue that it allows greater freedom and control for those people using it, but as these programmes only came into effect in 1997, few studies have tried to substantiate these claims. This paper reports on a two-year evaluation of two DP schemes in Wales. Using primarily users' feedback the paper focuses on the effects of DP and difficulties encountered, as well as why people chose--or did not choose--DP in the first place. User responses indicate a broad range of beneficial outcomes, including improved self-esteem, increased control over lives, deeper and more lasting relationships, and new interpersonal, vocational and lifestyle opportunities, as a result of the greater flexibility and freedom of choice enabled by DP. Family carers expressed similar satisfaction with DP schemes, also citing greater freedoms as a result of increased flexibility. While some potential users expressed concern over the administration of a DP scheme, users found that, with support from a user driven Independent Living Scheme, the administrative burden was manageable, and that ultimately the DP scheme was a welcome approach to support.

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<td>We describe research done in the London Borough of Tower Hamlets under the supervision of the local Coalition of Disabled People. It involved three different client groups - people with learning difficulties, mental health service users and those with physical disabilities. Few of these service users, their carers and staff had any experience or knowledge of people with disabilities receiving cash to purchase their own support. The study focused on several issues: how to provide effective information; what sorts of support could direct payments purchase; how could it be accessed; how could users handle the money; how could it all be evaluated? Most carers, staff and users considered this radical idea favourably, but were suspicious of their own local authority and would want independent systems of supervision and monitoring, accountable to other users, rather than professionals.</td>
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<td><strong>Subject Terms:</strong> PEOPLE with disabilities, MENTAL health services, DISABILITIES, PAYMENT systems, MEDICAL care.</td>
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The article reports on the results of a study conducted by the British Audit Commission on the administrative costs of direct payments in Great Britain. It has been found that for all 10 of the councils who provided the information, direct payments cost them more than they saved. Tim Hind, an adviser to the Local Government Association, comments on the high administrative costs of direct payments. Based on the study, the only way councils can make savings overall is to make the value of direct payments lower than the sums they pay to providers for equivalent levels of support.
|---|---|

**Country:** UK  
**Subject Terms:**  
- HOME care services -- Prospective payment  
- PEOPLE with disabilities -- Home care  
- MEDICAL personnel & patient MEDICAL care

This paper draws on interviews with users of direct payments and focus group discussions with the personal assistants (PAs) who assist them with personal and daily living activities. It discusses the benefits and the drawbacks of directly employing such assistance, from the perspectives of both the purchasers and the providers of these services. The paper shows that direct payments can enable disabled people to purchase a much wider range of flexible help, better continuity, greater control and an enhanced quality of life, compared with conventional services. PAs also valued the trust and close relationships they developed with their employers. However, these benefits were much less marked when direct payment users recruited and employed personal assistants through care agencies. On the other hand, both direct payment users and PAs also sometimes
experienced difficulties in managing the relationships between them. Some of these problems could be alleviated by changes in the support provided by direct payment schemes themselves; other difficulties were more intractable and arose from the nature of the work and the close relationships which it entailed. The paper recommends a number of measures which could reduce the risks and vulnerability of both disabled direct payment users and personal assistants, without reducing the enhanced quality of life which direct payments can confer.

**Country: Great Britain**

**Subject Terms:**
- PAYMENT
- SOCIAL service utilization
- PEOPLE with disabilities
- LEARNING disabled
- MENTALLY ill

Focuses on a report published in 2004 which found the low number of people using direct payments for social service in Great Britain. Use of direct payments by people with physical disabilities; Publication of guides aimed at increasing the number of people with learning difficulties using direct payments; Problem faced by older people with the use of direct payments; Reason
The article discusses the relationship of direct payments and fraud. Some may encourage the use of direct payments provided that an adequate level of support and procedures are available to protect from accusations of unlawful use of public money. Though direct payments give service users control and responsibility, enforcement and financial audit follow serious concerns over financial mismanagement. It is argued that the ability to purchase services must be underpinned by legislation.

**Country:** England  
**Subject Terms:** ACCOUNTING, TRANSFER payments, FRAUD, INVESTMENT of public funds, FINANCIAL management

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The article discusses the relationship of direct payments and fraud. Some may encourage the use of direct payments provided that an adequate level of support and procedures are available to protect from accusations of unlawful use of public money. Though direct payments give service users control and responsibility, enforcement and financial audit follow serious concerns over financial mismanagement. It is argued that the ability to purchase services must be underpinned by legislation.

**Country:** Great Britain  
**Subject Terms:**


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**Country:** England  
**Subject Terms:** ACCOUNTING, TRANSFER payments, FRAUD, INVESTMENT of public funds, FINANCIAL management

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**Country:** Great Britain  
**Subject Terms:**
Background The aim of this paper is to investigate the role parents are playing in direct payments provision for their son or daughter with intellectual disabilities. Materials and methods The paper draws on a UK-wide inclusive research project, carried out by researchers who were members of an organization of people with intellectual disabilities. The purpose of the project as a whole was to explore what support works best for people with intellectual disabilities to access direct payments provision in the UK, and one of the key supports for certain people was found to be parents and families. Results Drawing on interviews with 29 family carers, the researchers found that parents were often strong advocates of independence for their son or daughter, and only acted as barriers to direct payments when they did not have sufficient information. Parents were found to be playing significant roles as initiators, managers and supporters of direct payments for their son or daughter; however, these roles were matched by important gains in quality of life and relationships within the family. Conclusions The paper considers the implications of the power balance
between persons with intellectual disabilities, their parents and their staff. Direct payments can alter that balance radically, but it is still important to have a good, independent direct payments support scheme to enable the person with intellectual disabilities to be in control.


**Country: Great Britain**

**Subject Terms:**
- SOCIAL workers
- YOUNG women
- PUBLIC welfare
- LONG-term care facilities
- MEDICAL care, Cost of

The article presents the views of a social worker and a service user on a case involving a young woman with profound learning and physical disabilities in Great Britain. Social worker Ginny Moodie states that health funding can be paid into a user-controlled trust or managed by the local authority and used as a direct payment. Disability writer Simon Heng states that in the rush to continue to live in the community some of the practicalities of direct payment has been overlooked.
**Author-Supplied Keywords:**  
Community care  
empowerment  
independent living  
quasi-markets  
The Community Care (Direct Payments) Act 1996 enables local authorities to make cash payments to service users with physical and sensory impairments and learning difficulties under the age of 65. This gives users control over money spent on meeting their community care needs, rather than receiving services arranged for them by the local authority. The policy is often represented as a victory for the disability movement and as a push towards user empowerment and social justice. However, direct payments also need to be understood as part of a wider market discourse prominent in the restructuring of welfare. Therefore, a growing culture of localized care markets with increasing ideological diversity may ultimately erode its scope for a meaningful level of user empowerment. By examining these market and social justice discourses, this article draws on analysis of two local authority approaches to direct payments and examines the level of meanings of control. |
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<td>Direct payment*</td>
<td>Concannon, L. (2006). Inclusion or control? commissioning and</td>
<td><strong>Country:</strong> UK</td>
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| Academic Search Complete | contracting services for people with learning disabilities. *British Journal of Learning Disabilities, 34*(4), 200-205. | **Author-Supplied Keywords:**  
Commissioning and contracting  
direct payments  
new public management  
social work  

Accessible summary • The rise of new public management has seen the role of the social worker becoming increasingly administrative and less about face to face contact with service users. • When commissioning managers seek to help people with learning disabilities plan their services, who actually makes the decisions? • Direct payments are proposed as the answer for people with learning disabilities to take the lead, but is this a real shift in power from managers to service users? This paper examines what commissioning and contracting means for people with learning disabilities. It asks if the voices of service users are heard when it comes to planning their services and, more significantly, are their choices respected and acted upon by commissioners? The government believes the introduction of direct payments will change the way social care is administered, by placing both the decision-making and funding, firmly in the hands of people with learning disabilities. However, the question remains as to how far this can be successful, considering the complicated administration and |
financial processes involved. The paper explores new ground in terms of research by investigating the effects that new public management, in the form of commissioning and contracting, has on the lives of people with learning disabilities. It looks at the relationship between the service user, care manager and commissioner, and asks whether management structures help individuals or actually create further barriers to participation and inclusion. This paper seeks to critically assess the impact made by the introduction of commissioning and contracting as a new culture of social care in learning disability services. It offers an evaluation of the growth in importance of the user as consumer. Does the commissioning and the contract process give users with learning disabilities a greater influence over their services and ultimately their lives? It is suggested that far from empowering people with learning disabilities to have a say in the services they want, the emerging culture of business contracts and new public management transfers power firmly back into the hands of professionals making the decisions. Social work practice is changing in response to major shifts in social trends and at the behest of market values. Traditional models are being rejected and the challenge for social work is to adapt itself to operate within a competency
The paper argues that at the centre of this new culture is a government use of a system of performance management that successfully drives down cost. Thus there remain contradictions between the adoption of a mixed economy of care; services planning; consumerism; resource constraints; and the communication difficulties experienced by many people with learning disabilities.

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<th>Year</th>
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<th>Author-Supplied Keywords</th>
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<tr>
<td>Jones, K., &amp; Netten, A.</td>
<td>The costs of change: a case study of the process of implementing individual budgets across pilot local authorities in England.</td>
<td>2010</td>
<td>Health &amp; Social Care in the Community</td>
<td>18(1)</td>
<td>51-58</td>
<td>England</td>
<td>choice, costs, independence, individual budgets, personalisation, self-directed support</td>
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Individual budgets form a key element in the objective of the English Government to promote independence among people with needs for social care support. The initiative was designed to provide greater user control but the wider consequences, in terms of the implications for local authorities and their other responsibilities, remain to be addressed. An evaluation of the implementation of individual budgets in 13 local authorities was funded by
the Department of Health, using a mixed methods approach to explore the impact of individual budgets both in terms of service user experiences and the implications for the local authority social services. One aspect of the evaluation concentrated on the cost implications of implementing individual budgets for the local authorities. All pilot local authorities were invited to take part in an interview designed to obtain the resources required to implement individual budget. Twelve of the 13 local authorities were part of the study reported in this article. All quantitative analysis was carried out using SPSS 13. Excluding all expenses that might be at least in part associated with the pilot process, in the first year, the estimated mean average cost was £290 000 (median £270 000). This article will describe the initial approach adopted in estimating set-up costs, followed by a description of the findings for the first year of implementation and likely subsequent set-up costs. We also identify the range of factors that might affect reported costs.

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<td><strong>Subject Terms:</strong></td>
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<td>BUDGET CAREGIVERS CARE of people QUALITY of life</td>
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The article reports on the introduction of individual or personal budgets in adult social care in Great Britain. It states that this effort was set out as a shared commitment in the Putting People First Concordat of December 2007. It notes that through individual budgets, carers will be able to improve the quality of their life and will be able to have more control and flexibility in their daily routines. According to some carers, individual budgets also improved the quality of life of those people that they were looking after.


Country: England

Subject Terms:
- COST control
- HEALTH
- FINANCE
- LEARNING disabilities
- PEOPLE with mental disabilities -- Care

The article reports on the concern by leading learning disability organizations on the use of individual budgets by local authorities as a cloak to disguise a cost-cutting drive in England. It is said that the fears of the Learning Disability Coalition emerged in its
response to a Department of Health-commissioned report on individual budgets. According to Care services minister Phil Hope, individual budgets can put people back in control of their own care and give them a better quality of life.

|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country: The UK               | **Author-Supplied Keywords:** Disabled People's Movement personalisation self-assessment self-directed support social work  
In recent years, self-assessment and self-directed support have become mainstream options within disability services. The Disabled People's Movement has advocated the need for such change for a long time but this has been persistently resisted by many social workers. In this article, it will be argued that both self-assessment and self-directed support undermine traditional social work and that social workers need to begin to work alongside disabled people, rather than 'for' disabled people, in order to achieve substantial system change. |

|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country: England              | **Author-Supplied Keywords:** citizenship disability  
In recent years, self-assessment and self-directed support have become mainstream options within disability services. The Disabled People's Movement has advocated the need for such change for a long time but this has been persistently resisted by many social workers. In this article, it will be argued that both self-assessment and self-directed support undermine traditional social work and that social workers need to begin to work alongside disabled people, rather than 'for' disabled people, in order to achieve substantial system change. |
Personalisation is a new term that is being used in different ways. Often it is used as a shorthand for a range of new forms of practice, or technologies. These new technologies include direct payments, self-directed support, individual budgets and person-centred planning. The values which underpin these technologies have developed from the experiences of disabled people, but these values are not well represented in theories of social justice. This paper describes a new theory, a Citizenship Theory of social justice, that is based on two fundamental moral beliefs: (a) the equal dignity of all human beings; and (b) the positive value of human diversity and difference. Developing this theory of social justice leads to an inclusive model of citizenship and an imperative to organise society so that everyone can become a citizen. Social workers could see personalisation as an externally imposed dogma, but this will lead to defensiveness, resistance and cynicism. However the profession could instead embrace the technologies of personalisation, and the Citizenship Theory that should underpin it. It is this second path that will lead to critical engagement and the practical use and
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<td>Ebsco Host-Academic Search Complete</td>
<td>Personalisation AND Disability</td>
<td>Jukes, M. (2010)</td>
<td>Prepared for personalisation?. <em>Learning Disability Practice</em>, 13(4), 9.</td>
<td>Great Britain</td>
<td><em>NURSES</em> <em>LEARNING disabled</em> <em>MEDICAL care</em> <em>NURSING</em></td>
<td>The author explains why learning disability nurses in Great Britain should need to focus on health services and on developing specialist competencies. One of the major priorities of the Department of Health's Valuing People Now strategy is personalization. As personalized services become mainstream, the role of learning disability nurses can be applied in a variety of specialist settings.</td>
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<tr>
<td>Ebsco Host-Academic Search Complete</td>
<td>Personalisation AND Disability</td>
<td>Rogers, P. (2010)</td>
<td>Helping my daughter to buy her own home. <em>Learning Disability Practice</em>, 13(4), 34-37.</td>
<td>England</td>
<td></td>
<td>A personal narrative is presented which explores the author's experience on how...</td>
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she helped her daughter who has a learning disability purchase a house under a shared-ownership scheme in England.

**Country:** UK

**Author-Supplied Keywords:**
- autonomy
- choice
- control
- friendly
- institutional asymmetry
- learning disability
- personalisation

Personalisation is the new mantra in social care; this article focuses on how personalisation can be achieved in practice, by presenting an analysis of data from people with learning disabilities and their personal assistants (PAs), where traditional care relationships have often been shown to be disempowering (Antaki et al., 2007b). The focus here is on the ways in which both parties use references to shared knowledge, joint experiences or personal-life information. These strategies can be used for various social goals, and instances are given where shared references are used during non-task-related talk. Both parties are seen on occasion to attempt to refer to shared information, and dense layers of inference can result, which move the interaction onto an ordinary, more
Subject Terms:  
*LEARNING disabled  
*FINANCIAL aid  
*BUDGETS, Personal  
The article reports on the developments in the area of funding for people with learning disabilities in Great Britain in 2010. It cites the local authority circular issued by the Labour government, which mandates local authorities to introduce their personal budgets by April 2010. It presents the 2007 Social Care Institute for Excellence (SCIE) report on the Individual Budgets Evaluation Network, which was amended in 2009. According to SCIE's Sarah Carr, the individual's budgets were used in innovative ways. |
Author-Supplied Keywords: |
Mental illness is the country's leading cause of disability. However, approximately 60 percent of individuals with serious mental illness (SMI) are not receiving stable, ongoing treatment (Carper, 2005). One approach to combat this problem is to actively involve consumers in their treatment. Personal assistance services (PAS) assist individuals with disabilities with their daily living activities, and some, such as cash and counseling (C&C), empower individuals to make their own treatment decisions. Self-directed care programs have recently adapted from C&C programs targeting individuals with physical disabilities to models targeting individuals with SMI. The purpose of this article is to examine the effectiveness of these programs, explore their impact on individuals with SMI, and discuss the role of social workers in this new service delivery approach.


**Country:** USA

**Subject Terms:**
*PEOPLE with disabilities -- Housing

The last three decades of
deinstitutionalization have not fulfilled their promise of creating full lives in inclusive communities for persons with intellectual disabilities. There are too many adults still living with their aging parents, or in regimented group homes that seem like nothing more than smaller versions of the institutions they left. The recent initiatives for self-determination and self-directed services hope to restructure our approach to providing support and thereby finally fulfill the promise of building inclusive communities. This paper provides an informal case study of how one young man and his family have benefited from this move to self-directed services. We tell the story of Ian Ferguson moving into a home of his own. As part of that story, we describe two support strategies that have emerged as crucial to the success of his living a life on his own. We describe the Personal Support Agent (PSA) and Community Service Brokerage (CSB), connect them with the principles of self-determination and report how they have actually been applied in Ian's life.

Ebsco Host-Academic Search Complete

Cash and counseling AND Disability


**Country:** USA

**Subject Terms:**
*OLDER people -- Care
*LONG-term care of the sick
*DEVELOPMENTALLY disabled
*PEOPLE with mental
Person-directed service models have emerged as important initiatives in improving long-term care. Person-directed services typically have been targeted to particular groups, such as persons with mobility or developmental disabilities or elders with disability. Few attempts have been made to analyze the commonalities, differences, and relative efficacy of the various models. This article presents a cross-disability review of the common elements of person-directed services, describes three primary types of models (personal assistance services, brokered support, and cash and counseling), and summarizes the research evidence related to their efficacy. The major barriers that impede the expansion of person-directed services are discussed. Emerging research findings across disability groups suggest that person-directed services have a positive impact on factors such as quality of life, control, productivity, unmet need, use of preventative health care, and cost. The need to build the evidence base for person-directed services, to address barriers to the expansion of these service models, to support advocacy efforts, and to bolster the political will required for directing substantial resources to person-directed long-term services is emphasized.
Informal family assistance is often a key factor in determining whether a person with a disability can live in a community setting. However, the practice of paying relatives as caregivers remains controversial. This article reports findings from the Cash and Counseling Demonstration and Evaluation (CCDE) in Arkansas, in which consumers receive a cash allowance to purchase personal assistance services. In this comparison of consumers who hired family vs. non-family workers, consumers who hired relatives received more service and had equal or superior satisfaction and health outcomes, as compared to those who hired non-relatives. Findings are further clarified by drawing from worker focus group reports and program experience, and policy issues are specifically addressed.
Subject Terms:  
*DEVELOPMENTALLY disabled children  
*DEVELOPMENTALLY disabled  
*PEOPLE with disabilities -- Services for  
*DEVELOPMENTAL disabilities  
*HEALTH services administration  
Traditional personal assistance programs often lack a significant consumer-direction focus that allows or encourages consumers to be in charge of their services. Independent evaluations of the Cash and Counseling Demonstration and Evaluation (CCDE) project are comparing costs of, quality of, and satisfaction with traditional personal care services versus consumer-directed cash benefit and information services. Because the disability community is composed of diverse subgroups, each group having with its own needs and concerns, the interests of each of these various populations should be assessed. This article presents the results of a telephone survey conducted in Florida as background research for the CCDE project to assess the interest in a cash option among families of children and adolescents with developmental disabilities. The findings indicate |
overall high levels of interest in the cash option, especially among individuals who were willing to pay a worker directly, persons who desired more involvement with services, and consumers dissatisfied with the current services. The authors of this article also include suggestions regarding how to communicate with families when informing them of such an option.


Country: UK/Canada

Subjects:
- Disabilities
- Reimbursement
- Social workers

This article examines the link between a justice and rights discourse and disability policy and practice. Specifically, it considers social worker responses to direct payments, a policy which has been linked to a discourse of social justice and rights. The article initially considers the nature of justice and rights, arguing that these can plausibly be seen to be grounded in the idea of autonomy and that a rights or justice-based social policy and practice must be grounded in the protection, enhancement, and development of the capacity for autonomous action. The article then presents partial findings of a research project, which sampled social workers' views and attitudes towards direct payments in three local authorities. The findings suggest that
Social workers are aware of the link between direct payments and autonomy and are generally very supportive of the move to a rights-based approach to policy and practice as evidenced by programs such as direct payments. The paper also concludes that structural constraints limit social workers' ability to fully function from a rights-based approach to disability.

|----------------------------------|----------------|----------------------------------------------------------------------------------------------------------------------------------|

Country: UK

Subjects:
- Social workers
- Social care
- Independent living

Despite learning about the social model of disability in social work training, it is difficult to see how new workers can apply this model in practice in a care management system that seems so service-led rather than needs-led. Against this background, the advent of direct payments is a major opportunity to promote choice, control and independent living at the heart of 21st century social care. While direct payments can seem like a challenge to the role and professional expertise of qualified social workers, they are a unique chance to deliver genuine empowerment and person-centered, needs-led approaches in a system that all too often does not let its workers strive to achieve these goals.

<table>
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<tr>
<th>Ebsco Host-</th>
<th>Direct payment*</th>
<th>Cambridge, P. P. (2008). The case for a new 'case' management</th>
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Country: Britain
| Subjects: | Case management  
Learning disabilities |
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<td>Micro-organization is currently fragmented in services for people with learning disabilities. Care management, person-centred planning (PCP) and direct payments have developed through separate policy strands, with tasks and agency responsibilities blurred. A wide diversity of care management arrangements currently operate, with the relationship between care management, PCP and direct payments imprecisely defined. PCP and direct payments have also been variably implemented. This paper argues for a new 'person-centred case management,' with these different devices better integrated and decision-making and action more person-centred. Drawing on practice experience from the original British case management experiments, the new 'case' management would be centred on the needs and wants of individuals, be conducted independently from assessment, operate outside the public sector and be able to access personal budgets. It would consequently have the capacity to further de-institutionalize services and support and transfer more control to people with learning disabilities.</td>
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Within the context of modernization, there has been a trend towards "cash-for-care" schemes designed to bring choice and control closer to the service user. In England, Individual Budgets (IBs) are being piloted, with the aim of promoting personalized support for disabled people and other users of social care services. This study reports on the experiences and outcomes of early IB users two to three months after first being offered an IB. The users included adults with physical/sensory impairments, learning difficulties, mental health problems and older people. Semi-structured interviews were carried out with nine service users and five proxies. The findings suggest that IBs have the potential to be innovative and life-enhancing. However, achieving this potential in practice depends on a range of other factors, including changes in the routine practices and organizational culture of adult social care services and ensuring users have access to appropriate documentation and support. Any conclusions drawn from the experiences of these early IB users must be treated with caution. The findings nevertheless indicate some of...
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<td>UBC library</td>
<td>Individualized funding</td>
<td>Individualized Funding for people with developmental disabilities experienced increases in community integration and monthly wage.</td>
<td>Canada</td>
<td>individualized funding, Individualized Coalition of Ontario facilitators</td>
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In the current study we examined the impact of family support programs for adults with developmental disabilities. Results of the study indicated that participants had fewer unmet needs and used more services than the control group. Participant caregivers were more satisfied with the services their relative received, experienced greater self-efficacy, and were less likely to desire an out-of-home placement than the control group. Participants with developmental disabilities experienced increases in community integration and monthly wage.
Increasingly being seen as valuable for self-determination and inclusion. Recently, the Individualized Coalition of Ontario commissioned a study to explore the practice of individualized funding. The researchers examined 130 files of people receiving individualized funding and interviewed 18 families. The results showed that people with individualized funding experienced positive outcomes. The support plan provided a foundation for building a good life. Facilitators played a major role in assisting people with planning and network development. Individuals and families generally received less funding than they requested and funding often came from multiple government sources. Although families were generally very satisfied with individualized funding, they raised a number of concerns.


**Executive Summary**
We have completed our assessment of the Ministry of Children and Family Development's (the ministry) ability to respond to the following selected risks associated with the Interim Early Intensive |
Intervention (IEII) and Extended Autism Intervention (EAI) programs:
- some families may lack the capacity to manage funds and/or treatment;
- expectations for the ministry and families may not be clear; and
- some families might misuse program funding.

We found that many families are experiencing difficulty with these individualized funding programs. Regional staff advised that most parents are not complying with the programs' accountability requirements, and social workers are experiencing an overwhelming volume of questions from parents. In our view, the ministry is not well positioned to address the risk that families may lack the capacity to manage individualized funding. The regions advised us they are unable to administer the programs as intended, due to a lack of resources, so families are not receiving the ongoing feedback and assistance needed to manage the program successfully. There are few supports available to build family capacity, and also very limited programming options for families who do not have the capacity to manage individualized funding. In our opinion, the ministry needs to more clearly communicate
The program materials were consistently faulted for not communicating program expectations effectively, particularly parents' responsibility to develop and manage treatment plans for their children. There are limited resources available to parents seeking information on these matters, and regions are not able to respond to the volume of inquiries from parents.

**Country: USA**

Discussion of the dynamics of individualized funding for providing services to people with developmental disabilities focuses on how individual funding may drive the changes necessary to develop services that offer highly customized assistance. This discussion considers why the concept of paying customers is powerful but misleading in light of such realities as the mismatch between what is wanted and what is offered, the lack of competition in the market for developmental disability services, and the need for customized services to be provided not at a single point but over long periods of time as people's requirements change. It suggests that what is needed is a market that stimulates innovation. Policymakers are urged to harness three interlocking processes: variation (many agents...
pursue different strategies in a shared environment); interaction (agents create exchanges, make use of things, and inform themselves about other agents' strategies; and selection (of some strategies over others). The paper suggests that a system with the best chance of continuing adaptability and success must have: (1) lots of agents; (2) some connections among agents; and (3) willingness and ability to try and tell. Policies and structures are judged by the criterion of whether, over time, people with disabilities and their families are more able to act as agents in customizing the assistance they require.

Country: Canada

The purpose of this study was to explore the intricacies involved in creating safe, effective, individualized services for people with developmental disabilities. Community Living British Columbia (CLBC) has adopted a new approach where people with developmental disabilities receive individualized funding to purchase or create the support services they require. Community Living Victoria (CLV) is one of the first service providers to become a host agency which enables CLV to receive and disperse individualized funds to qualified care providers on behalf of the individual.
CLV is committed to promoting full citizenship and inclusion for people with developmental disabilities along with their families, and has altered its service methods to adapt to this paradigm shift within the community living sector. This project has determined how to deliver these services, while ensuring all safeguards are in place in order to assist people with disabilities and their families create the supports they require.

|-----------------------------|-------------------------------------------------------------------------------------------------------------------------|

Country: England

Country: Canada

The purpose of this report is to highlight and analyze the existing models of individualized funding (IF) and individually funded services (IFS). IF/IFS models are examples of disability supports designed to help people with disabilities overcome societal and individual barriers or limitations so that they are able to carry out their daily activities and fulfill their daily needs. The IF/IFS models from other jurisdictions discussed in this report vary in the length of their implementation and in the number of users each program serves. Overall, the purpose of IF/IFS models is to bring to the table an alternative way of distributing monies to people with disabilities to meet their disability-related needs.

Individualized funding has four
principles:
1) Individuals can use informal and formal support networks to develop their plans.
2) Funding allows individuals to purchase supports and services.
3) Individuals must have control over the funds.
4) Funding must be portable within jurisdictions.

Country: Canada
Self-Directed funding models provide public funds to individuals with intellectual disabilities to help them fulfil their unmet needs and allow them to reach their goals. SDF is based on principles of self-determination, choice, and equality. In a more functional sense, SDF allows persons with disabilities to choose and purchase which programs and services will support them. With these principles in mind, this report seeks to examine the complexities, challenges, and strengths associated with SDF models.

The literature review and interviews focus on:
- sustainability of SDF
- accountability measures related to the allocation of funds, including the design of appropriate reporting requirements
- quality and risk management to ensure
clients’ funds are managed properly
• labour market and staffing issues related to the availability and retention of personal support workers
• equity among different user groups

**Key words:**  
Personalisation  
autonomy  
independence  
care relationships  
direct payments  
personal assistants  
homecare  

The personalisation of adult social care has the potential to create support that is individualised, and it is the reality of this support relationship that forms the basis of this article. To date, there have been few studies that focus on the association between care users and their workers. Here, we consider research from a Ph.D. study that allows for comparison between two sets of relationships: between disabled adults and homecare workers employed by a local authority, and between disabled adults using direct payments to employ their own personal assistants. The research pays attention to the meanings attached to the concepts of... |
independence and autonomy, with a model of autonomy applied to aid clarity and develop our understanding of complexities in support relationships. The research uses a grounded theory approach with qualitative interviews of matched samples of respondents, providing new evidence about the personalised relationship. Based on the research, we argue that direct employment of support workers appears to facilitate greater autonomy for disabled adults than traditional homecare relationships. However, the research goes on to suggest that greater autonomy for disabled adults may have a downside for support workers.


Three research teams collaborated to carry out a UK-wide survey of direct payments. One team came from the Personal Social Services Research Unit at the London School of Economics; another from the Universities of Leeds, Edinburgh and Glasgow; and a third team from the Health and Social Care Advisory Service, the Foundation for People with Learning Disabilities at the Mental
States are struggling with extraordinary budget deficits. In some states, major budget shortfalls are leading to serious consideration of large cuts in programs and services, including participant direction. To respond to this reality, the National Resource Center for Participant-Directed Services (NRCPDS) has worked with state partners, advocates, and program participants to identify key budget concerns that put participant direction at risk. This Toolkit is intended to serve as a resource for informing decision-making during these difficult times. |
| http://www.individualizedfunding.ca/resources.html | Received from Individualized Funding Coalition for Ontario website under Resources | Individualized Funding Coalition for Ontario (2007). *Transformation of Developmental Services: Expanding the Possibilities for Citizenship*. | Country: Canada
A Signature Paper developed by the Individualized Funding Coalition for Ontario. This document is a synthesis of many of the writings produced by the |
Individualized Funding Coalition for Ontario on the subject of Individualized Funding and Independent Planning and Facilitation.

Across Canada, people with disabilities, their families, friends and others -- those in their personal networks -- as well as People First, family groups, forward-thinking agencies and even governments are actively promoting citizenship and the transformation of systems and services for people with disabilities.

The cry for change at this time in history is for people with disabilities to be able to live their lives as full citizens with the supports they need. Experiencing a good life means not being dependant on systems built on decades old principles. It means changing things for the better. We know so much more in the year 2007 than we did fifty years ago at the onset of a service system that was developed to support people with disabilities. We know that it is possible for people with disabilities to direct their own lives, often with the assistance of family, friends and others. We know that individualized funding and supports like independent planning and facilitation and network development -- building and maintaining relationships with family, friends and others -- moves us closer to empowerment for all citizens. This new knowledge and
This report discusses the need to provide people with disabilities with accessible opportunities for community contribution and to provide the individualized supports and assistance necessary to enable their participation. Two strategies are discussed for realizing these objectives: adequate individual funding controlled by people with disabilities and their families and friends; and a process of culture change through community engagement. Two models of the community engagement process are presented that directly involve more people and associations and promote higher levels of organization among people with disabilities and their families and friends. Possibilities for action are described and include: (1) create more family groups; (2) support leadership actions that are needed form the essence of this paper.

| Country: USA |
| Descriptors/Keywords: Accessibility (for Disabled); Adults; Advocacy; Attitude Change; Community Involvement; Community Programs; Community Support; Depleted Resources; Disabilities; Financial Needs; Independent Living; Models; Political Power; Resource Allocation |

The article reports on research on the variable take-up of direct payments. Direct payments offer huge potential for people with learning disabilities, but implementation has been patchy. Care managers are crucial to getting more people on to direct payments, but many feel ill-equipped to help people take advantage of direct payments, and also doubt their usefulness, either to their clients or to the development of services. Creative solutions, such as an active peer-support group and using circles of support or trusts, coupled with user-friendly systems backed up with training and managerial support, can result in greater take-up and more success stories.
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<td>Received from Individualized Funding Coalition for Ontario website under Resources</td>
<td>Individualized Funding Coalition for Ontario (2006). <em>Rationale for Independent Planning and Facilitation in Ontario Why MCSS Should Move Quickly to Implementation</em>.</td>
<td><strong>Country: Canada</strong> This document details why Ontario should provide Planning and Facilitation that is independent of service provision. Independent planning and facilitation that provides ongoing support for people with disabilities, their families and support networks over time is most important. This is a key component of individualized funding. This information is incorporated in the Signature Paper, however this document provides detailed rationale. Individualized Funding Coalition for Ontario. November 2006</td>
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<td>Received from Individualized Funding Coalition for Ontario website under Resources</td>
<td>Family Alliance Ontario, The Individualized Funding Coalition for Ontario, People First of Ontario, &amp; Special Services at Home Provincial Coalition. (2005). <em>Common Vision Newsletters, Part One and Part Two</em>.</td>
<td><strong>Country: Canada</strong> Two comprehensive Newsletters that reflect agreement through the ‘common vision’ of four provincial organizations with regards to transformation of developmental services in Ontario.</td>
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<td>Lord, J. (2006). <em>Moving Toward Citizenship: A Study of Individualized Funding in Ontario</em>. Individualized Funding Coalition for Ontario.</td>
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<td><a href="http://www.individualizedfunding.ca/resources.html">http://www.individualizedfunding.ca/resources.html</a></td>
<td>Received from Individualized Funding Coalition for Ontario website under Resources</td>
<td>Lord, J. (2000). <em>More Choice and Control for People with Disabilities Review of Individualized Funding</em>. Ontario Federation for Cerebral Palsy.</td>
<td>Country: Canada</td>
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<td>URL</td>
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<td>Video and offsite link: <a href="http://www.nc-ddc.org/video/self-determination-complete.html">http://www.nc-ddc.org/video/self-determination-complete.html</a></td>
<td>Developmental/Intellectual disabilities Search term used: Self determination</td>
<td>Twelve voices define self determination and the challenges it faces with current attitudes and policies toward individuals with disabilities who want to take charge of their own lives. View five segments of the 16 minute video, view the complete video, or contact the Council for your own DVD copy.</td>
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<td><a href="http://www.centerforself-determination.com/sd.html">http://www.centerforself-determination.com/sd.html</a></td>
<td>Received from the Centre for Self-Determination website Search process: Resources, Articles, and then Self-Determination</td>
<td>Nerney, T. &amp; Harris, K. <em>Center for Self-Determination Policy Analysis of New Jersey's Self-Determination Effort.</em> Country: USA The meaning of self-determination since its inception a decade ago has always rested on a set of principles: Freedom, Authority, Support, Responsibility and now Confirmation of the important role that individuals with disabilities must play in the development of this movement. In this ten-year time frame our understanding of self-determination has deepened and broadened. New and highly relevant issues surface as more and more individuals in states across the country begin to implement self-determination for themselves, and issues surface as well for the systems that are the stewards of public funds. Just as individuals with disabilities and families have taught us so much as they gain control of the funding, so, too, have we learned about the systems change elements that make the goal of self-determination more attainable.</td>
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| http://www.cent erforself-determination.c om/sd.html | Received from the Centre for Self-Determination website  
**Search process:** Resources, Articles, and then Self-Determination | Nerney, T. *Communicating Self-Determination: Freedom, Authority, Support and Responsibility.*  
**Country:** USA  
With the vast extension of self-determination projects across the country and the wide adoption of the principles of self-determination, it may be helpful to step back for a moment and reflect on what we have learned thus far about some of the technical and structural issues associated with truly successful individual budgets, support brokering and fiscal intermediaries. Not every issue is yet crystal clear and it is anticipated that some ambiguity may remain especially in those projects that are still experimenting with systems change. |
| | | Nerney, T., Crowley, R., & Kappel, B. *An Affirmation of Community: A Revolution of Vision and Goals Creating a Community to Support All People Including those with Disabilities.*  
**Country:** USA  
Maybe it is the times, or maybe it is the fact that we have had some time to examine how it is that we interact with and support children and adults with disabilities in communities. Or maybe it is simply that people with disabilities are sick and tired of being controlled by others. Whatever the reason, self-determination has emerged as the agenda of the 90's. As Bob Williams says: "Self-determination is just another word for freedom." Freedom to live with whom you want, freedom to live a productive life, freedom to attend school with your friends and brothers and sisters, freedom to get around your community, freedom to love and reject. |
| http://www.centerforselfdetermination.com/new.html | Received from the Centre for Self-Determination website  
Search process: Resources, Articles, and then New Articles | Nerney, T. *The Purpose of Public Funding for Individuals with Disabilities*. Centre for Self-Determination. | **Country:** USA  
The failure of public policy to adequately address the issue of the common humanity of individuals with disabilities has resulted in the substitution of human services and human service environments and programs for real life and high purpose. Individuals with disabilities have become human service subjects within a system of long-term supports that has no expectations that common life goals based on universal human aspirations can add great depth to the notion of addressing the health and welfare of individuals with disabilities. |

| http://www.centerforselfdetermination.com/new.html | Received from the Centre for Self-Determination website  
Search process: Resources, Articles, and then New Articles | Nerney, T. *Self-Determination: Individual Coasts, System Costs and Quality of Life*. | **Country:** USA  
Self-Determination is a movement to change long term care by shifting power over resources directly to individuals and their family and allies. As such it requires fundamental structural changes (fiscal management agencies, independent brokering and highly personal budgets) and a leadership commitment that moves the present system from a highly paternalistic and costly one to a system that promotes both freedom and responsibility while achieving better value for the public dollars that are appropriated. |
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**Country: USA**
This first written description of "Self-Determination" was based on a set of *principles*, and in a demonstration of their efficacy, funded by a grant from the Robert Wood Johnson Foundation, targeted a group of individuals with significant brain injury and a group with developmental disabilities beginning in 1993. The principles have remained as a foundation for this effort ever since.

**Country: England**
This paper shares our learning from our work with more than 30 children's services over the past four years. This work has seen 480 individual budgets agreed and put in place, links built with wider work on commissioning and budget holding, and a growing involvement from national children's organisations.

The report is aimed at policy leaders, influential people, managers and directors, as well as those leading work across the whole of the children's world.

This paper is the first of three Briefings to be published by In Control which will describe the organisation’s work and vision for personalisation in the children’s world. The paper does not set out to
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<td>In June, in partnership with Action for Children, we hosted a Round Table discussion on the personalisation agenda for children and how we can take this work forward. Representatives from children's services and other organisations across the country took part in the event.</td>
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<td>We also held a similar discussion with a group of young people at the My Fantastic Life Youth Club in Ely, Cambridgeshire.</td>
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<td>The results of these discussions are shared in this report.</td>
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<td>This paper focuses on our work with families in Newham, with some additional information from work with Middlesbrough children's services. It highlights the positive impact across a range of outcomes for disabled children and includes</td>
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more detailed discussion with families and professionals.

We will be following this paper up with our 'Agenda for Change' for children's services, which will set out the necessary actions for the Government and local children's services, as they move to introduce individual budgets and self-directed support for the children and families they support.

This is the third publication in a series of three briefing papers produced by the In Control Children’s programme. The first sets out how In Control sees personalisation working in practice and highlights work from four years of support to children’s services. The second sets out a Round Table discussion held in June 2010 with additional input from a number of the participants. This, the third report, sets out evaluation work from across our children’s service members, and includes more detailed input from one children’s service, Newham. Together these briefing papers will form the basis of a comprehensive report to be published in January 2011 which
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<td><a href="http://www.in-control.org.uk/releted-pages/publications/the-7-steps.aspx">http://www.in-control.org.uk/releted-pages/publications/the-7-steps.aspx</a></td>
<td>Received from “In Control” website Under: Publications, DVD and Audio, then click “how to be in control DVD” heading, click the 7 steps heading</td>
<td>Youtube videos—No Citation</td>
<td>These videos are taken from the In Control DVD 'How to be in control'. The 7 steps take you along the path towards successfully directing your own support.</td>
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<td><a href="http://www.in-control.org.uk/releted-pages/publications/stories.aspx">http://www.in-control.org.uk/releted-pages/publications/stories.aspx</a></td>
<td>Received from “In Control” website Under: Publications, DVD and Audio, then click “how to be in control DVD” heading, click on stories, and then click on each individual story to link to a Youtube Video</td>
<td>Youtube videos—No Citation</td>
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This book by Caroline Tomlinson offers suggestions about how you can help your relative - son, daughter, husband, wife, partner or friend - to get a better life.
| Source                                                                 | Received from *In Control* website          | Duffy, Simon. *Keys to Citizenship: A guide to getting good support services for people with learning difficulties.* | Simon Duffy's book about how people with learning difficulties can be supported to take their place as citizens (rather than be just the recipients of care) says there are six keys to people getting a good life. These are: self-determination, direction, money, home, support and community life. Simplicity is not about doing less, it’s about doing the right things and doing those things really well. Similarly, the main aim of support is not to make the user’s life easier, it is about helping them to do more of what they want to do, with less difficulty. It’s about self-determination, direction, money, home, support and community life.

A guide to getting good support services for people with learning difficulties. |

| Source                                                                 | Received from “In Control” website Under: Publications, and then Books | Haworth, Kim. (2009). *Self-Directed Support in Lancashire: An Interim Report.* London: in Control Publications. | In this report, Kim Haworth of Lancashire County Council writes about some of the changes that have happened in the Council over the past five years. The report details practical experience of applying In Control's model and gives 'a flavour of some of

| Source                                                                 | Received from “In Control” website Under: Resources, and click Adult Social Care | **Country: England** | In this report, Kim Haworth of Lancashire County Council writes about some of the changes that have happened in the Council over the past five years. The report details practical experience of applying In Control's model and gives 'a flavour of some of
Kim addresses many of the questions local authorities ask as they move from small-scale pilot to Total Transformation.

**Chapters in the Report:**

1. Service users are now Customers
2. People's Personal Budgets
3. Case studies
4. Providers
5. Scaling up.

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Country: England

A guide showing how the local authority can make support planning as easy as possible for people - and how to agree the plan.

A guide showing how the local authority can make support planning as easy as possible for people - and how to agree the plan.
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<td><a href="http://www.in-control.org.uk/resources/adult-social-care/a-menu-based-approach-to-pricing.aspx">http://www.in-control.org.uk/resources/adult-social-care/a-menu-based-approach-to-pricing.aspx</a></td>
<td>Under: Resources, and click Adult Social Care</td>
<td><em>A Menu Based Approach to Pricing</em></td>
<td>This paper is a discussion paper that explores a menu-based approach to providing and pricing services. It gives an example of testing the approach in a day services in Leeds.</td>
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<td><a href="http://www.in-control.org.uk/resources/adult-social-care/self-directed-support,-social-">http://www.in-control.org.uk/resources/adult-social-care/self-directed-support,-social-</a></td>
<td>Under: Resources, and click Adult Social Care</td>
<td>Tyson, A. (2009). <em>Self-Directed Support: Social Workers’ Contribution.</em> London: In Control Publications.</td>
<td>This paper is one in a series from In Control’s Total Transformation Project 4 on social work, one of ten Total Transformation projects. Together these projects will enable</td>
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<td>Progress for Providers: Checking your progress in delivering personalised services. Alternative Futures Group.</td>
<td>Received from “In Control” website Under: Resources, and click Adult Social Care</td>
<td>Simple self assessment tool developed by providers and commissioners to help providers think about their progress in responding to the personalisation agenda. The tool particularly focuses on delivering personalised, individually costed services and individual service funds.</td>
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<td>Market Management: A Guide for Local Authorities on Creating a Local System of Self Directed Support</td>
<td>Received from “In Control” website Under: Resources, and click Adult Social Care</td>
<td>A guide exploring options for the local authority in stimulating creative support responses for people who have an individual budget.</td>
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<td>Duffy, S. &amp; Gillespie, J. (2009). Personalisation &amp; Safeguarding. London: In Control Publication.</td>
<td>Received from “In Control” website Under: Resources, and click Adult Social Care</td>
<td>This discussion paper is primarily focused on the issue of the relationship between personalisation and safeguarding.</td>
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<td>My Staff My Say: Training Instructions Choosing Your Own Staff</td>
<td>Received from “In Control” website</td>
<td>Easy read booklet about Training and choosing your own staff. This book will</td>
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<td>Resource</td>
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<td><a href="http://www.in-control.org.uk/resources/adult-social-care/my-staff-my-say-training-instructions.asp">http://www.in-control.org.uk/resources/adult-social-care/my-staff-my-say-training-instructions.asp</a></td>
<td>Received from “In Control” website</td>
<td>Under: Resources, and click Adult Social Care. My Staff My Say Little Book of Evaluation: Checking if Something is Any Good! Help you to train other people how to choose their own staff. Inside are all of the exercises that you will need with instructions on how to do them.</td>
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<td><a href="http://www.in-control.org.uk/resources/fact-sheets.aspx">http://www.in-control.org.uk/resources/fact-sheets.aspx</a></td>
<td>Received from “In Control” website</td>
<td>Under: Resources, and click Fact Sheets. Click on Each Fact Sheet. A collection of 41 Fact Sheets. <em>Please refer to website to obtain each individual fact sheet</em></td>
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<td><a href="http://www.in-control.org.uk/resources/procedures-guidelines-and-templates.aspx">http://www.in-control.org.uk/resources/procedures-guidelines-and-templates.aspx</a></td>
<td>Received from “In Control” website</td>
<td>Under: Resources, and click Procedures, Guidelines, and templates. A collection of procedures, guidelines and templates that local authorities are able to adapt for their own purposes.</td>
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*Country: England*
John Wheeler, a Signs of Safety Trainer, joined us for the day and led much of the work and discussion about safeguarding. It proved a useful and at times provocative day. There was common assent across the group that there were enough commonalities identified to suggest that both are similar ways of achieving the same goals. Following the workshop John Wheeler and Nic Crosby put down their thoughts on this in the paper available to download below.

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<td><a href="http://www.in-control.org.uk/resources/children-young-people/focus-on-northumberland.aspx">http://www.in-control.org.uk/resources/children-young-people/focus-on-northumberland.aspx</a></td>
<td>Northumberland County Council talks about their experiences of the programme and on implementing self-directed support.</td>
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<td>Received from “In Control” website Under: Resources, and click Children and Young People</td>
<td>Alison Upham, her colleagues, young people and families in Halton have been looking at how they could increase their offer to disabled children in their community through their Aiming High offer. Could small budgets make a difference to the outcomes for young</td>
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<td><a href="http://www.incontrol.org.uk/resources/health/direct-payments-carers-ukpdf.aspx">http://www.incontrol.org.uk/resources/health/direct-payments-carers-ukpdf.aspx</a></td>
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| Source                                                                 | Received from “In Control” website Under: Resources and then click research and evaluations-pg 1 | Peak, M. and Waters, J. (2008). *My Budget My Choice: Implementing Self-Directed Support in the City of London*. In Control Publication. | **Country: England**<br>This report documents work in the City of London that led to people from different social care groups taking control of a personal budget.<br><br>It describes, for example, how a couple who had been married for many years used a personal budget to avoid separation and a move into residential care. |