DEVELOPMENTS IN DIRECT PAYMENTS

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Notes on contributors

Simone Baker is 42 years old and was born with severe shortening of her arms and legs as a consequence of the drug Thalidomide that her mother took during pregnancy to counteract the effects of severe morning sickness. Despite her physical impairment, she describes her life as "fairly normal", having never needed to rely on a huge amount of personal support until she became a parent in 1996. Simone's daughter, Lois, is now aged eight. Simone has used direct payments since 2002, primarily to assist in her parenting role.

Joanna Bornat is Professor of Oral History in the Faculty of Health and Social Care at The Open University, UK. She has a particular interest in biographical and oral history research and has researched and published in this area for some years. She has edited and co-edited collections including: *Reminiscence reviewed: Perspectives, evaluations, achievements* (1993); *Community care: A reader* (1993); *Oral history, health and welfare* (2000); *The turn to biographical methods in social science* (2000); *Understanding health and social care* (2002); *Biographical methods in professional practice* (2004).

Jane Campbell is chair of the Social Care Institute for Excellence (SCIE), a government-funded, independent organisation dedicated to improving the quality of social care across the UK. She became a Commissioner of the Disability Rights Commission at its inception in 2000. Jane has written a number of books on disability issues and speaks at a wide range of conferences and events.

Jeanne Carlin MASW, CQSW has worked as a freelance social work consultant in children's disability services for the past four years. She has written two books on direct payments and delivers training and lectures in this area across the UK. She is also a parent of a disabled young woman with multiple impairments.

Dr Heather Clark is a Reader in Social Gerontology at University College Chichester, UK. She has extensive experience of research with and involving older people and is the lead author of *Going home: Older people leaving hospital*; *'That bit of help': The high value of low level preventative services for older people*; *Piloting choice and control for older people*; and *'It pays dividends': Direct payments and older people.* She is currently a member of the secretariat team to the Older People's Inquiry into 'That Bit of Help' established by the Joseph Rowntree Foundation.

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Christine Erskine trained as a nursery school teacher and raised three children before moving into the commercial world, where she ran a successful sign business before retiring. Christine has always had an empathy with youngsters with learning disabilities and has worked for a local charity in this field.

Margaret Fletcher has been the director of UK operations with the Princess Royal Trust for Carers since September 2003. She has a Bachelor of Social Work degree from the University of New South Wales, Australia, majoring in community development. Margaret has over 25 years' experience working in the health, social services and voluntary sectors in Australia and the UK.

Jackie Gelling is a nurse, and she met her husband, Colin, when they were both in the army, over 38 years ago. They have three grown-up children, who now have children of their own. Jackie and Colin became involved with direct payments while working as trainers for Cambridgeshire Social Services. They were the first people in the county to receive money for direct payments.

Kathryn Gilbert is a linguist who qualified as a stockbroker and worked in stock market analysis and as an IT contractor for international blue chip companies before an industrial injury put her on the corporate scrap heap. Working in the voluntary sector with support from Access to Work has proved that her working life is not over.

Kathryn is an active trade unionist and a passionate believer in equality for all, especially for disabled people with whom she identifies.

Dr Jon Glasby is a senior lecturer and head of health and social care partnerships at the Health Services Management Centre, University of Birmingham, UK. A qualified social worker by background, he is also a board member of the Social Care Institute for Excellence (SCIE) and the Centre for the Advancement of Interprofessional Education (CAIPE).

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Frances Hasler is head of user and public involvement at the Commission for Social Care Inspection, UK. She was co-founder and chief officer of the National Centre for Independent Living. She was active in the campaign to legalise direct payments and has researched and written extensively on direct payments. Her publications include *Direct routes to independence* and *Making direct payments work*.

Andrew Holman works for Inspired Services (previously known as Community Living) and has written extensively about the use of direct payments by people with learning difficulties. Recent work includes the support of service user involvement in the development and implementation of the government's White Paper, *Valuing people* (the National Forum), as well as the production of easier-to-read information.

Peggy Hutchison is a Professor in Recreation and Leisure Studies at Brock University in St Catharines, Ontario, Canada. She has been actively involved in research and education related to inclusion, empowerment, the independent living movement, individualised funding, and community building. One of her recent publications, *A textured life: Empowerment and people with developmental disabilities*, researched individualised funding's impact on people's lives.

Helen Lee is a support worker for Stockport Sharecare, working in both specialised childcare and play scheme support. During the week she is a sixth-former at Tytherington High School studying for A levels. She hopes to go on to do a degree in architecture.

Janet Leece is a registered social worker working as a commissioning officer for Staffordshire Social Care and Health Directorate, UK. She is also an honorary research fellow at Staffordshire University. Janet has written extensively in the area of direct payments, her publications including the *Practitioner's guide to direct payments* published by Venture Press in 2003.

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Dr John Lord is a researcher, consultant, and parent from Waterloo, Ontario, Canada. He is a founder and first coordinator of the Centre for Research and Education in Human Services, a non-profit, independent community-based research centre. John has published widely in areas such as deinstitutionalisation, the new paradigm, and individualised support and funding. John was recently chair of the Ontario Round Table on Individualized Funding.

Laura Luckhurst is a freelance disability researcher and consultant specialising in direct payments and independent living. Much of Laura's work has focused on the needs of people excluded from direct payments, such as people with learning disabilities and survivors/users of the mental health system. Her report *Wider options* was published by the National Centre for Independent Living in 2005.

Charlotte Pearson is a lecturer in public policy at the Department of Urban Studies, University of Glasgow, UK. She has been researching direct payments over the past eight years and is currently working with colleagues at Edinburgh and Leeds Universities on an ESRC-funded study, which is examining their impact across the UK.

Dr Julie Ridley is a freelance researcher who live and works in Scotland. While employed by Scottish Health Feedback, she was commissioned by the Scottish Executive to carry out research into direct payments for people with mental health problems. She also brings to direct payments an insight from a community care planning perspective, as well as an advocacy perspective through supporting individuals with learning disabilities to be part of their community. Over the past 20 years she has carried out research in various aspects of health and community care policy and practice. Her main research interests include supported employment, user involvement and participation, and participatory research.

Brian Salisbury is a part-time faculty member in the Community Support Worker Program at Kwantlen University College in Langley, British Columbia, Canada. He has consulted extensively in the US, Canada, Australia and the UK on various disability policy issues including individualised funding and independent planning support. Most recently he has been a senior advisor to the Ministry of Children and Family Development and interim authority for Community Living British Columbia on that province's move to a community governance model.

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Simon Stevens is chief executive of Enable Enterprises, a leading provider of disability and accessibility services. In 2004, he won the community category of Enterprising Young Brits. He has employed personal assistants since 1992. For more information, visit his website (www.enableenterprises.com).

Angie Stewart is 27 years old and lives in Newcastle upon Tyne with her assistance dog, who is called Lulu. Angie works as a case advocate with people who have learning disabilities and are leaving long-stay residential hospital to live in their own homes in the community. In her spare time, Angie does disability equality training and enjoys going out with friends.

Lyn Tidder is 54 years old and divorced, with three daughters, two of whom are identical twins. She ran her own curtain business for 27 years, before going into care work five years ago. Lyn is currently not working due to ill health.

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Val Williams is a researcher at the Norah Fry Research Centre, University of Bristol, UK. She is particularly interested in inclusive ways of working with people with learning difficulties and other disabled people to enable them to conduct their own research and take part in projects. She previously worked with Swindon People First on their research about direct payments and is currently working with the West of England Centre for Inclusive Living on a project called 'Skills for Support'.

Rob Wilson is chief executive of the Rowan Organisation, which is one of the largest direct payments support organisations in the UK. He has previously worked for Birmingham Social Services in both older people's services and disability services, having originally started his working life as a child care officer.

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Introduction

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When Vic Finkelstein, the veteran disability rights activist, was imprisoned under the apartheid regime in South Africa, he recalls that, having insisted on the right to exercise, twice each day a black prisoner was detailed to push him "... round and round the courtyard (after I had been to the toilet)". He remarks wryly that this was "[the] only time I have ever been given a free personal helper" (Finkelstein, 2002).

Forty years on, in another country, and under somewhat different conditions, direct payments legislation (the 1996 Community Care Direct Payments Act; the 2000 Carers and Disabled Children Act; the 2002 Community Care and Health (Scotland) Act) means that someone who has been assessed for community care can now be given a budget and choose how to spend the money allocated to them. If they want to pay for someone so that they can visit friends, go to a meeting, eat out at a restaurant, buy helpful equipment, spend time away from home or simply buy help with the basic tasks that use up all their energy, then the choice is theirs. As the website of the UK Department of Health (DH) explains: "Direct payments create more flexibility in the provision of social services. Giving money in place of social care services means people have greater choice and control over their lives, and are able to make their own decisions about how care is delivered". (DH, 2004a).

For Vic Finkelstein and other disabled people, direct payments came into being as the result of decades of campaigning against a society which turns disabled people into dependants without choice, control or independence in their lives. Their organisations, the Union of Physically Impaired Against Segregation, the Disability Alliance and the British Council of Disabled People (BCODP), have been at the head of an international movement that sought and still seeks to establish a citizenship-based, human rights-defined case against disabled people's exclusion from society (Campbell and Oliver, 1996). With the establishment by Act of Parliament in 2000 of the UK Disability Rights

Commission came the incorporation in policy terms of independence and participation as rights:

> 4.1 There should be a basic enforceable right to independent living for all disabled people. Policy objectives for social care services need to include guaranteed minimum outcomes, backed up by a right to independence. The provision of social care must extend beyond functional 'life and limb' support to include support to enable participation in social and economic activities.
> 4.1.1 All social care support services should be based on the principles of independent living. All organisations commissioning and providing services should be aware of the social model of disability and be fully committed to delivering services that enable choice, control, autonomy and participation. (Disability Rights Commission, 2002)

The chapters in this book, each in their different way, pay eloquent testimony to this determination and campaigning, as well as the political and theoretical conceptualisation of disabled people's lives and their "real needs and wishes" (Campbell and Oliver, 1996, p 1). Indeed, leading participants in that movement are contributors to this collection. They have personal and policy-based experience as well as research evidence to contribute to an understanding of the development of direct payments.

However, this is not yet a story with an ending, or even an ending that might be predicted. Our inclusion of a chapter (Chapter Four) describing developments in North America, which have a much longer history, confirms that even there the course of personalised payments is not yet clearly defined. And comparisons with other European countries, set out in another chapter (Chapter Fifteen), show how arrangements building on rather different welfare systems are identifying issues that those of us in the UK may need to pay heed to. We chose the title 'Developments in Direct Payments', because we are aware that in these different accounts and analyses we are capturing a moment when the workings of a challenge to traditional provision of care and support are being exposed to critical comment and evaluation. Despite government espousal of the principle of direct payments and despite evidence of the very real and positive difference such a new system of support can make to people's lives this is not proving a straightforward transformation. More than that, the very nature of direct payments raises questions about the future direction of health and social care provision in the 21st century. It is with such a sense of proviso that the introduction to this book has been written.

The many facets of direct payments reflected in the contributions make up a complex picture once they are assembled. In writing this introduction I am attempting not only to introduce the parts that make up this whole, but also to suggest some organising edges from which it might be viewed. From these it might be possible to scan the terrain, noting similarities and links as well as differences and discontinuities. With this to hand, the challenges that direct payments make to support systems, to providers, and to users and workers may become plain. Before going on to identify these edges, I provide a brief sketch of the antecedents and the run-up to direct payments.

The route from the out-relief of the Poor Law to direct payments is a troubled and winding course, but the tracing of continuities and discontinuitites along the way is illuminating. Glasby and Littlechild's chapter in this volume (Chapter Two) provides an outline account of the history of the late 20th-century re-emergence of cash payments in the UK welfare system. From this, it seems that the resurrection of cash payments provides an ending, one can only hope, to the stigma of a form of support that had been deliberately associated with workhouse ideology (Thane, 1982, 2000).

The story of direct payments is closely linked to the development of representative and campaigning organisations in response to negative and disabling stereotypes. Some groups of disabled people had formed their own organisations (in 1890 the British Deaf Association; the National League of the Blind in 1899; and the Disabled Drivers Association in 1947), but otherwise, until the Disablement Income Group was set up in 1965, people looking for ways to change social attitudes to disability tended to be represented by non-disabled parents, relatives and others through charities and other voluntary organisations. As Borsay argues, disabled people's rights "... were a low priority within (the) agenda of rebuilding post-war Britain" (2005, p 161).Of course, individual disabled people were drawing on experience of oppressive and segregated treatment to press for equal treatment (Humphries and Gordon, 1992) and some older people were beginning to formulate specific demands (Bornat, 1998). Campbell and Oliver's history of disability politics uses testimony to plot the changes in awareness and commitment that led to the politicising of a generation of disabled people, culminating in the movement that, following the United Nations Declaration of the Rights of Disabled Persons in 1975, "... saw a transformation in our understandings of disability" (1996, p 19).

The idea of independence as a right, which disabled people promoted in securing the steps towards the 1996 direct payments legislation, is well documented. Glasby and Littlechild's chapter (Chapter Two) provides the background to the new law and the role of the disabled people's movement in achieving this. With subsequent Labour government support, direct payments have now become a change agent in social care provision, with self-assessment being identified as a natural precursor. The implications for service providers are as dramatic as they are for service users, as a Minister for Community Care explained to a meeting of people working in the mental health services:

> What's being asked of you is not easy, I know that. It means a change in approach. It means going much further in treating people you work with as individuals and tailoring support around them. It means letting them be in charge. And it means really signing up to the principle of independent living, and helping people move away from being dependent on you for help to being dependent only on themselves. (Ladyman, 2004)

How can we understand this shift in policy and identify the direction in which direct payments may be taking social welfare? Earlier, I mentioned the idea of edges from which to oversee this new landscape. As vantage points I offer four such edges: disability's influence; direct payments as co-production; costing support; and the worker as stakeholder.

I will begin with disability's influence. Several of the chapters included here allude to an unevenness in take-up across the UK. Some, such as Charlotte Pearson (in Chapter Three), point to resistance to the mixed economy of care in Scotland. Where the ethos of public service has survived longest there seems to be the greatest reluctance to move towards a more personally oriented system. Annette Lomas (in Chapter Seventeen) looks to poor levels of awareness and support for care managers for explanation, while chapters from Heather Clark, Frances Hasler, and Rob Wilson and Kathryn Gilbert (Chapters Six, Eleven and Twelve, respectively) emphasise the significant role of support systems and their uneven spread across the UK. However, none of these has perhaps had such a broad influence as the leadership role of the disability movement in unwittingly contributing to a stereotypical image of the direct payments user. Although older disabled people shared many of the early apprehensions concerning the administration of direct payments and their own personal safety in employing personal