

Disability, Independence and Care (DIC): a cross-national study of cash-for-care in the UK and Norway

Author: Karen Christensen, 2005–2006

Key search terms:

Disciplines: sociology, social policy, social work.

Topics / themes: governance (welfare regimes, welfare states), health (disability, well-being), interactions (communications, relationships), policy (health and social care, implementation, policy development, public / private sector, social exclusion / inclusion, social security, social services, welfare reform), working life (household labour, employer / employee flexibility, employment, work organisation, working time).

Units of comparison: employment (occupational mobility, pay structures, working time regimes), social protection systems (service providers, social policies, welfare professionals), spatial units (countries).

Concepts: politics (empowerment, participation, rights), socio-demographic processes (caring, gender, household, negotiation), values (identity, individualisation of rights, inequality, integration, social exclusion, social inclusion, well-being), welfare (care, social solidarity, stigma, welfare (in)dependency), work (domestic labour, flexibility, informal economy, labour market concentration and segregation, reconciliation of paid and unpaid work, workplace).

Funding: National research agency (The Research Council of Norway).

Methodological approaches: case studies (embedded case study), comparative methods, documentary searches (content analysis, literature review), qualitative approaches (ethnographic methods, in-depth interviews, narrative method, participant observation, policy analysis, semi-structured interviews).

Methodological issues: case selection, comparability, contextualisation, explanation, generalisation, interpretation, recruitment and retention of respondents, transparency.

Research context

The research project was carried out in 2005–06 by the author as a lone researcher, but with previous experience of conducting research on welfare and expertise in qualitative research, including teaching research methods. It was carried out as an independent project but as part of a larger Norwegian disability project entitled: 'Identity Politics among Disabled People and Public Service Provisions in a New Landscape'. The larger project was coordinated from the Stein Rokkan Centre for Social Studies at the University of Bergen, Norway. The funding for 'Disability, Independence and Care' (DIC), which came from the larger project, enabled a one-year stay in London where the project was based at the Rehabilitation Resource Centre at City University, London. The Centre offered a stimulating environment for discussing disability issues throughout the project.

Research topic / theme

Due to the challenges associated with an ageing population and the increasing need for long-term care services, as well as New Public Management inspired ideas for transferring management techniques and practices from the private to the public sector during the 1990s, the alternative of giving people cash instead of care was welcomed in both Norway and the UK. The original ideas for this scheme, however, came from the US Independent Living movement, which was driven by disabled people who claimed a right to an independent life outside long-term care institutions and not under the direction of professionals with their medical (treatment) perspective on disability.

These ideas were later developed in the UK into the social model perspective (Oliver, 1990), which holds society responsible for removing barriers that prevent disabled people from living self-determined and meaningful lives. The social model inspired the disability movement to put pressure on the UK government (as in Norway) to develop an alternative welfare scheme that would strengthen the possibilities for control and choice by service users. The specific history of the development of the cash-for-care schemes in Norway and the UK explains the kind of topics that require investigation.

The main topic in this case study is concerned with independent lives for disabled people, and the extent to which their independence is limited by the way in which local authorities who are responsible for this particular welfare scheme implement it. However, while earlier research in the field had a thematic focus, mainly on the achievement of disabled people's independence with the help of the scheme, the case study reported here includes a focus on user—care worker relationships as well as the role of, and impact on, the care workers looking after disabled people. Additionally, the DIC case study contributes to the existing comparative research on this topic (Ungerson, 2005) by including a Scandinavian country.

Aims, objectives and research questions

The overall aim of the research project was to compare the Norwegian cash-for-care system (user-controlled personal assistance) with the British one (direct payments) by using a bottom-up perspective that focuses on the experiences of those directly involved in the scheme on a day-to-day basis: disabled people and their care workers, described as 'personal assistants' under the scheme.

The project addressed the following more specific objectives and research questions:

1. To map the differences between the Norwegian and British cash-for-care schemes and relate them to the different kinds of welfare regime types that the two countries represent: a social democratic welfare regime and a liberal one (Esping-Andersen, 1999).
2. To understand the impact of different welfare political contexts on how the scheme is intended to be implemented throughout the process from assessment of eligibility to daily life under the scheme.
3. To compare the two countries, by asking: How strong is the focus on cash (instead of services) in each country? How strong is the idea of choice? What impact do organisations supporting cash-for-care users in the two countries have on the ways in which disabled people use the schemes, including the recruitment of personal assistants? And are differences found in the recruitment process as a result of the (different) ways in which the scheme is managed, for example regarding fixed or non-fixed wages?
4. To examine the different ways in which disabled people use the cash-for-care system in approaching an independent life, including possible barriers to independence, by asking: How is the search for an independent life reconciled with the situation of being dependent on social services? Are there boundaries to independence within the framework of the cash-for-care scheme? What are the concrete aspects of the scheme involved in creating barriers to independence?
5. To examine the different ways in which personal assistants choose to fulfil their role as workers for disabled people using a cash-for-care scheme, by asking: What kind of roles do personal assistants assume towards the disabled people for whom they work? Do they risk being exploited? Are they aware of the difference between assisting a self-determined disabled person and caring for someone in traditional home care services? Which characteristics of the care work conditions make a difference?
6. To explore the ways in which disabled people and their personal assistants develop their relationships, by asking: What are the different relationships revealed by the empirical material? How are these relationships related to different welfare contexts? What are the challenges to developing sustainable relationships based on cash-for-care schemes?
7. To discuss the policy implications of the study's findings, by asking: What kind of welfare ideas, arrangements for organising the cash-for-care scheme, and regulations, for example with regard to wages, do the findings from this case study point to as options for developing a cash-for-care scheme that takes into consideration the interests of the care workers and of disabled people?
8. To disseminate the study's findings to a wider audience and to contribute to academic and policy debates on disability issues and more general welfare service issues.

Resources, governance and management

The resources making it possible to collect the British data for the project during the stay in London included financial support from the larger Norwegian Research Council financed project and a sabbatical year (August 2005 to August 2006) from a permanent full-time paid position as associate professor in the Department of Sociology, University of Bergen. The funding from the larger project of £10,000 was used for carrying out the project fieldwork abroad, but did not include transcription of interviews. This was done by the researcher herself, except for a small number of interviews conducted at the end of the project.

The researcher managed and governed the DIC project, including data collection and analysis, during the sabbatical year. In 2007, the project made a contribution to the organisation of an international postgraduate research workshop in Bergen on 'New Perspectives in Disability Research: globalization, technologies, governmentality, performance, identity, aesthetics, culture, bodies and gender'. The project contributed to the understanding of how 'gender' is dealt with as an issue in welfare services for disabled people.

Professional and ethical standards

The main ethical issue raised by the DIC project was the fact that it included interviews with disabled people, who – as research subjects – are viewed as a group of vulnerable people that have to be protected against unnecessary 'intrusion' into their private lives, including the personal assistance they receive. The need for professionalism and high ethical standards on the part of the researcher was therefore paramount.

While the cross-national project included data from both Norway and the UK, it remained a Norwegian-sponsored project. Therefore ethical approval was sought from the Norwegian Social Science Data Services.

Three ethical issues arose from this situation. First, permission had to be sought from local authorities and other organisations in the UK on which the researcher was reliant for making contact with disabled people and personal assistants. As the approval from the Norwegian Social Science Data Services was written in Norwegian, and the project was being directed by the researcher carrying out the fieldwork, the authorities had to be persuaded that the project met the necessary ethical standards.

The second ethical issue concerned the information given to disabled people and care workers who took part in the project. Since the project had been initiated in a foreign country, the detailed information about the project and, not least, the assurance of confidentiality given in the covering letter were very important and often required additional verbal assurances before the interview could take place. Obviously therefore, the researcher's ability to develop trust in the relationships with the interviewees was crucial.

The third issue concerned payments for interviews, which seems to be widespread in the UK but is less so in Norway, particularly in social science research. The support funding for the project did not include any payments, partly because the budget was small, and partly because of the controversy surrounding the question of whether a social science project could maintain high ethical standards if interviewees were being paid. Evidence (for example from Thompson, 1996) suggests that, for some groups, it helps in recruiting interviewees if they know that they are to be financially rewarded. However, this project was conceived on the basis that all interviewees would be willing to participate in the research without being rewarded.

A final issue concerned the basic intention of the case study, which was to advance knowledge substantively and theoretically: on the one hand, by approaching disabled people and care workers (the interviewees) as experts; and, on the other, by learning from discussions with a variety of people who are knowledgeable about cash-for-care systems in the UK and Norway. Knowledge was also sought through immersion in the existing literature on cash-for-care in the UK, and through discussions of preliminary findings with disability researchers at City University. The dialogue between data collection on the one hand and theoretical reflection on the other was an essential tool in taking forward the study.

Rationale for the research design

A core decision for the design of the project was to apply a case study method (Yin, 2003) in combination with a comparative method (Ragin, 1987). Because, at a general level, the comparison concerned two different countries, the study had a cross-national case study design. The idea behind the design was to produce empirical material that would make it possible to look at the concrete everyday life cash-for-care experiences of disabled people and care workers within different welfare state contexts. Crucial to the project therefore was the selection of two countries that were clearly different with regard to their welfare regimes. The rationale for carrying out the case studies in the two countries was that Norway represents a Nordic social democratic welfare regime type and the UK a liberal type, as noted above. The fact that both countries are modern western European countries means that they also exhibit similarities.

To compensate for the researcher's Scandinavian background additional 'British' empirical work was carried out. Whereas the key material in both countries was intended to include personal semi-structured interviews with adult disabled people and personal assistants, the intention was to interview more people in these groups in Britain than in Norway. Also, to gain a better understanding of how the British cash-for-care system operated, interviews were carried out with local authority staff in charge of direct payments and support organisation staff. The plan was to conduct around ten shorter interviews with administrative staff from different local authorities and support organisations. Two assessments of disabled people wanting to obtain direct payments were observed, and arrangements were made to attend conferences of disabled people.

Regarding the selection of interviewees, the intention was to include both men and women, to cover a broad age distribution, and to select disabled people in receipt of different amounts of allocated hours of services and different lengths of time on the cash-for-care schemes. Personal assistants were selected by type of employment (for example directly employed by the disabled person or through a support organisation, for-profit or non-profit) and by country of origin (for those in the UK), as migrants represent an increasing number of care workers, particularly in the UK. The intention was to interview around ten disabled people in each country (with a few more in the UK and a few less in Norway) and up to eight personal assistants in each country, with a few less in Norway.

A final rationale for the research design was to view disabled people and personal assistants as two separate groups of interviewees for the project, not as pairs. This implied that, if a disabled person on cash-for-care was interviewed, her / his care workers would not be interviewed. The reason for this decision was to allow the interviewees to feel free to talk about their experiences without fearing that their views might be revealed to the other party. As the cash-for-care scheme encourages the disabled person to be the employer

of her / his care workers – with or without help from a support organisation – obstacles arise in contacting the care workers if the disabled person has not first been contacted. Although this constraint made the access to care workers even more difficult, it was decided not to let the selection of care workers be steered by the disabled interviewees to avoid increasing the risk of reaching only those care workers whom the disabled interviewees selected for reasons that would be unknown to the researcher. It was finally decided to use different sources for gaining access to interviewees, in particular via local authorities or municipalities and support organisations. Snow balling within the interviewee group was used when it was difficult to obtain sufficient numbers by other means.

Rationale for the research methods

The main method used in the project was a personal semi-structured life world interview (Kvale, 2001), stressing the interviewees' subjective perspectives, and carried out as in-depth interviews. A guide was used for both groups of interviewees – one for personal assistants and another for disabled people – to provide a set of similar starting points for the analysis, for example with regard to life background, current situation and everyday life experiences related to being a cash-for-care user or personal assistant. The in-depth part of the interview was seen as important for the project in obtaining the interviewees' reflections on their decisions and experiences and, more generally, in capturing 'private' rather than 'public' accounts (Cornwell, 1984) from their narratives. While public accounts are important for obtaining knowledge, for example about the formal intentions, plans and ideas related to the cash-for-care system (those in charge of the scheme would typically provide such accounts), private accounts are those given on the basis of personal experiences and subjective interpretations. They represent, in other words, a subjective bottom-up perspective, in our case on the cash-for-care welfare scheme.

The reason for including some observations (in the UK material) was not to confirm or disconfirm the interview data, but simply to obtain more insider knowledge about how the British scheme was working. This knowledge was gained from observing two assessments of the cash-for-care scheme carried out by a social worker, yielding insights into the situation of a disabled person wanting to use direct payments, and from observing a few conferences (discussion forums) for disabled people on disability related issues, for example about inclusive or special education for disabled children. The latter provided insights into the way disabled people receive personal assistance in a 'pure' disability environment including many disabled people who did not need assistance.

Conceptual issues

The key conceptual issue of the project concerns independence, one of the most central concepts of the twentieth century (Fraser and Gordon, 1994). Within the field of disability the concept obtained its first public and concrete voice through the Independent Living movement and its fight for civil rights for disabled people. When the concept was implemented in welfare service provision in Norway and the UK, it was supported by different discourses: one stressing the ability of individuals to influence their own lives (in line with the Independent Living idea) and the other stressing individual freedom and choice. This mix of discourses constitutes an ambiguous framework for the cash-for-care system and justifies the development of empirically-based case studies taking the 'from below perspective', while simultaneously relating it to different welfare contexts. Based on these reflections, the study's findings make two different conceptual contributions to the overall debate on independence. The first contribution is to operationalise independence in the field of disability and welfare services through the ways the cash-for-care scheme is encouraging disabled people's independence. The second is more theoretical, including its own developed concepts in analysing the findings, namely: discussion of boundaries to independence and whether 'interdependence' is a more appropriate concept; discussion of care workers' situations in terms of risks of exploitation, and development of their own competencies and careers; and typologies of user—care worker relationships within modern more user-controlled welfare services.

Data collection and analysis

Working full time alone on a project for an uninterrupted period and being responsible for all aspects of it has advantages: the research process is steered consistently by the same researcher; the interviewer and interviewing style do not vary; the interviews are similarly transcribed, and the interpretation of the data does not need to be negotiated between different researchers. As a lone researcher, it is also important to locate the project in a wider research setting, in the case of DIC at City University. Contact with disability researchers in London included discussion of interpretations of concepts and data, thereby affording a way of validating the material.

All aspects of the data collection were carried out while the researcher was based and living in London, which meant that the Norwegian data had to be collected by travelling backwards and forwards to Bergen. For logistic reasons, it was necessary to obtain the agreement of the disabled people and personal

assistants before travelling to Norway. While it was possible to plan the Norwegian interviews in advance and concentrate them into a few short periods, this was not a realistic option for the British data, partly because of the long distances between some of the locations in which the interviews took place in a city with around 7.5 million people at the time of the research, and partly because the data collection in London was dependent on developing access to local authorities and support organisations, largely through personal approaches.

The main analytical approach in DIC was inductive in the sense that the project did not start with specific hypotheses but was developed through a constant dialogue with the data (Christensen, 1998), beginning on the first day of data collection, early in the autumn of 2005. One aspect of this inductive analytical approach was to generate concepts (grounded in the data) that might develop further the concept of independence for people dependent on welfare services.

Since DIC was designed as a cross-national project, comparison was a central aspect of the analysis throughout the process. Given that, at a general level, the analysis included two different welfare regime types, country comparisons were key. In addition to inter-country analyses, intra-country analyses were carried out, for example between care workers' experience of being directly employed by disabled people and their experience of being employed by a support organisation.

The project also included policy analysis to understand the impact of the country and institutional contexts. However, within the limited resources and time available, this analysis is less developed than that of cash-for-care experiences in line with the main objective of the study. Policy analysis was therefore confined to understanding the legislative roots of the schemes in the two countries, the key political concepts by which the schemes are presented to welfare service users, and the concrete ways in which they are implemented in practice. In other words, the policy analysis was used to contextualise cash-for-care everyday life experiences.

Interpretation and dissemination of findings

The study's cross-national comparison involving a Nordic social democratic and a liberal welfare regime gives rise to two important issues. Firstly, the context matters: for example it makes a difference whether only one non-profit support organisation is available (as was the case in Norway at the time when the data were collected), whether a cash-for-care market is developed, including different types of support organisations (Independent Living based organisations, and for-profit organisations as in the UK), or whether the care workers' wages are mainly non-negotiable (based on collective working life agreements as in Norway) or negotiable formally at a minimum level (the case in the UK). The context thus influences the situation and risks for both users and care workers of the cash-for-care schemes. However, the other issue, arising from the study's data on everyday life experiences, is that these different contexts, although very important, can never fully explain the practices of cash-for-care schemes. Disabled people and personal assistants are active agents making (active) choices and decisions within the frameworks they are given; they can even reject some of the options. Policy implementation, as shaped by specific ideas and intentions, has a formative influence on the ways in which cash-for-care schemes function. To understand the concrete consequences and implications of a welfare scheme, the interpretation of 'from below experiences' of schemes is vital. The literature on cash-for-care schemes was still very limited at the time when the project took place. In particular, the perspectives of care workers were not receiving much attention from researchers. Thus DIC represents a contribution to the inclusion of both user and care worker perspectives in the field of disability, independence and care.

DIC has been presented both in learning environments and at research seminars at City University, London, at the Rehabilitation Resource Centre and the Disability and Social Inclusion seminar series, University of London, Institute of Education, and at the University of Bergen, Department of Sociology and Rokkan Centre.

A report was presented to the Department of Sociology in Bergen on the preliminary analysis of the study (Christensen, 2006b). Two short articles were written for a wider readership (Christensen, 2006a; 2007). The project was also presented during a national doctoral research course organised by the Department of Sociology in Bergen in 2007, focusing on comparative methods and entitled: 'Analysing comparative research: qualitative and mixed methods'.

The findings concerning challenges to independence were further disseminated as part of the reporting arrangements for the larger project, including a paper in a special issue of the *Scandinavian Journal of Disability Research* (Christensen, 2009), based on a presentation at a postgraduate workshop in Bergen. Three further scientific articles based on specific empirical findings have been published in British and

Scandinavian / Norwegian journals, covering different aspects of the DIC issues: care workers' strategies (Christensen, 2010) and the development of different relationships between disabled people and their personal assistants (Christensen, 2012a; 2012b).

Lessons learned

Lessons learned from the project include the following:

- The selection of countries in a cross-national study is crucial to the outcomes. However, while there should be some important and relevant differences, it might also be an advantage that the countries share some basic similarities.
- To develop a lone researcher study is time consuming and challenging. The part of the research process that could easily be done by assistants without disturbing the stability and consistency of the project would be the transcription of interviews since the interview in its original form is still available to be listened to when carrying out the analysis.
- A lone researcher study is more dependent on a stimulating research environment than a project based on team work.
- Although access to data, crucial to all empirical studies, should be considered in detail beforehand, the researcher should always be prepared to meet obstacles and unexpected challenges that have to be solved in the course of the research.
- Cross-national studies are often expected to include quantitative data. This expectation needs to be taken into account in cross-national studies based on qualitative data. It may put pressure on the researcher, but has the advantage of requiring a high level of methodological awareness on the part of the researcher throughout the research process, including dissemination.

References

- Christensen, K. (1998) 'I skyggen af Hellevik. Om udfordringer ved at arbejde empirinært' ['Shadowed by Hellevik. On challenges in regard to working close to data'], in K. Christensen, E. Jerdal, A. Møen, P. Solvang and L.J. Syltevik, *Process og metode. Sosiologisk forskning som ferdighet [Process and Method. Sociological research as skill]*, Oslo: Universitetsforlaget, pp. 68–87.
- Christensen, K. (2006a) 'A stark choice', *Community Care* (UK magazine: The Voice of Social Care), 6–12 July, pp. 32–3.
- Christensen, K. (2006b) 'Direct Payments and Personal Assistance in a Late Modern World. First report and preliminary findings'. Rokkansenteret / Department of Sociology, University of Bergen.
- Christensen, K. (2007) 'Valgfrihetens pris' ['The price of free choice'], *Velferd* (Magazin for work, welfare and health), 96 (2): 26–9.
- Christensen, K. (2009) 'In(ter)dependent lives', *Scandinavian Journal of Disability Research*, 11 (2): 117–30.
- Christensen, K. (2010) 'Caring about independent lives', *Disability and Society*, 25 (2): 241–52.
- Christensen, K. (2012a) 'Towards sustainable hybrid relationships in cash-for-care systems', *Disability and Society*, 27 (3): 399–412.
- Christensen, K. (2012b) 'Turbulente velferdsrelasjoner: Om ulike norske og britiske erfaringer med personlig assistanse' ['Turbulent welfare relationships: on different Norwegian and British experiences with personal assistance'], *Tidsskrift for velferdsforskning [Journal of Welfare Research]*, 15 (4): 263–74.
- Cornwell, J. (1984) *Hard Earned Lives. Accounts of health and illness from East London*, London and New York: Tavistock Publications.
- Esping-Andersen, G. (1999) *Social Foundations of Post-Industrial Economies*, Oxford: Oxford University Press.
- Fraser, N. and Gordon, L. (1994) "'Dependency" demystified: inscriptions of power in a keyword of the welfare state', *Social Politics*, 1 (1): 4–31.
- Kvale, S. (2001) *Det kvalitative forskningsintervju [The Qualitative Interview]*, Oslo: Ad notam.
- Oliver, M. (1990) *The Politics of Disablement*, London: The Macmillan Press.
- Ragin, C. (1987) *The Comparative Method: moving beyond qualitative and quantitative strategies*, Berkeley, California: University of California Press.
- Thompson, S. (1996) 'Paying respondents and informants', *Social Research Update*, Issue 14. Guildford: University of Surrey, UK. Available at: <http://sru.soc.surrey.ac.uk/SRU14.html>.
- Ungerson, C. (2005), 'Care, work and feeling', *Sociological Review*, 53 (2): 188–20.
- Yin, R.K. (2003) *Case Study Research: design and method*, London: Sage.