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Anderson, Bridget

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HUMBOLDT-UNIVERSITÄT ZU BERLIN

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Capability, Care, and Personal Assistance: Making Connections

Bridget Anderson (bridget.anderson@bristol.ac.uk)

Abstract: The Capability Approach/Capability Theory (CA/T) makes the normative claim that freedom to achieve well-being is of primary moral importance. It has made significant contributions in its original field of Development Studies and has also been used in other fields as a framework to assess the relation between well-being and socio-economic contexts, to inform policies for social change. CA/T's move from a focus only on resources (redistribution) reveals how the relation between the elements of participation and freedom in the achievement of well-being becomes contested. This paper will use two examples from empirical research conducted with disabled people, their personal assistants and care workers to explore how attention to participation, connection, and affiliation can further develop CA/T.

Keywords: Capability Approach; Care; Contract; Disability; Ethics

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Introduction

The Capability Approach/Capability Theory (CA/T) makes the normative claim that freedom to achieve well-being is of primary moral importance. It has made significant contributions in its original field of Development Studies and has also been used in other fields as a framework to assess the relation between well-being and socio-economic contexts, to inform policies for social change. CA/T's move from a focus only on resources (redistribution) reveals how the relation between the elements of participation and freedom in the achievement of well-being become contested. This paper will use two examples from empirical research conducted with disabled people, their personal assistants and care workers in two highly contrasting situations to explore the applicabililty of CA/T. In particular, I consider the relevance of autonomy, social relations, and affiliation, and invite reflection on how this points to the importance of dialogue between scholars and practitioners coming from the perspectives of ethics of care on the one hand, and critical disability studies on the other.

The Capability Approach

The Capability Approach (CA), first developed by economist and philosopher Amartya Sen (1985, 1993, 1999), attends both to inequalities of income and to inequalities of substantive freedoms to live in the world as one chooses. Set firmly within the liberal tradition nevertheless it is critical of both utilitarianism and Rawlsian thinking: Sen observes that considerations of distribution are not sufficient to evaluate well-being because people differ in their ability to convert the goods, services, and other resources to which they have access into outcomes. CA starts from a position of human diversity rather than assuming the white male able body as the norm as in classical liberal theory. Recognising the normative significance of individual and social diversity, Sen argues that each person has a unique profile of personal, social, and environmental conversion factors that work to convert resources into sets of possibilities. These possibilities are capability sets that enable one to flourish. In this way CA facilitates an appreciation of the importance of particularity but also pays attention to how capability sets are shaped by the political, social, and economic landscape.

This recognition of different starting points, constraints, and expectations has meant CA has been particularly useful in analysing gender and social justice, public policies, discrimination, and social hierarchies. Sen considers subjective happiness an inadequate measure of well-being because people may adapt to restrictive conditions and limit their expectations – the phenomenon of "adaptive preferences" (Sen 1984, 309). Thus he invites us to strive for lives people have good reason to value. However, the concern to neutralize adaptive preferences raises the question, what is a life that one has (good) "reason to value" (Sen 1999; Khader and Kosko 2019)? Sen is reluctant to engage with more general questions about entitlements, preferring to advocate for public reasoning that allows people to scrutinise and revaluate what they have reason to value. This "differs both (i) from trying to justify the ethics of human rights in terms of shared – and already established – universal values [...] and (ii) from abdicating any claim of adherence to universal values [...] in favor of a particular political conception that is suitable to the contemporary world" (Sen 2004, 321).

Martha Nussbaum has worked to develop Capability Theory from Sen's Capability Approach. She departs from Sen in her proposal of a list of ten "central human functional capabilities" that are required for human life to exceed "bare humanness" (Nussbaum 2010, 306). The list includes relational capabilities such as emotional well-being, affiliation, and interaction, that is being able to do things for oneself and for others. Thus participation both in the sense of deliberation and as partnership in social interaction, is recognized by both these foundational capabilities thinkers as important to quality of life. This bears comparison with Nancy Fraser's "participatory parity" (Fraser/Honneth 2003) which also is both processual (a process of deliberation from a position of equality) and an outcome (all adults are enabled to participate in society as peers). Fraser emphasizes the importance of "institutionalized patterns of cultural value [that] express equal respect for all participants and ensure equal opportunity for achieving social esteem" (Fraser/Honneth 2003, 36), but there are potential tensions between the cultural value of autonomy and Nussbaum's relational functional capabilities, that become particularly evident in issues related to disability, care, and personal assistance.

The disability movement has demonstrated the many ways in which disabled people are excluded – including exclusions from deliberation about what constitutes a good life. Domination, manifest in paternalism/maternalism, institutionalisation, and medicalisation has meant that disabled people have been excluded from decisions about their own lives, as well as from practice, analysis, and theory, at times with truly horrific consequences. The so-called

"social model" of disability distinguishes between impairment and disability arguing that disability is caused by a disabling society that discriminates and puts in place physical, attitudinal, and organizational barriers that disable people who have impairments. Built environments, system designs, and environmental "dis-enablings" result in people with certain traits being made "disabled" (Oliver 1983; Oliver 2013).

CA/T's starting point of human difference and its focus on connections between individual characteristics and wider socio-economic factors very much speaks to the social model. For example, when Sen discusses a bicycle as a resource he recognizes it can be used as a means of transportation only if a person has certain characteristics (such as two legs, strength, and knowledge of how to ride a bicycle) and is socially permitted to ride the bicycle. There has been considerable interest in the Capability Approach in disability studies (e.g., Mitra 2006; Norwich 2014; Terzi 2005; Trani/Bakhshi 2008; Trani et al. 2011) .Scholars and practitioners have explored how Capability Approaches to disability can facilitate a useful analytical distinction between disability and individual factors, disability and resources, and disability and politico-socio-economic context thus enabling an analysis that is relational and situated (Mitra 2006; Terzi 2010).

Scholars and activists with roots in feminism in common with disability scholars have engaged with capability approaches and theories, as one way of making visible the experiences and relations of people whose overlooking by mainstream theory and practice contributes to their oppression. But there are interesting and important debates between these traditions about the relationship between dependence, inter-dependence, and self-determination. Self-determination for many disability scholars is desirable as both process and outcome: "Self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer 2005, 117). It may be closely related, but not equivalent to autonomy as "our freedom to define who we are and what we value" (Guess et al. 2008, 77). Disability activists and scholars have argued for the importance of the recognition of personal autonomy as a pre-requisite for participation.

Some feminist theorists are wary of what they regard as the overvaluing of autonomy in mainstream political theory which they see as disregarding inter-dependence. Feminist theorist Eva Kittay, for example, referring to her child, who has profound intellectual and physical disabilities, asserts: "No, I don't take independent living as Sesha's goal, as much as I admire it as an aim for so many other disabled individuals. Independent living is a subsidiary goal to living as

full and rich a life as one's capacities permit" (Kittay 1999, 172). Kittay argues that all people move in and out of dependency, and that society must accommodate and make dependency into a resource that connects, rather than treat it as a deviation from the norm. If autonomy is not taken as the norm for all human interaction then alternatives other than paternalism become open to us (e.g., "co-operative, respectful, attentive relations" (Kittay 2011)). However, not all dependencies are the same, and one can seek to avoid certain kinds of constructed dependencies while not claiming that the self-servicing and independent individual is the ultimate goal. The dependence of a stay-at-home housewife on her husband is not equivalent to the dependence of the husband on the stay-at-home housewife. Understanding autonomy as a *social* right has been advocated by disability scholars (Boyle 2007) and feminists who have sought to rehabilitate autonomy through "relational autonomy" that does not assume an atomized self (Stoljar 2018) and there is broad agreement that social relations can facilitate or diminish autonomy. However, from the 1990s there have been criticisms of feminist work on care as entailing complex oppressions (Silvers 1997; Saxton et al. 2001; Priestley 1999; Morris 1991). Relations of care are inevitably at times conflictual. These conflicts may be experienced as personal and emotional but they are also structurally shaped and may also be grounded in conflicts of interest. Such conflicts become particularly visible in the case of paid service provision. Here, there has tended to be a divergence of focus in the feminist and disability literatures, with feminist scholars focusing on paid care workers, and disability scholars on the users of personal assistance (Boyle 2008).

For some time then there was a divergence between the feminist work on ethics of care and critical disability studies and work by disabled activists. For the latter, 'care' was bound up with institutionalization, forced dependence, and passivity, in direct contradiction to demands for autonomy and empowerment. Care researchers, who focused on the situation of formal and informal carers, paid little attention to disability studies. However, when Teppo Kröger asked "Care research and disability studies: nothing in common?", he urged for a dialogue between these fields given the overlap in concerns and very real shared social challenges (Kröger 2009). The 2015 special issue of *Alter* on Care and Disability exemplifies such engagement and the mutual concerns with how care is organised and the desire for emancipation and transformation: "Analyzing concrete care situations and revealing the ambiguities in the relationships at work, each article examines in its own way the limits of both the ethics of care and disability studies" (Winance/Damamme/Fillion 2015, 165).

Methodology

The research drawn on for this paper was conducted under the Horizon 2020 project "Towards an Empirically Informed European Theory of Justice" (ETHOS). The ETHOS project engages with the challenge of taking a bottom up approach for hybrid empirical/normative theorizing to develop theoretical insights that speak and respond to what are perceived as contemporary challenges for justice (Rippon et al. 2018; van den Brink et al. 2018). It had a particular interest in the conflicts between different justice claims of oppressed groups and how these are negotiated in the day-to-day. ETHOS comprised a number of sub-projects and these in turn drew on country case studies to inform sub-project papers. One element of the ETHOS research programme was to draw on and develop Capability Approaches/Theory. What follows draws on a sub-project that was focused on Capability Approaches/Theory. Its aim was to explore people's capacity to live the kinds of lives that they value, through an analysis of the actions, understandings, and relationships described in national case studies of support services for elderly and disabled people in private households. ETHOS country research teams used mini-ethnographies and semi-structured interviews conducted with care recipients, care workers, disabled people, and personal assistants, and, in some cases, with the family members of disabled people. Ethnography is a useful method through which "to explore the feelings, beliefs, and meanings of relationships between people as they interact within their culture or as they react to others in response to a changing phenomenon" (Fields/Kafai 2009, 923). We opted for focussed field visits with some researchers accompanying care workers over the course of their working day across multiple sites, and others following care/personal assistant users. We did not insist on restricting the study to disabled people in youth and middle years and included people who had been disabled as they aged. Due to the complex ethical issues involved, we did not include people with cognitive impairments. (For more details on case selection, access, and ethical issues please see Anderson 2020).

Research was conducted in Austria, Hungary, the Netherlands, Portugal, and Turkey. While informed by all of these studies, this paper particularly draws on the Austrian and Portugal work. The quotations from the interviews that follow are taken from previous publications from the ETHOS project (Brito 2018; Meier 2018).

Country	Service users	Service providers	Provision: private/ state
Austria	One blind single, one blind couple, one person with cerebral palsy	Students, household help, self-employed personal assistants	State
Hungary	An older woman recovering from an operation, one person with cerebral palsy	Two retirees, one professional physical therapist	Private
Netherlands	One disabled older woman, one married couple both with long term care needs	One district nurse, one homecare nurse, one nursing auxiliary	State
Portugal	One housebound older man, one elderly woman, one elderly couple in an institution	Four professional care workers	State
Turkey	Two elderly couples, two older women, one older man all with long term care needs	Ten live-in migrant care workers	Private

Table 1: Ethnographic participants by country

The Austrian ethnographies were conducted in private households, but also in other spaces, including workplaces, where personal assistants accompanied employers. The Portuguese study comprised care assistants who visited homes and care assistants who worked in an institution, both as employees of the same organisation. Finally, it should be noted that there are different positions on associating the fields of disability and older life studies, and some people reject the negative connotations that are felt to transfer from one to the other. However, there are strong arguments for applying the social relational model of disability to the situation of older people with impairments who use services (Oldman 2002). While there are important distinctions between ageing with and ageing into disability,

> "creative and generative possibilities emerge when aging is situated within a disability politics and when interpretations of disability take account of the weaving of material, social and cultural relations in and through which the meanings of bodies as young or old are made or unmade." (Aubrecht/Kelly/Rice 2020, 5)

A Tale of Two Service Users

Portugal and Austria have different ways of institutionalising and organising care. In brief, the Portuguese state has political responsibility for organising social protection and administering the welfare state, often using the Private Institution for Social Security (IPSS), a non-profit institution "giving an organized expression to the moral duty of solidarity and justice between individuals" (Brito

2018, 9). Responsibility is divided between family, state, third sector, and market. Support is available for "the satisfaction of basic needs and/or activities of daily living" (Brito 2018, 13). In Austria the federal government disburses funds to provinces to pay for community based services including daycare centres, care homes, and live-in care. People whose impairment requires assistance for 65 hours a month or more are entitled to a care allowance (*Pflegegeld*) with an allowance based on level of assistance needed. This can be used to pay family members, professional care services, or individual care workers (Meier 2018). Thus while both states are in the European Union they exemplify the very different care cultures that are critical in shaping the relationships and conversion factors from which derive the capability sets, or possibilities to flourish, available to individuals. As CA/T has emphasised the importance of conceptual and practical work accommodating both contextual and individual diversity I have selected two very different situations to use when examinining CA/T, autonomy, and social relations.

António

António is 71 years old and suffers from severe rheumatism. He has significant mobility problems, needing help to leave his bed, move around his home, and do the basic activities that are necessary for survival. He lives in the Portuguese village he was born in – though he left for work when he was 18 – and in his parents' former house. It is damp, cold, and dark, and smells unpleasant. He lives alone and sees no one apart from his sister who lives far away and visits only very occasionally. He is very lonely and feels trapped. His principle care workers are Maria and Ana, both older women who have worked for at least fifteen years for the Home Support Service (HSS). It offers personal services including help with personal hygiene, housekeeping, and food preparation to improve the quality of life of individuals and families and to delay or avoid the institutionalisation of older people. It is paid for by the state and in Maria and Ana's case, their employer also offers related residential provision – again paid for by the state. Maria and Ana are two of a mobile unit of ten workers, and while António receives assistance from all of them, they are his principle workers to try to ensure some continuity in the relationship.

In the morning António is one of four households to be visited in the first two hour shift. The two workers wash and dress him, prepare his breakfast and install him in front of the television. In the middle of the day they bring him lunch and stay for 15 minutes only. He is also visited in the evening. The visits are strictly routinised and time very limited leaving little room to accommoda-

te António's wishes. Maria and Ana are dedicated workers and do their best in the short time they have available, including doing his laundry more often than the weekly service sanctioned by the institution. He appreciates their work and looks forward to their visits: "It takes a very big heart to do this work and they work hard. But some people don't value their work, they must think it's nothing special, but it is, they are taking care of people. It is almost as they are a mother, and being a mother is beautiful" (Brito 2018, 32). However, there are other team members who he doesn't like "it seems that they don't want to be here, and they do everything in a hurry and I don't like that. I'm not a bag of potatoes... I don't trust them... When they are mean, I don't answer their questions, I'm not playful... I think they realize that I don't like their attitude..." (Brito 2018, 33). For their part Maria and Ana feel he is in a miserable situation. They are deeply sympathetic to his circumstances, but also unintentionally demeaning and patronising: "António doesn't receive any visitors, neighbours give him little or no attention: 'He looks like an abandoned dog', Maria tells me with a certain pain in her eyes" (Brito 2018, 22).

Desipte the centrality of autonomy to disability research and activism, there has been little attention paid to the autonomy of older disabled people, although autonomy has been identified by older people as critical to their quality of life (Boyle 2007). This is reflected in António's situation and there is a startling lack of institutional engagement with António's strong desire to leave the house, which he values and which would contribute to his quality of life:

> "I wish I could go outside more often. I don't remember the last time I went to the city... sometimes I go to see the doctor, but it's not the same thing. I guess it's the more unfair thing, not having someone to go out with me, the girls can't, they don't let them..." (Brito 2018, 32)

It has been deemed unsafe for him to leave the house unaccompanied, but one day, while alone in the house, his desperation to leave was such that he broke the lock on his door and was found wandering outside by a neighbour. One of the HSS assistants fixed it temporarily with string, and Maria and Ana find a knife on the floor which they realise António has used to cut the string. Pressed for time, the "solution" is to hide the knife.

> "They explain to him: 'You know that you cannot leave the house alone...' António answers: 'Not alone, nor accompanied, I don't leave the house!'. Silence. Caregivers don't insist on the subject and they dress him and take him to the kitchen to have breakfast." (Brito 2018, 27)

Maria and Ana are not able to respond to António's clear statement of wishes – they have, they say later, already spent too much time trying to resolve this situation and must hurry to the next house. They discuss their anxiety about António's situation at length in their breaks. António would prefer a live-in carer, because he is very lone-

ly, especially at night but they feel that the "independence" of non-institutional care is illusory and offered by HSS to save money rather than because it is the best option for him. They think his situation would improve if he were to access residential care. However, they can only "signal the case" (Brito 2018, 25) as they put it, but have virtually no contact with the administration team in their institution, and themselves feel disempowered and complain of not feeling free to change even small details of their interaction with their clients.

Arguably, António does not enjoy even "basic human flourishing" (Nussbaum 2010, 310). There are multiple factors that limit his capability sets. His impairment of arthritis impedes his physical movement, but factors like his lack of financial resources, poor family networks, and limited state provision dis-enable him by trapping him in his house. António is literally invisible, and his claims are heard only by his care workers who treat him kindly but as an object of care rather than a person with agency. Those who have institutional authority are removed from the daily practicalities of António's life, and gerontologists for example are available only in emergencies (Brito 2018, 29). He participates neither in deliberation nor in full social interaction, but it is the social interaction that he experiences as the most severe lack. Maria and Ana, who do their best in difficult circumstances, regard his situation as problematic, and recognize that his quality of life seems to be very poor, but their short term solutions end up further dis-enabling him (he is convinced that there are thieves in his house because all the knives have disappeared). Furthermore, his affective potential, his capacity to emotionally engage with others, which an ethics of care position would recognize as critical elements of what António offers, passes unrecognized by those who see him most regularly. He is treated as an object of concern. Nussbaum's central human capabilities cannot be traded off: "We cannot satisfy the need for one of them by giving a larger amount of another one. All are of central importance and all are distinct in quality" (Nussbaum 2010, 311). António's situation alerts us to the fact that in practice, supporting someone to live a bare life is seen as an end in itself, rather than necessary but not sufficient.

John

John is a partially sighted and disabled father, his female partner has no sight, and they have three children aged six months to seven years. Both work outside the home and require assistants for mobility, household tasks, and supporting their childcare. The province where the family lives is one of five provinces which offer a personal budget to persons with impairments, in addition to the federal-

ly mandated care allowance. The personal budget can be used to buy personal assistance that maximises self-determination and the number of hours to be paid for is assessed by a group of independent experts. This family has seven personal assistants whom they pay to be on standby for one day a week.

In this case, personal assistants are expected not to participate in decisions or social interactions and not to share opinions. Among our interviewees, John is unusual in that he regards the personal assistant as an extension of his physical body and says ideally he would have a machine rather than a person performing this function. He is very polite but considers that assistants should be as invisible as possible: "If I am in some meeting, I always do it the same way when I introduce myself: And to my left Miss X is sitting. You don't need to pay attention to her. She only needs some air to breathe" (Meier 2018, 24). The couple give their assistants a set of some 50 rules, developed, according to John, to facilitate clarity, transparency, and equal treatment between personal assistants and ensure a clear boundary between work and friendship.

John has a life he has good reason to value, facilitated by personal characteristics, social resources, and access to personal assistance. The personal assistants are resources that contribute to a capability set and enable a desirable functioning. The service is a response to the demand for justice in terms of self-determination that is both recognitive (recognising autonomy) and redistributive (providing the means to enable those who have been socially dis-abled). He and his partner select, train, and manage their personal assistance, participating both in deliberative and social interactive senses. In CA terms, public policy provides a resource that improves individual conversion factors in the face of social norms and environmental infrastructure.

In contrast to Maria and Ana, who found managing the institutional limitations of their role difficult, John's assistants noted the transactional nature of the relationship but did not object to it. "You basically hold yourself back and are really only the substitute, like it's here, the substitute for the eyes and maybe the hand, but … you are not more than that" (Meier 2018, 25). Under the arrangement of this particular household, PA's were paid using a service voucher system, meaning work is conducted under precarious, short-term (maximum one month) contracts that can be renewed repeatedly. Notably, only one of the personal assistants was not a student working to supplement their income rather than engaging with this role as a long term career. This likely contributed to their attitude to their employment and their satisfaction with the demarcation of tasks and responsibilities finding their conditions 'flexible' rather than exploitative and appreciation of the contractualised and boundaried nature of the personal assistance relationship.

Discussion

CA/T emphasises the range of resources that contribute to capabilities, but it is important to acknowledge the fact that our research found that those with higher income were able to bypass obstructions to the formation of decent capability sets and class position cushioned participants from the worst effects of state disinterest and dismissal. The fact that people with this capital can escape social impediments and vent in private rather than through public contestation potentially diminishes overall capacity to protest. However, resources are not only about income and those with human and social capital also found it easier to navigate complex bureaucracies enabling them to access services more readily than those with less of these resources. António's lack of social contact is a vicious circle. It not only a source of frustration and unhappiness for him. It also contributes to his difficulty in accessing rights and services that could improve his quality of life. His situation as a single man with no relatives nearby, and John's who lives with his partner and children, illustrates the role of the family in preserving the balance between autonomy and participation in social interaction and the challenges of passing this on to care workers. It also points to the relation between participation as interaction and participation as deliberation: until António's social interaction is better enabled it is difficult to see how he can participate in decision-making so dependent is he for social interaction on care workers. Maria and Ana wish to intervene on his behalf, but within the confines of their roles and institutionalized status hierarchies they also risk infantilising him.

In her critique of the direction taken by the social model of disability, Carol Thomas (2004) argues for the recapturing of the social relational model of disability developed by Finkelstein and Hunt:

> "disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are wholly social in origin. Such a social relational view means that it is entirely possible to acknowledge that impairments and chronic illness directly cause some restrictions of activity. The point is that such non-socially imposed restrictions of activity do not constitute 'disability'" (Thomas 2004, 580).

Using relationality as a lens and taking disabled people's subjective descriptions of their experiences as a starting point exposes the importance of understanding the relation between economic and social resources in order to explicate the role of the former in responding to social disenablings. For policymakers, it is the money that pays for care workers that is the key resource that people in different ways are to convert into capabilities to attain a life that they have rea-

son to value. However, our findings suggest that for the service providers and service users, even those who are handed direct budgets for care, the resource is *experienced* as time. For John but also for personal assistants and care workers this was 'contractual time', time experienced as a resource that can be measured and that has to be distributed *fairly* between multiple users. António's workers complained for example: "We don't have enough time... we wish that we could spend half an hour or even one hour with each one of them. But the houses are far apart, we lose a lot of time in the way and all of them need to have the same type of care. We cannot be more time with some of them and less with others" (Brito 2018, 23pp.).

Time is implicated in the building of relationships. António does not want more time so the workers can do more things for him, but so they can sit down (or go outside) and talk. This relational aspect of time is well understood by institutions and by individual employers. Timetabling is not only about logistics. Timetables can be drawn up to avoid too strong an attachment developing to particular individuals, or to facilitate relationships with individuals, or prevent relationships between support workers. The management of time is also the management of relationships and keeping them within or testing contractual boundaries. Yet for António being contractually recognized is not enough to constitute social participation, he seeks the kind of recognition that is captured in Nussbaum's affiliation. His situation also illustrates the importance of time to decisional autonomy – in cases such as his, assistants and others need time to enable them to support and talk through disabled people's decisions.

This contrasts with John whose use of personal assistance is set within a policy devised to facilitate individuals to be self-determining. Personal assistants are not simply allocated as a service to disabled people, but, as advocated by elements of the Independent Living Movement, policies require that the service users recruit, train, direct, and manage the personal assistants. Self-determination and independence signify not only that one is self-governed, but that one is able and is given the authority to govern others. However, ensuring that service users have a *sense* of self-determination is an important part of the personal assistant's job description and previous research has found that 97% of service users consider they live a self-determined life, but only 60% of personal assistants agree (Esterer 2012, cited in Meier 2018, 9). This suggests that the scheme and the personal assistants are indeed succeeding in establishing a sense of self-determination on the part of the service user. It can sometimes be experienced as challenging by the service provider: "What's not so good is you need to be able to hold back, to hold yourself back very well, and in many issues that's... difficult sometimes" (Meier 2018, 25). I am not arguing that the service users are not self-

determined (other than in the ways that no individual human being can be completely self-determined), but rather that this invisibilising of the inputs of personal assistants is itself work. Kittay has written about the "transparent self" of the dependency worker: "a self that defers or brackets its own needs in order to provide for another's... a self through whom the needs of another are discerned, a self that, when it looks to gauge its own needs, sees first the needs of another" (Kittay 1991, 51). However, unlike Kittay's transparent selves, personal assistants do not tolerate invisibility because they have interests vested in the wellbeing of another, but rather because they have entered a contract. Rather than transparency this is more akin to the invisibility of many service workers whose achievements at smooth running remain unnoticed until there is a problem.

This work can be more visible in family relations. One personal assistant contrasted her response to her disabled brother with her response to her disabled employer: "When my brother comes and says he needs something, that I should go and get it for him, I will say: Yes, I will finish that first, and then I will come... [But] in her case I know I am there for that, and I am also paid for being here, so I also can't take forever to do it" (Meier 2018, 55). We found that for our disabled interviewees while commodified support given by non-family members was considered assistance to be independent, unpaid support from family and friends was often experienced as dependence. Many people specifically sought to avoid being "dependent" on family often on the grounds that, unlike workers, they have not been able to choose their relationship. The benefit of contract to the service user is that they can limit their engagement with the service provider and vice versa.

There can be policy sleight of hand here, as in policy terms, relying on family members is often constructed as living independently because independence is strongly associated with not being institutionalised. António may be living in his own home, but the fact that he is locked in against his will indicates that while he may be classed as independent by officials he is by no means self-determined. Yet he chaffs at the limitations of the contractual model, adapting the familial story of care – the care workers are "like mothers". However the familial model has been challenged, not only by the Independent Living Movement but also by domestic workers and trades unions: justice claims for wages, reasonable working hours and conditions are claims of workers not mothers. On the other hand, the more like a worker the more alienated and instrumentalized the labour, and as many of the care workers in the national case studies aver, it is the relationality of care that gives them pleasure in their work and makes them feel their contribution is recognized. Maria and Ana have both worked in the sector for over a decade, and a life that has value for them includes not just perfor-

ming work tasks but providing *good care*. "A good caregiver cannot go to work by force. You have to like what you are doing. If not, it's better to go and find another job" (Brito 2018, 19). While emotion and affiliation are often associated with the private, for these care workers it is integrated into their working lives. As noted above, they are protected by contract, but in contrast to the student personal assistants, contractual governance disregards the cost of their emotional investment in their work.

What does this mean for CA/T and in particular for matters of participation? Many of our participants are not starting from a position of separation from which they are seeking connection and relationality but rather are seeking to *manage* connections, whether by contract and rules, professional distance, particular use of space, or depicting people as family members. Capabilities are conferred, shaped, and refused through connections with other people, connections which are experienced and institutionalised in ways that mean that, even as our starting point is individual difference, systematic assessment must take others into account. We need to understand how our capabilities are imbricated and this is particularly the case in relations of care, support and assistance. The interacting capability sets of António, Maria, and Ana, and of John, the household, and personal assistants must be analysed together. In situations marked by injustice this analysis requires dealing with messy emotions, not only because emotions infuse personal relationships, but because injustice, perceived or actual, generates an emotional response. The arguments of affected individuals may not, in consequence, always be "reasoned" but expressed with rage, passion, and sorrow.

Conclusion

Capability Theory is a non-ideal theory of justice. It starts from the world as it is rather than first arguing for the principles of justice that would prevail in an ideal world. Starting from the world as it is means starting from injustice that is embedded not only in personal relations, but in histories and institutions. Experiences of injustice in relation to personal assistance/care in private homes is instructive because these are not the great injustices of torture or starvation that Sen criticises ideal moral theory for not engaging with, but injustices that are part of daily life for many in Europe. They include injustices that are perpetrated unthinkingly and without reflection. It draws attention to the politics of contract and possessive individualism. It also invites questions about how claims can be

enforced including what the mechanisms are that can promote certain types of affective relations. In Nussbaum's framing, the state has the responsibility to promote core functional capabilities, but we need a more expansive understanding of the public sphere drawing on thinkers like Fraser who explore the importance of civil society and the myriad forms of associational and disputational life that make up civil society in contemporary democratic states. This is key to understandings of how our interdependence and autonomies are made, managed, and imagined. Attention to António, John, Maria, Ana, and personal assistants suggests the importance of a dynamic analysis of the relation between resources, conversion factors, and capability sets that is sensitive to temporalities, and to the emotional work we all perform in managing our connections with others. It points, too, to the importance of dialogue between feminist and disability scholars, activists, and practitioners, who while they have very different starting points, are concerned to build more equitable social worlds.

References

Anderson, Bridget (Ed.) (2020): Methodological Note to Accompany D5.3 national case studies. https://migration.blogs.bristol.ac.uk/research-projects/bodies-borders-justice/ethos/ethos-outputs/ (04.09.2020).

Aubrecht, Katie/Kelly, Christine/Rice, Carla (2020): The Aging-Disability Nexus. Columbia: The University of British Columbia.

Boyle, Geraldine (2008): Autonomy in long-term care: a need, a right or a luxury?. In: Disability & Society, 23 (4), 299–310. doi: 10.1080/09687590802038795

Brito, Laura (2018): Being Paid to Care For or Care About? Ethnographies of Home Care, National Report, Portugal. https://www.ethos-europe.eu/working-papers-country-reports (04.09.2020).

Fields, Deborah/Kafai, Yasmin (2009): A Connective Ethnography of Peer Knowledge Sharing and Diffusion in a Tween Virtual World. In: International Journal of Computer Supported Collaborative Learning 4 (1), 47–68. doi: 10.1007/s11412-008-9057-1

Fraser, Nancy (2005): Mapping the Feminist Imagination. From Redistribution to Recognition to Representation. In: Constellations 12 (3), 295–307. doi: 10.1111/j.1351-0487.2005.00418.x

Fraser, Nancy (1998): From redistribution to recognition? Dilemmas of justice in a „post-socialist" age. In: Willett, Cynthia (Ed.): Theorizing Multiculturalism. A Guide to the Current Debate. Malden, Massachusetts: John Wiley & Sons, 19–49.

Fraser, Nancy/Honneth, Axel (2003): Redistribution or Recognition? A Political-Philosophical Exchange. New York: Verso.

Gellert, Paul/Feldman, Shelley (2006): The Seductive Quality of Central Human Capabilities. Sociological Insights into Nussbaum's and Sen's Disagreement. In: Economy and Society 35 (3), 423–452. doi: 10.1080/03085140600845008

Guess, Doug/Benson, Holly Anne/Siegel-Causey, Ellin/Agran, Martin (2008): Concepts and Issues Related to Choice Making and Autonomy among Persons with Severe Disabilities. In: Research and Practice for Persons with Severe Disabilities 33 (1–2), 75–81. doi: 10.2511/rpsd.33.1-2.75

Kittay, Eva (1999): Love's labor: essays on women, equality, and dependency. New York: Routledge.

Khader, Serene/Kosko, Stacey (2019): "Reason to Value": Process, Opportunity, and Perfectionism in the Capability Approach. In: Keleher, Lori/Kosko, Stacy J. (Ed.): Agency and Democracy in Development Ethics. Cambridge: Cambridge University Press, 178–204. doi: 10.1017/9781108163880

Kröger, Teppo (2009): Care Research and Disability Studies: Nothing in common?. In: Critical Social Policy 29 (3), 398–420. doi: 10.1177/0261018309105177

Leahy, Ann (2018): Too Many "False Dichotomies"? Investigating the division between ageing and disability in social care services in Ireland: a study with statutory and non-statutory organisations. In: Journal of Aging Studies 44 (1), 34–44. doi: 10.1016/j.jaging.2017.09.005

Meier, Isabelle (2018): "You really need to hold back – you are only the surrogate eye". Personal Assistance in Austria. https://www.ethos-europe.eu/sites/default/files/5.3_austria.pdf (11.05.2021).

Mitra, Sophie (2006): The Capability Approach and Disability. In: Journal of Disability Policy Studies 16 (4), 237–247. doi: 10.1177/10442073060160040501

Norwich, Brahm (2014): How does the Capability Approach Address Current Issues in Special Educational Needs, Disability and Inclusive Education Field?'. In: Journal of Research in Special Educational Needs 14 (1), 16–21. doi: 10.1111/1471-3802.12012

Nussbaum, Martha (2003): Capabilities as Fundamental Entitlements. Sen and Social Justice. In: Feminist Economics 9 (2/3), 33–59. doi: 10.1080/1354570022000077926

Oldman, Christin (2002): Later Life and the Social Model of Disability: A Comfortable Partnership? In: Ageing and Society 22 (6), 791–806. doi: 10.1017/S0144686X02008887

Oliver, Mike (2013): The Social Model of Disability: thirty years on. In: Disability and Society 28 (7), 1024–1026. doi: 10.1080/09687599.2013.818773

Oliver, Mike (1983): Social Work with Disabled People. Basingstoke: MacMillan.

Priestley, Mark (1999): Disability Politics and Community Care. London: Jessica Kingsley Publishers.

Rippon, Simon/Theuns, Thomas/de Maagt, Sem/Zala, Mikos/van den Brink, Bert (2018): Report on the European Heritage of Philosophical Theorizing about Justice. https://ethos-europe.eu/sites/default/files//docs/d2.1_website_report_complete.pdf (18.12.2018).

Robeyns, Isabelle (2003): Is Nancy Fraser's Critique of Theories of Distributive Justice Justified? In: Constellations 10 (4), 538–554. doi: 10.1046/j.1351-0487.2003.00352.x

Saxton, Marsha/Powers, Laurie/Eckels, Karyl/Curry, Mary-Ann/Maley, Susan/Gross, Jacqueline (2001): "Bring me my scooter so I can leave you". A Study of Disabled Women Handling Abuse By Personal Assistance Providers. In: Violence Against Women 7 (4), 393–417.

Sen, Amartya (2004): Capabilities, Lists and Public Reasons: Continuing the Conversation. In: Feminist Economics 10 (3), 77–80. doi: 10.1080/1354570042000315163

Sen, Amartya (1999): Development as Freedom. New York: Knopf.

Sen, Amartya (1993): Capability and Well-being. In: Nussbaum, Martha/Sen, Amartya (Ed.): The Quality of Life. Oxford: Clarendon Press, 30–53.

Sen, Amartya (1985): Well-being, Agency and Freedom. The Dewey Lectures 1984. In: Journal of Philosophy 82 (4), 169–221.

Sen, Amartya (1984): Resources, Values and Development. Oxford: Basil Blackwell.

Silvers, Anita (1997): Disability Rights. In: Chadwick, Ruth (Ed.): The Encyclopedia of Applied Ethics, ed. Ruth Chadwick. San Diego: Academic Press, Inc.

Terzi, Lorella (2010): Justice and Equality in Education. A Capability Perspective on Disability and Special Educational Needs. London: Bloomsbury.

Terzi, Lorella (2005): Beyond the Dilemma of Difference. The Capability Approach to Disability and Special Educational Needs. In: Journal of Philosophy of Education 39 (3), 443–459. doi: 10.1111/j.1467-9752.2005.00447.x

Thomas, Carol (2004): How is disability understood? An examination of sociological approaches. In: Disability & Society 19 (6), 569–583. doi: 10.1080/09687590420002525 06

Trani, Jean-Francois/Bakshi, Parul/Bellanca, Nicolò/Biggeri, Mario/Marchetta, Francesca (2011): Disabilities through the Capability Approach Lens. Implications for Public Policies. In ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap 5 (3), 143–157. doi: 10.1016/j.alter.2011.04.001

Tronto, Joan (1993): Moral Boundaries. A Political Argument for an Ethic of Care. New York, Routledge.

van den Brink, Bert/Rippon, Simon/Theuns, Thomas/Zala, Mikos (2018): Report on the workshop "Ideal and Non-Ideal theories of Justice": Towards a Non-Ideal Theory of Justice in Europe. https://ethos-europe.eu/sites/default/files//docs/d2.2_loaded_website_version.pdf (18.12.2018).

Wehmeyer, Michael (2005): Self-Determination and Individuals with Severe Disabilities: Re-examining meanings and misinterpretations. In: Research and Practice for Persons with Severe Disabilities 30 (3), 113–120. doi: 10.2511/rpsd.30.3.113

Winance, Myriam/Damamme, Aurélie/Fillion, Emmanuelle (2015): Thinking the Aid and Care Relationship from the Standpoint of Disability: stakes and ambiguities. In: Alter 9 (3), 163–168. doi: 10.1016/j.alter.2015.05.007