Comparing experiences of users/care workers in cash-for-care systems in the UK and Norway

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Disability and Social Inclusion Seminar
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Publications from the study

• “A Stark Choice”, in Community Care, 6-12 July, pp.32-33, 2006.
• First report and preliminary findings: “Direct Payments and Personal Assistance in a Late Modern World.” Bergen: The Rokkan Centre/Department of Sociology, University of Bergen. 2006 (Contact: karen.christensen@sos.uib.no)

• Towards sustainable hybrid relationships in cash-for-care systems. (The article will appear in Disability & Society, vol.27, no.3, May 2012).
The presentation

- Introduction and history of cash-for-care
- Norway and UK - differences and similarities
- The qualitative cross-national study

- Challenging the independence rhetoric
- Care worker strategies
- Types of relationships - disabled people & care workers
- Main issues for further discussions and analyses
Cash-for-care: Money for employing own care worker

- Cash-for-care is a social service
- Only for those eligible to social services
- The basic idea: giving those eligible for social services cash instead of traditional care services

- ‘Employer’-role
- More control
- More choices
- Independence
History of cash-for-care for disabled people?

- Independent Living Movement (ILM), Berkeley in California in the 1960s - students requested equal treatment
- ILM’s first centre 1972 in Berkeley: the fight against discrimination, power of professionals and institutions
- The movement extents across the world…
- Personal assistance in day-to-day life for disabled people an aim of high priority of the disability movement
- Implementation in social politics …
Cash-for-care in politics

Characteristic feature:
Supported by left wing and right wing politics
- disability movement
- the Margaret Thatcher government introduced the first Independent Living Fund in 1988

Democratic values
Different political models of empowerment
Liberal values
What are the issues here?

- **Public payments and private use**
  - What is going on in the private sphere, behind closed doors, with the public payments and intentions, what kind of relationships has the public pushed forward?

- **Individual – state in terms of power**
  - State accountability, the idea of empowering the user (personalisation), what kind of empowerment, from the perspective of those involved? Revolution or continuation?

- **The impact on all this by different contexts**
  - Different welfare regimes, different cultural values, different job markets, educational options etc.
  - Different orientations regarding *services* vs. *cash payments*
  - Makes comparative studies relevant
Cash-for-care and cash-for-care

Norway: Typically, no cash directly to the user, underlining the control of assistance

User controlled personal assistance (BPA)

UK: Normally cash more directly to the user, underlining cash payments

Direct Payments
- or now also Individual budgets (putting more funding streams into the individual’s budget)
- and Personal budgets (giving the option of choosing either direct payments or an arrangement where the local authority provides support with managing the budget) – (Little step towards Norwegian model?)
Cash-for-care figures from Norway and England

<table>
<thead>
<tr>
<th></th>
<th>Norway (Population: 0.497mill.)</th>
<th>England (Population: 51.4 mill.)</th>
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<tbody>
<tr>
<td>Users (2010)</td>
<td>2.300</td>
<td>86.000</td>
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<td></td>
<td></td>
<td>(about 90% of DP users in UK)</td>
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<tr>
<td>Rise</td>
<td>392% from 2000</td>
<td>358% from 2004-5</td>
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<tr>
<td>Personal assistants</td>
<td>7.000 (estimated)</td>
<td>129.000</td>
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British and Norwegian legislation

**UK**

1994: Community Care (Direct Payments) Act
- DP introduced

1996: Extended to older disabled (65+)
- Also to carers, parents of disabled and 16 and 17 years old
- All councils must inform people about direct payments

2000: Health and Social Care Act 2001
- BPA included in The Social Services Act
- BPA becomes “practical assistance”

2003: Extended to groups who cannot take over the manager-role (persons with mental health problems, parents with disabled children)

2001: Government plan made BPA one of the areas of priority

2005: New: Health and Social Care Act 2012 (all social services now “personal assistance”)
Different welfare contexts – different schemes

Local authorities do assessments → Choice between services or cash → Everyday life practice

Similar in N and UK

N: Municipality’s decision (More paternalistic politic) → UK: User’s decision

N: Lower expectation of self-support → UK: High expectation of self-support
Only a few employer models in Norway
Big variations in the British model:

Administrative support (N=526, England):
- Yes
- No

The 42% get help from:
- Local authority
- DP support groups
- Relatives etc.
- Accountant
- Care worker agency
- Other

Differences/similarities Norway and UK

**Similarities are:**
- Legislation basis
- Extended user-groups
- Social politics oriented at more choice, control, independence, personalisation agenda
- Increasing numbers
- Majority physically disabled people

**Differences are:**
- UK user choice, N local authority choice
- UK employer role, N manager role
- Third party homogeneous in N, heterogeneous in UK
- «No» for-profit experiences in N
- Disabled people normally don’t use relatives as PAs
- No traditions for live-in in N
- Context: stronger welfare system and more regulated labour marked
Qualitative study with data from London and Bergen

Total sample: 47 interviews and some observations

- In-depth interviews with 20 disabled people (UK:11, N:9)
- In-depth interviews with 13 personal assistants (UK:8, N:5)
- Dialogues about their situation, challenges and reflections
- Inductive analyses looking for narratives about independence, care work, relationships
Challenging the concept «independence»

- Theoretical tool: cultural and personal language (here about dependency and disabled people)

- **Cultural hegemonic language** about disability: disabled people are dependent and helpless (traditional services, medical model inspired)

- **Cultural challenging language** challenging this: disabled people are independent (being ‘complete’)
  - Looking at the semantic history of the concept, “dependency” has become a dirty word (Frazer & Gordon 1994)
  - In this situation cash-for-care risks idealising independence: if care is commodified (people get their own money to employ care workers) they will somehow reach independence

- **Personal language** about disability and independence in everyday world (different from cultural language) – narratives from interviews
Challenging two implications of the new cultural language about independency

Two implications of “independence” are:
✓ Being in control
✓ No need for care

My study points at two examples of personal language:
❖ A personal narrative about *limited control*
❖ A personal narrative about *care*
The personal narrative about care

Cultural language says: not care, but assistance
(Using Clare Ungerson’s difference between «caring of» and «caring about» means avoiding the last one)

John (disabled man): «it’s nice if you’ve got a girl working for you … who is also pleasant to be with and talk to about things other than purely getting me up in the morning and putting me to bed at night.»

Same in Norway, although stressing boundaries more.
The personal narrative about *limited control*

Compared to conventional services, you can (as listed in e.g. report by Dawson 2000):

- Employ the one you choose
- Determine the hours (not the amount of help)
- Determine the tasks
- Gain flexibility
- Decrease involvement with professional people

Yes, somehow increasing control, but not «independence», points from my study:

- Dependent on the market of care workers
- Dependent on local available third parties (particular in the UK)
- Depending on skills to choose the «right» persons (experience mistakes)
- Depending on when you get the money in your account and can pay …
Care worker strategies

A CONTINUING CARER BIOGRAPHY

• The wish to continue a carer-role, not motivated by independence, not looking for new chances in life, a fundamental biographical identity of being a caring person
• “I’m just a carer” type
• Women in low-paid «female» jobs (e.g. housewives)

Example: Julia, British, 48 years old, doing 8 hours/week in London, left school when she was 15, became a personal assistant through voluntary work (dog-walking), sees the disabled woman she is working for as an important friend:

Julia, working in London: “I go in there for other reasons [than personal assistance work] regardless of the hours. That’s what commitment to care is all about.”
Another care worker strategy:

SEARCHING FOR NEW HORIZONS

• The wish to get new experiences, travelling, learning languages, new cultures
• On their way to improve their position in the labour marked - but still a vulnerable care worker group
• Migrants central in this group (attracted also by the live-in model offering work, place to live and a beginning network)
• The third parties play an important part in recruiting these PAs; they are more dependent of organisations arranging a job for them

Peter from Poland, working in London: “For people from abroad, it’s a fantastic opportunity … I wanted to get some really new experiences.”
A third care worker strategy:

THE PRAGMATIC STRATEGY

- The wish to do something meaningful while preparing for another (higher) position
- Aiming at independence themselves, therefore fully aware of doing assistance work supporting independence
- More or less certain about improving their live conditions while temporarily working as personal assistants

Linda from Bergen: “This is not an occupation for me, because I have always felt like aiming at a profession, that I reach a position and that I’m qualified for that.”
The care worker strategies – gender issue

PA work gendered – features from traditional (female) care work, pushing:
- LOW STATUS
- TEMPORARY AND PART TIME WORK
- LOW WAGES
- UNPAID WORK
- “CARING ABOUT” ROLES

Important differences regarding the strategies:
- Assistants aiming at more cultural capital
- Not aiming at more cultural capital

Explaining a hierarchy …
Relationship types found

MASTER-SERVANT – SERVANT-MASTER

Disabled people:
• Challenging the traditional relationship by reversing it
• Treating personal assistants as staff (e.g. aggressive talk, waking up at nights etc.), “Cold relationships” (Ungerson 2005)
• Risk of servant role, particularly among “looking for new horizons”

Personal assistants:
• Assistance behind closed doors, based on trust
• Misusing the “personalised and private” situation:

Disabled young man: “She (PA) moved in with her two children … left me alone when she was on holiday, had two kids looking after me … her oldest son… he wouldn’t do what I told him to, so I said “Dave if you not do it, I call your mum” and he said “if you do that I break your fingers” (and he did)… I wrote letters to the agency, but she (PA) didn’t post them …”
Another relationship type

DEGREES OF SOLIDARITY

• Clear examples in N and UK data about solidarity (two oppressed groups: care workers and disabled people)

• Examples: **disabled people** who wanted higher wages for their PAs, **PAs** expressed opposition to prejudices towards disabled people

A risk of exploitation for PAs more in the UK data:

• Examples: doing unpaid work etc. and developing emotional relationships

• Risk in particular for **those with a continuing carer biography**
A third relationship type

PROFESSIONAL FRIENDSHIP

- Friends but with clear boundaries, not getting too personal and emotional with each other
- More balanced relation between power and emotionalism

Disabled woman, Bergen: “They (PAs) can’t replace friendship, so we should not start a friendship with them … on the other hand it becomes friendship in one respect, but in a different way. The friendship has started on false premises; it becomes purchased and paid friendship.”
About the strategies and relationship types:

- They are empirical based on this study’s sample - other studies could show more strategies and relationships.
- Strategies and relationships are developed out of structural conditions and individual choices.
- Found here:
  - The more personalised British model: greater risk of creating strongly hierarchical (servant <-> master) or emotional relationships.
  - The more regulated Norwegian model: pushes forward professional relationships.
Issues for further investigation

• Is there a fundamental interest conflict between disabled people’s independence needs and care workers’ needs of good labour market conditions? (The hours, the flexibility for the users etc.)

• How much is cash-for-care an alternative to traditional services? (Catching up with the current critics of traditional home care services of high turnover, dignity issues etc., according to the new Equality and Human Rights report 2011)

• The third party model: the need for at third party regulating the relationships (incl. working conditions for PAs) and a need for regulating the third party?