Section 8: Disability and care

Disability and society, 2016

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Learning objectives/Key points

- Feminist perspectives on care: care as work, ethics of care
- Disability studies critique of care and solution promoted by Independent Living
- Differences between feminist and disability perspectives on care
- Interdependence and relational autonomy
- Formal and informal care for disabled people
- Social control over disabled mothers

Outline

"The personal is political"… in so many ways: politicizations of the care relationship in feminist research and disability studies

>Feminist research: care as work, care as ethics
>>What is care?
>>Care as work
>>Care as ethics
>
>Understanding the disability studies/movement critique of care
>>A critique of dependence, as a label and as a reality
>>Independent Living as a solution
>
>Feminist and disability perspectives on care: building bridges
>>Summary of the oppositions
>>Possible common grounds
>>Different standpoints

Formal and informal care for disabled persons

>The experience of personal assistants
>The experience of parents

Caring as a disabled person: the case of disabled mothers

>The social control of reproductive choices
>Social obstacles in the experience of disabled motherhood

What is care?

- Work provided to address the needs of children and "dependent" adults

- Material tasks and "emotional labor" (Hochschild, 1983)

- Connection with the gendered division of labor

- Diverse circumstances of provision (formal/informal, paid/unpaid, professionalization, welfare regime), but a form of labor strongly marked by gender, race and class

Feminist perspectives on care

- Care as work

Goal = "make visible the nature and extent of the unpaid work carried out by women in the private domains of the family and home" (Fine & Glendinning, 2005, p. 603)

→ In the disability sector, a critique of "community care" policies as patriarchal (see Morris, 1993 on the limit of this perspective: objectification of disabled people as a "burden")

Feminist perspectives on care

- The ethics of care : **a normative, philosophical perspective** regarding the need to recognize human beings' universal dependence and the positive role of caring

- "the theorists of care believe that we are all dependent upon one another, and that we are all involved in affective and asymmetrical relationships of care; independence is a fiction, an illusion". (Winance, 2010)

- Most disability studies critiques focus on this philosophical dimension of feminist analysis (based on general idea that it « values care »)

Understanding the disability studies critique of care

- A critique of the term « care »…

- … which should not be undermined (it results from a history of oppression in the name of care)

Understanding the disability studies critique of care

A critique of dependence as a label… and as a reality

- A critique of **being portrayed as passive**, dependent objects of care/burdens

- A critique of **the power relations which characterize traditional care arrangements**: DPs at the mercy of their care providers/victims of abuse and violence on their part.

→ a key aspect of the disabled movement's critique of **institutionalization**

"Care is associated with institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion. To be cared for is to be in deficit and to have one's competence as a social actor denied or questioned" (Hughes et al., 2005, p. 260).

Understanding the disability studies critique of care

Independent Living as a solution

- Reframing and reclaiming independence

Common answer to those two critiques = Reframing issues of dependence and independence, based on the social model, to make independence possible for DP

- Social model → dependency derives from social forces, not functional limitations
- Independence as a mind process/focus on choice and control over the provision of care:

"To us, independence **does not mean doing things physically alone**. It means being able **to make independent decisions**. It is a mind process not contingent upon a normal body"(Judy Heumann)

- The care provider becomes an instrument in this process: care provision as « prosthesis » to permit independence → an instrumental vision of care

(Kittay, 2011)

Understanding the disability studies critique of care

Independent Living as a solution

- From objects of care to « self-managers » (Kelly, 2014)

Against traditional forms of care provision (within institutions or families), the Independent Living Movement (ILM) promoted the direct employment of personal assistants (PAs) by DP

- Freedom to recruit and train PAs

- Direct payment ($\rightarrow$ 1997 community care direct payment act in the UK, 2005 creation of the Prestation de compensation du handicap in France)

- A general change in vocabulary : from "care" to "help," "support" or "personal assistance" (Winance, 2010)

Understanding the disability studies critique of care

Independent Living as a solution

- *The empowerment of disabled people through PA management*

" The person previously "cared for" now becomes an employer, and their relation a "business arrangement" (Watson et al., 2004, p.337).

- *Consumerism against professionalization*

IL derives from a consumerist approach (adapting services to each DP's individual wishes and needs) as opposed to a professional approach (applying a uniform set of norms) (Fine & Glendinning, 2005, p. 585).

→ Testimony of an IL employee "we have to un-train [the attendants w/ prior training] and then train them again" (Kelly, 2014)

Understanding the disability studies critique of care

Independent Living as a solution

- *« Task-centred » rather than emotional work*

"PAs [do not] require repeated expressions of gratitude. Their role is task-centred, involving response to instruction"(Watson et al., 2004, p. 336).

- *A reversal of subject/object relation?*

DP become active in the process, and PAs considered a mere tool

→"risk of creating one oppression in the effort to alleviate another"(Kittay, 2011, p.51)?

Feminist and disability perspectives on care: building bridges

Summary of differences between the 2 perspectives:

- Standpoints: care provider or person cared for

- Who is oppressed by what in the care relationship? Women, undirectly, or DP, directly

- Dependence and care as conflictive concepts

- Professionalization of Pas

- Residential vs community care

Feminist and disability perspectives on care: building bridges

Possible common grounds (Kittay, 2011; Winance, 2016)

- *« the virtues of acknowledged dependence» (Kittay, 2011)*

Problem with equating dignity with autonomy and seeing « dependence as a denigration of the person » (Kittay, 2011, p.51), notably for people for whom making choices is very problematic

Vs care builds dignity: **"**care is an indispensable, and even a central good—one without which a life of dignity is impossible and which is itself an expression of a person's dignity. [...]the ability of a being to give and receive care is a source of dignity for humans no less than the capacity for reason" (Kittay, 2011, p.52).

Feminist and disability perspectives on care: building bridges

Possible common grounds (Kittay, 2011; Winance, 2016)

- *Redefining autonomy:*
  - Autonomy through interdependence/relational autonomy
  - Capacity of rupture/refusal/being recalcitrant (Winance, 2016)
- Bringing emotions back in? The limits of the instrumental vision of care

Yet different standpoints

Formal and informal care for DP

Context: excessive focus on care-providers in feminist research on care → reluctance of disability studies to address the experience of care-providers

Formal and informal care for DP

The experience of personal assistants (Ungerson, 1999)

- British context of direct payment for PAs

- « a hybrid form of work and care »

- Risk management in the recruitment process

- Issue of « boundary maintenance »

Formal and informal care for DP

« The disabled family »: The experience of parents (McLaughlin, 2006)

- Facing cultural discourses on disability…

Example: The « disaster scenario » and the paediatrician's « hit and run »

« One couple spoke about the grief and sense of loss they experienced when told by a paediatrician that their child had Down's syndrome. The doctor had 'hit and run': leaving the scene as quickly as possible and appeared very uncomfortable around the subject, as if he were the bearer of the most profoundly distressing news. However, three years on, the fact their child has Down's syndrome is for them merely one element of who he is, and the condition itself has *not* meant the loss of his humanity. It took them some time to be able to appreciate this, time they felt stretched because of the disaster scenario suggested by the original consultant's manner" (McLaughlin, 2006)

Formal and informal care for DP

« The disabled family »: The experience of parents (McLaughlin, 2006)

- Facing cultural discourses on disability...
- ... and cultural expectations of parenting/mothering
- Common tendency to assert the « ordinariness » of the child: disability denial or inclusive strategy?
- Lack of institutional support/definition of care as a private/family (and gendered) matter
- Withdrawal of family and friends
- New support networks (other parents of disabled children)
- Redefinition of parental role: caring and fighting injustice

Caring as a disabled person: the case of disabled mothers

The social control over reproductive choices and women's bodies (Thomas, 1997)

- « Risk management » before and during pregnancy
  - ex. 1: Sheila: advised to get sterilized after a diagnosis of degenerative visual impairment
  - Ex. 2: Terry: facing the dilemmas of medication during pregnancy

Caring as a disabled person:
the case of disabled mothers

Social obstacles in the experience of disabled motherhood (Malacrida, 2007): examples:

- Inaccessible playgrounds and schools

- Assumptions of incapacity to care on the part of social services

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