

**A critical companionship? The relation between Disability Studies and Care Ethics in the context of Humanization research.**

**Graduate School Research Network Care Ethics Meetings**

**Date: Monday 20th June and Tuesday 21st June 2016**

**Location: University of Humanistic Studies, Utrecht**

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**Background**

If humanization can be defined in a general sense as ‘cultivating the right conditions for personal meanings of life, within equitable institutions and in a sustainable world society (Nussbaum 2006), then research geared towards humanization is not simply restricted to theoretical reflection and clarification, but also aspires to making a practical contribution to fostering specific humanization processes in diverse practical contexts. The orientation to humanization issues leads among other things to research into the social, economic and political conditions that may enable people to shape what they deem to be a meaningful life.

However, the definition of what is deemed ‘humane’ and even ‘meaningful’ invariably depends on the historical dynamics of meanings (of life) and constantly shifting articulations of a good life. This is particularly pertinent in (institutionalized) care, as neo-liberalist policies have urged more and more people living with illness and disability to take control over their own health and life and act accordingly as independent users and consumers (Teunissen et al, 2013). Thus, what is deemed as ‘good’ or ‘humane’ care seems to be underpinned by a standard ideal of an able-bodied, rational human being, which not only underlies those ‘social and professional structures within which narratives and decisions regarding various impairments are held’ (Ho, 2011), but also co-shape these structures.

Both Disability Studies and Care Ethics can be conceived of as critical enterprises with much in common, whereby the ‘critical’ in ‘critical enterprise’ entails that the accounts, the representations

of what is for example depicted as ‘humane’ and as ‘caring’ have to be seen through specific (trans-disciplinary) lenses. These critical lenses enable us to see more richly and at the same time challenge standard concepts such as ‘the humane’, thereby viewing them in a different light. This might for instance be done by studying everyday care practices, connecting critical events to daily routines of people living with disease or disability and the everyday aspirations of caregivers. Both Disability studies and Care Ethics have the potential to inform us about *why* and *how* what might be conceived of as ‘good’ or ‘humane’ emerges, and under what conditions (cf. Pols, 2013; Klaver et al, 2014).

### Focus

The theme of this month’s GS theme days is: care ethics, disability (studies) and humanization: a critical companionship. Given the fact that Disability Studies (DS) and Care Ethics (CE) are very similar fields of research, one of the main aims of this day is to see how these two critical enterprises overlap and where they might inform each other. Accordingly the following questions will be addressed: What does it mean being a human being (with or without a disability), being ‘moral’ or ‘humane’, in a late modern neoliberal society (both from a DS and CE perspective); how can DS and CE inform each other and what are the implications for doing humanization research? Joining us will be Dr. Alice Schippers (Directeur DSiN), Jacqueline Kool (Kennismanager DSiN) and Dr. Paul van Trigt (Leiden University).

### Program (outline)

#### 1. Monday June 20 “What is human(e)?”

14.00-14.05	Welcome. Short introduction by Dr. Alistair Niemeijer
14.05-14.30	TEASER to kick off the afternoon: LUCA BADETTI TEDX TALK
14.30-14.45	Central concepts Contested Humanity: Dis/human; In/ability; Be/longing Overview by Dr. Paul van Trigt. Background Reading: Goodley, D. and Runswick-Cole, K. (2014) <i>Becoming dis/human: Thinking about the human through disability, Discourse: Studies in the Cultural Politics of Education.</i>
14.45-15.00	Current trends in Disability Studies Dis/Performance by Dr. Alice Schippers & Jacqueline Kool
15.00-15.15	Special Issue Contested Humanity in the journal <i>Social Inclusion</i>

	Dr. Paul van Trigt & Alice Schippers
15.15-15.30	Discussion
15.30-15.45	Short break for coffee and tea
15.45-16.15	Auto-ethnographizing chronic illness: a relational performance Dr. Alistair Niemeijer & Dr. Merel Visse
16.15-16.30	Discussion
16.30-17.00	Open Discussion to examine future collaboration opportunities
17.00	End

**2. Tuesday 21st June. HARVESTING AFTERNOON: ‘Researching the human(e)?  
Presenting, reviewing and discussing of future articles**

14.00-15.00	Dr. Hanneke van de Meide & Prof. Leo Visser. Discussion of the article ‘Why people with relapsing-remitting Multiple Sclerosis succeed in the labor market – personal narratives on what it takes to continue working’ (empirical paper - work in progress). This paper reports on the findings of a narrative study on MS and work participation. Referee: To be announced
15.00-16.00	Presentation of research (and/or research plan) by Irene Caubo, PhD student Disability Studies in Nederland, Vu University Medical Center. Referee: To be announced
16.00-17.00	Presentation of research (and/ or research plan) by Anaïs van Ertvelde, PhD student at Institute of History, Leiden University. Referee: To be announced.
17.00	End