

# **At the crossroads of care and disability: Historical variations and international perspectives**

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In the first issue of *Alter* devoted to this topic, “Care and Disability” (Vol. 9, No. 3, 2015), we collected articles that analyzed everyday care relationships. They showed the tensions and ambivalence inherent in these relationships, thereby shedding light on the debates between *disability studies* and the *ethics of care* around the nature of care or the care-giving relationship (service relationship versus emotional relationship), the identity and positions of people, care receivers and care givers, etc. In that first issue devoted to care, most articles examined in-home care. This second issue continues these reflections, broadening the topic to the issue of the social and political organization presiding over the care provided for some disabilities. The aim is to examine the places and implicit forms of care to reveal a set of preconceived ideas that have accompanied the recent history of how disabilities are treated from a social standpoint. The topic covered in this issue is a diverse exploration of how care giving is distributed among a limited number of parties—the State, the family, communities and the private sector.

Indeed, care, as a set of activities done for others, is provided in several places but the location that imposes itself spontaneously for the provision of care is within families. This presupposition of family is tenacious despite the ways in which it has been contested, initially in the field of *disability studies* but also in the literature on social care and the *ethics of care*. And for good reason: the family is still in many countries the main player, even when institutional forms of care are well developed. Yet, the fields of *disability studies* and *ethics of care* meet around a shared observation: there is a major risk involved in concentrating care within families because, as a “natural” location for care, families may absolve other players from the need to mobilize. Very early on, *disability studies* pointed out society’s

responsibility in overcoming the social barriers that society throws up in the paths of people with disabilities and avoiding these forms of dependency on family. Authors in the field of the *ethics of care* also insist on the difficulties that the provision of care within the family alone raise, breaking with the interpretations of care inspired by the mother-child dyad model as in NelNoddings (Tronto, 1993): they criticized the assigning of care giving to women and the most “minoritized” categories of people; and pointed out the dangers of care giving that does not comply with the criteria of democracy and was not subject to the principle of justice (Tronto, 1993). Kittay (2003) also emphasized the risks of “secondary dependence” for the main care giver.

The position of communities or groups in the organization and provision of care was initially conceived in the description of the role of different actors, with this position varying; according to the State model (Jenson, 1997; Lewis, 2002; Martin, 2008; Dang and Letablier, 2008). In the history of movements of disabled people, the independent living movement was a very early defender of forms of community organization of care (independent living centers) over the predominating institutional and family-based forms of care giving (Barral *et al.*, 2000). This second issue of *Alter* about “Care and Disability” is an opportunity to pay special attention to groups and associations in the area of disability. More broadly, it is an invitation to explore the roles and places of various protagonists and analyze the relations—both real and supposed—between them in diverse social and historical contexts: from the Paleolithic era to contemporary times marked by low public financing, budget cuts, and even by forms of territorial inequality in the allocation of benefits. Finally, it examines the political forms of care giving over time and space.

Four sets of questions in conjunction with this topic are notably raised by the articles we are publishing. One first set of questions deals with the very nature of the behaviors we see in different societies: What is care and what is compassion? Are the presence and survival of disabled people enough to indicate the existence of caring behavior towards them? Is qualifying these behaviors as care or compassion not linked from the get-go to a specific interpretation of the relationship societies have with their disabled members? If this is the case, should one not therefore, when describing a relationship in terms of care, question the organization and characteristics of the society in which this relationship exists?

A second set of questions deals with the normative models that define how the appropriate care is envisaged. Despite their distinct histories, *disability studies* and the *ethics of care* have converged in their criticism of the monopoly of professional standards: whether as negating the knowledge of disabled people (Finkelstein, 1980) or in minimizing the practical skills developed by care givers (Tronto, 2001; Damamme & Paperman, 2009). This examination of the outlines of expertise has also been the subject of closer attention with the rise in power of patients’ groups (Akrich *et al.*, 2009; Dodier, 2003) and the legal recognition it has received over the past twenty years. This line of questioning around care standards is also found notably in Judith Mac Kenzie’s survey (regarding couple protection / independence) and also in the research of Gaël Villoing, Sébastien Ruffié and Sylvain Ferez analyzing the discourse and actions of the associations and organizations of disabled people in Guadeloupe over several decades and revealing a tension between the demand for equal treatment and the demand that one’s specificities be acknowledged.

A third set of questions deals with the processes by which care-related groups emerge and change, and correlatively, the form that this care takes depending on groups. The articles by Tomas Sanchez-Criado, Israel Rodriguez-Giralt and Arianna Mencaroni, by Jeannette Pols and Maartje Hoogsteyns, and by Gaël Villoing *et al.* show that the creation of groups engages different timescales for action, causes reflection on the defended causes, and accordingly questions the care arrangements in place, proposing original forms of collectively-conceived technical aid (Sanchez-Criado *et al.*), calling out interlocutors for their indifference or relative

lack of involvement (Villoing *et al.*), or defining the profiles of participants on a discussion website (Pols *et al.*). The article by Tomas Sanchez-Criado *et al.* shows how the suppression of physical barriers to access for people is a concern that can be thought to be ordinary, associating movements with different backgrounds, initiated by people with disabilities, or by a broader front of criticism of political and social institutions. It shows how discussions on technical arrangements are updating the lines between non-experts and experts and reigniting the questions of sharing knowledge, the legitimacy and skills of the various parties to invent care systems, etc. The article by Villoing *et al.* makes tangible the immediately political dimension of how care sites are organized for people with motor disabilities in Guadeloupe, placing the issues of the elaboration of local disability policy in the context of the power structure between mainland France and the French West Indies. The historical perspective also accounts for changes in expectations and images of care, given the very evolution of living establishments for people with disabilities and criticisms regarding institutional care on both sides of the Atlantic. While equality of treatment with mainland France had been defended by the first self-managed associations in the early 1980s, more oppositional discourse regarding the mainland and its care model also emerged, showcasing the unique qualities of pre-existing care in Guadeloupian society, thereby seeking to encourage practices that are respectful of people facing disabilities without erasing the dimension of emotional relationships seen as an advantage.

Finally, the question “who is speaking, and in the name of whom or what?” is present in most of the articles. For instance, the description of care givers had a primary objective of giving a voice to people made invisible by their position in social gender relations (Gilligan, 1982) and also by their class, race or position in the North/South divide (Glenn, 1992; Ehrenreich *et al.*, 2003). By covering concerns generally pushed to the private arena, the *ethics of care* aimed to make visible figures whose position is often minimized—professionals or family members present in the domestic sphere and in institutions. *Disability studies* authors for their part emphasized the little consideration given to the voice of “recipients.” If the issue of narratives was more controversial within the field of *disability studies*, it was because it was seen as a risk of a new arm against a social interpretation of disability or a way to again reduce the disabled to their deficiencies and ultimately their biological identity. Not staying silent about the risks associated with their speaking up, authors such as Jenny Morris (2001) and Susan Wendell (1996) nevertheless attempted to give accounts of the difficulties they encountered and made it possible to recall the ways in which certain voices can be minimized within groups.

Each of the articles that we publish here addresses the question of the legitimacy of speech, initiative and regulation, along with the philosophical, historical and political backdrops that support the forms of care rolled out in the area of disability.

In the first article, David Le Doat covers the debate that has notably raged around thinking on the presence of care attitudes following the discovery of adult individuals with major disabilities. In this way, he revives reflection on the role of the various anthropological currents underpinning the research: anthropology of the autonomous liberal being that would adopt a compassionate attitude towards weaker and vulnerable people, or an anthropology that could be described as that of “vulnerability” and would not assume from the outset any strict opposition between two categories of people. His article strongly re-examines the assumptions at work in interpreting data and shows that it is crucial, in our research, to question how the terms “care” and “compassion” are defined and what they suppose.

In the second article, Tomas Sanchez-Criado *et al.* take an interest in how, in Spain, the paths of the movement for an autonomous life and the anti-austerity movement (of May 2011) crossed, renewing the debate on assistance services for the disabled and their participation in society. Based on an ethnographic study, they analyze the process of producing a folding

access ramp that above all can be easily and freely made by anyone. They show how this process can be interpreted as a “criticism” of care and more broadly the group providing care and where care happens.

The third article, by J. Pols *et al.*, also questions the group, provider and location of care. J. Pols *et al.* take an interest in an Internet forum where people experiencing incontinence express themselves. These questions cover group formation and more specifically how this group builds a collective experience of life and incontinence-related practices. They show that the experience of living with incontinence is the result of a process of collective sharing that then takes the form of know-how, capacities and interpretations—that is to say it takes the form of practical knowledge. This knowledge may be mobilized by others, contested and modified by them, transforming in turn their own experience of incontinence.

The fourth article, by Villoing *et al.*, analyzes the forms of collective implication by people with motor disabilities in Guadeloupe, a former French colony turned overseas department. They show that the definitions of what would be appropriate care arise not only from concepts of the disabled person and his or her autonomy but more broadly from the geopolitical organization in which these concepts take form. Thus, the post-colonial context makes relationships especially complex between disabled people and the care public “held” entirely by mainland France. The authors show that after a first period during which associations attempted to take French republican egalitarianism literally and demanded the same services as those available in mainland France, the more recent mobilizations intend to rehabilitate private care, provided by family, as a specific component of Guadeloupean culture.

The last article, by Judith Mac Kenzie, analyzes expectations regarding care formulated by people with mental disabilities and their families in Cape Town, South Africa. This research, conducted through individual interviews and focus group discussions with people facing disabilities and their families reveals the variations in needs depending on the point of view adopted (disabled person or family member), with the demand for protection being more recurrent among family members than among disabled people themselves, with the exception of a shared demand for greater protection from violence and particularly rape. The author emphasizes the importance of the *ethics of care* and a relational approach to take into account the support provided by families in a context where the human rights model is not accompanied by sufficient resources nor sufficiently takes into account the specific nature of certain disabilities (here, mental disabilities).

## References

- Akrich, M., Meadel, C., & Rabeharisoa, V. (Eds.), (2009). *Se mobiliser pour la santé : des associations de patients témoignent*, Paris : Les Presses de l'École des Mines.
- Barral, C., Paterson, F., Stiker H-J., & Chauvière, M. (Eds.), (2000). *L'institution du handicap. Le rôle des associations*, Rennes : Presses Universitaires de Rennes.
- Damamme, A., Paperman, P. (2009). Care domestique : délimitations et transformations. In P. Molinier, S. Laugier, & P. Paperman (Eds.), *Qu'est-ce que le care ? Souci des autres, sensibilité, responsabilité* (pp. 133-155). Paris : Payot.
- Dodier, N. (2003). *Leçons politiques de l'épidémie de sida*. Paris : Editions de l'École des Hautes Etudes en Sciences sociales.
- Ehrenreich, B. & Hochschild, A.R. (2003). *Global Woman: Nannies, Maids, and Sex Workers in the New Economy*. New York: Henry Holt and Company, Metropolitan Books.
- Finkelstein, V. (1980). *Attitudes and Disabled People : Issues for Discussion*. New York : World Rehabilitation Fund.

- Gilligan, C. (1982). *In a Different Voice. Psychological Theory and Women's Development*. Cambridge: Harvard University Press.
- Glenn, E.N. (1992). From Servitude to Service Work: The Historical Continuities of Women's Paid and Unpaid Reproductive Labor, *Signs*, 18(1), 31-43.
- Kittay, E. F. (2003). When Caring is Just and Justice is Caring: Justice and Mental Retardation. In E.F. Kittay, & E. Feder (Eds.), *The Subject of Care. Feminist Perspectives on Dependency* (pp. 246-256). New York: Rowman and Littlefield.
- Jenson, J. (1997). Who cares. Gender and welfare regimes. *Social Politics*, 4(2), 182-187.
- Letablier, M.T. (2009) (avec Ai-Thu Dang), [Citoyenneté sociale et reconnaissance du « care »](#). *Nouveaux défis pour les politiques sociales*, *Revue de l'OFCE*, 109(2), 5-31
- Lewis, J. (2002). Gender and welfare state change. *European Societies*, 4(4). 331-357.
- Martin, C. (2008). Qu'est-ce que le social care ? Une revue de questions. *Revue Française de Socio-Économie*, 2, 27-42.
- Morris, J. (2001). Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights. *Hypatia*, 4, 1-16.
- Tronto, J. (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.
- Tronto, J. (2001). Does managing professionals Affect professional Ethics ?Competence, Autonomy, and Care. In P.Desautels, & J. Waugh (Eds.), *Feminist Doing Ethics*(pp.187–202). New York: Rowman & Littlefield.
- Wendell, S. (1996). *The rejected Body. Feminist Philosophical Reflections on Disability*, London: Routledge.

