



UvA-DARE (Digital Academic Repository)

The Limits of Autonomy: Ideals in Care for People with Learning Disabilities

Pols, J.; Althoff, B.; Bransen, E.

DOI

[10.1080/01459740.2017.1367776](https://doi.org/10.1080/01459740.2017.1367776)

Publication date

2017

Document Version

Final published version

Published in

Medical Anthropology

License

CC BY-NC-ND

[Link to publication](#)

Citation for published version (APA):

Pols, J., Althoff, B., & Bransen, E. (2017). The Limits of Autonomy: Ideals in Care for People with Learning Disabilities. *Medical Anthropology*, 36(8), 772-785.
<https://doi.org/10.1080/01459740.2017.1367776>

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.



Medical Anthropology

Cross-Cultural Studies in Health and Illness

ISSN: 0145-9740 (Print) 1545-5882 (Online) Journal homepage: <http://www.tandfonline.com/loi/gmea20>

The Limits of Autonomy: Ideals in Care for People with Learning Disabilities

Jeannette Pols, Brigitte Althoff & Els Bransen

To cite this article: Jeannette Pols, Brigitte Althoff & Els Bransen (2017) The Limits of Autonomy: Ideals in Care for People with Learning Disabilities, *Medical Anthropology*, 36:8, 772-785, DOI: [10.1080/01459740.2017.1367776](https://doi.org/10.1080/01459740.2017.1367776)

To link to this article: <https://doi.org/10.1080/01459740.2017.1367776>



Published with license by Taylor & Francis. © 2017 Jeannette Pols, Brigitte Althoff, and Els Bransen.



Accepted author version posted online: 24 Aug 2017.
Published online: 22 Sep 2017.



Submit your article to this journal [↗](#)



Article views: 1475



View Crossmark data [↗](#)



OPEN ACCESS



The Limits of Autonomy: Ideals in Care for People with Learning Disabilities

Jeannette Pols^{a,b}, Brigitte Althoff^b, and Els Bransen^c

^aDepartment of General Practice, Section of Medical Ethics, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands; ^bDepartment of Anthropology, University of Amsterdam, Amsterdam, the Netherlands; ^cTrimbos Institute, Netherlands Institute of Mental Health and Addiction, Utrecht, the Netherlands

ABSTRACT

In the Netherlands, autonomy is a key ideal in visions of care for people with learning disability. This ideal can lead to tension when clients, in the opinion of their caregivers, overuse alcohol or drugs. In this article, we analyze how professional caregivers understand the ideal of autonomy in care for people with learning disability, and articulate the tacit attempts of caregivers to provide “good care,” which can be understood as care for relationships. This relational view includes caregivers, care recipients, and their networks and infrastructures in the vision of care.

KEYWORDS

Netherlands; empirical ethics; people with learning disability; substance use; visions of care

Autonomy—understood as the ability to direct one’s own life and live according to one’s own preferences—is a key ideal in the Dutch vision of care for people with mild or moderate learning disability. However, living up to this ideal can lead to conflict, which emerges, for example, when clients overindulge in alcohol or drugs in the opinion of their caregivers, but not in their own view. We conducted an ethnographic study and an empirical ethical analysis of how Dutch professional caregivers understand the ideal of autonomy in care for people with learning disability by analyzing the problems related to substance use. How do professional caregivers understand autonomy? Where do they encounter conflicts related to substance use, and why? What strategies do they use to manage tensions and find constructive solutions in care?

Social background

For a long time, the Netherlands was at the top of the list of countries that provided institutionalized care for mental health care patients, people with learning disability, and frail older people. However, rising costs and changing ideas about quality of life have driven deinstitutionalization since the 1980s (Pols 2016; Tonkens and Weijers 1999). The process of deinstitutionalization began slowly, but gathered speed when anticipated increases in health care costs led the Dutch government to rapidly dismantle the welfare state.¹ Although cost is now the dominant motive, *citizenship* and participation in society used to be stated ideals too. The ideal of citizenship made patient autonomy and self-determination core values (Pols 2006). As citizens, everyone, including people with disabilities, should be allowed to live according to their own rules, norms, values, and choices (Meininger 2001).² Institutional care had prevented this, the reasoning went, because professionals and institutional rules defined the lives of those who Goffman (1968) called the “inmates” (see also Tonkens and Weijers 1999). Inmates had to move out of institutions to become citizens who could govern their own lives (Pols 2006, 2016). Practical ways to implement this were to provide housing to people in ordinary neighborhoods and to support their move from sheltered workplaces to the regular labor market.

CONTACT Jeannette Pols  a.j.pols@amc.uva.nl  Department of General Practice, Section of Medical Ethics, Academic Medical Centre, University of Amsterdam, PO Box 22660, 1100 DD Amsterdam, the Netherlands.

© 2017 Jeannette Pols, Brigitte Althoff, and Els Bransen. Published with license by Taylor & Francis.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

At the turn of the twenty-first century, the Dutch formulated the “citizenship paradigm” as a vision guiding the care of people with learning disability (Frederiks, van Hooren, and Moonen 2009:7; Hutchison and Lord 2001; Renders and Meininger 2011:17; Van Gennepe 2000). The citizenship paradigm provides a care model in which people live in ordinary neighborhoods, in an inclusive community (Wilde 2015). Policy vision documents, such as the one by the Organization for Care for the Intellectually Handicapped in the Netherlands, incorporate the citizenship paradigm’s notion of autonomy (*eigen regie*: to direct oneself) alongside the promotion of the quality of life for people with learning disability (VGN 2007). Critics, however, have accused policymakers of using these ideals as a way to contain healthcare costs: to withdraw institutional care and force people to take care of themselves, instead of promoting good care and well-being (Frederiks et al. 2009; Gennepe 1997). Some declared the citizenship paradigm bankrupt for this reason (Moonen 2015); independence, they argued, came to represent “do whatever you want, but don’t ask for support.” The deinstitutionalization program ignored the need to support people with learning disability to help live meaningful lives. If they are not supported, they will be marginalized, unable to live up to society’s demands, lack job opportunities, and receive low pay rates when they do have work, and they have great difficulties with digital society (Woittiez et al. 2014). This led Moonen (2015) to proclaim the “right to support” as a basis for a new care vision, as also stipulated in the Convention on the Rights of Persons with Disabilities (CRPD 2006; Flynn and Arstein-Kerslake 2014).

Substance use and the limits of autonomy

The research on which this article reports was conducted in response to problems with substance use by people with learning disability. In the Netherlands, care for people with learning disability is organized separately from the specialist services for substance abuse and addiction. These services do not match well, due to the particular problems and needs of people with learning disability (see below) and the distance between neighborhood care programs and specialist services. Specialist services provide treatment to people who present to the clinics on their own initiative; there is no outreach service. This resonates with the philosophy of these clinics that people with substance use problems can only be supported when they are sufficiently motivated to accept treatment. Hence, the different care organizations stress autonomy in different ways.

According to the citizenship ideal, caregivers of people with learning disability are supposed to act only when clients ask for advice or consent to suggestions made. However, this leads to friction when differences in opinion arise on what constitutes a problem. Clients saw little problem in their use of alcohol or cannabis, both readily available in the Netherlands (see also Clarke and Wilson 1999). When caregivers thought that their clients’ alcohol or drug use was excessive and thus detrimental to their ability to live a valuable life, they saw no legitimate way to intervene timely. If clients did not share this perception, the caregivers had no grounds to justify their efforts, and they could act only if and when clients met the legal criterion of becoming a “danger to self or others.” But they preferred not to wait for extreme situations to happen and wanted to intervene at an earlier stage.

Intervention is tightly regulated in the Netherlands. The BOPZ law (*Wet bijzondere opnemingen in psychiatrische ziekenhuizen* [Law for special admission to psychiatric hospitals]) aimed to safeguard patient autonomy, formulating the criterion of “danger to self or others” as the only reason for involuntary admission to a psychiatric hospital. Once in hospital, people could be treated against their will, but only if there was “severe danger for self or others.” Hence, degrees of coercion were regulated. New laws, currently under discussion in parliament, aim to allow coercive treatment to take place at home.³

In our study, we found many situations where caregivers saw problems their clients did not see, often in relation to the use of alcohol, drugs or medication. The citizenship paradigm makes the client’s decision the only valid grounds for caregiver intervention. It does not, however, describe the place of caregivers in the lives of their clients, other than generally stating that caregivers should respect and stimulate the autonomy of their clients. In this article, we demonstrate that autonomy gains the specific meaning of “governing one’s own life” in care visions, and that this autonomy is achieved in practice without the need for support. However, when caregivers talk about the problems

they have in relation to client autonomy, they reframe autonomy as a competence. This happens when they perceive clients making *wrong* decisions for themselves, and so contradictory to the client's capacity to lead a meaningful life. Caregivers worked tacitly around ideas of what a meaningful life is or should be. We will articulate these ideas in the second part of the article. Rather than reframing notions of autonomy (see Foster 2009; MacKenzie and Stoljar 2000), we argue that a relational view of care forms a suitable framework to understand this tacit work as "good." This is work oriented toward a vision of what good care entails, and so is linked to an ethics of care (Tronto 1993; Walker 1997). In this perspective, caregivers actively support their clients to build relationships and infrastructures to create a meaningful life. Rather than focusing on individuals governing themselves, relationships become both the means and the ends in the provision of care for people with learning disability.

Substance use and learning disability

Engaging in cultural habits like drinking can be seen as a way to access culture and society (Manthorpe 1995; Simpson 1998). However, most researchers focus on problems that come with substance use. Bransen and colleagues (2009) have shown that Dutch people with mild to borderline learning disability are more likely than young people in the general population to engage in binge drinking and heavy use of cannabis. Staff from 39 services for people with learning disability report that cannabis and other (illegal) drugs are used more often in comparison to the general population, whereas alcohol consumption was less (Van Der Nagel et al. 2011). Estimations of harmful use or addiction for people with mild to borderline learning disability range from 15 percent to 42 percent (Kaal et al. 2009; Tenneij and Koot 2006). People with learning disability are reported to be more vulnerable to the negative consequences of substance abuse, including victimization, dropping out of school or leaving work, psychiatric problems and other health-related problems (Taggart et al. 2007; Van Der Nagel et al. 2011).

Notwithstanding these problems, staff from both learning disability and addiction care services maintain that coaching people and "discouraging" or "forbidding" the use of alcohol or drugs is difficult (Van der Nagel et al. 2011:147). The organization Mainline (2013), for example, argues that forbidding is "not effective" and promotes policy aimed at harm reduction rather than abstinence (Marlatt and Witzkiewitz 2010; Roe 2005; Stevens 2011), with emphasis on the consequences of use, such as criminal behavior and harassment. The second problem is that there is no authority to implement restrictions on use, unless things go seriously wrong and legal interference is warranted. This situation points to a problem of principles: if people do not perceive a problem themselves, others can do nothing about it. According to the Guideline on Substance Use for People with Learning Disability, supervised by Mainline (2013), "discouraging substance use" should be the strategy of choice for caregivers. But, even if one took up this advice, it is hard to know how exactly to put it into practice, particularly, when it is "the client who decides whether he/she wants to tackle his/her substance use" and "the supply of care should be [...] aimed at the request for help from the client."

The recommendations of the more widely supported Vision Document on Care for Addiction show the same ambivalence. This document subscribes to the autonomy of alcohol and drug-users, but makes room for "assertive interventions" when substance use jeopardizes the autonomy of the individual (GGZ Nederland 2013). The substance user is hence ambiguously both autonomous and not autonomous.

Methods

To explore the normative tensions in the practice of care enshrouded by an autonomy-based vision, we conducted an empirical ethical study. Empirical ethics ethnographically studies normativity (ideals, values, laws, or different "forms of the good" (Thévenot 2001)) as it takes shape *in practice*. It studies the nature and function of ideals and values that emerge in the material and semiotic

relations between actors (Mol 2008, 2012; Pols 2015; Willems 2010; Willems and Pols 2010). This includes material “actants”, such as technology, alcohol, or care infrastructures (Danholt and Langstrup 2012; Langstrup 2013). Professionals and clients are approached as actors who aim to bring about “good care,” where “good” is a deliberately open concept that demands empirical concretization.

The preferred methods for empirical study are ethnographic. This takes the study of values out of the domain of academic ethics and into the realm and expertise of anthropology. The ethnographic study of values allows the analyst to talk not only with informants about their general understanding of good care, but also to observe their practices and the ideals embedded in these. This grounds talk about care in actual care activity and allows us to take the position of clients into consideration. Although we interviewed several clients, verbal articulacy was not a strength, and observations were invaluable here. For instance, clients may not be able to express that they do not want to take particular advice, but it becomes apparent through what they do. It was hard, even impossible, to discuss alcohol or drug use with some clients as they did not perceive it to be a problem, and we were wary of making it one by talking about it. Observation was one way of taking into account the views of verbally weak subjects (Pols 2005).

In this article, we focus on the visions of caregivers. For them too, what they said often tells only part of the story. Talk about good care often alludes to inspirational statements. The multiple interpretations of citizenship are a case in point (Ootes et al. 2010); these unite political, legal and financial vocabularies to frame notions of good care. As we will show, observing caregivers at work and relating interviews to actual events gave us a practice-oriented vocabulary to discuss care in terms of relationships rather than in terms of individual autonomy.

Articulating what is deemed good in empirical settings is not the endpoint of the empirical ethical analysis. Good intentions can lead to “bad care,” or care that is not optimal. Our observations formed the starting point of considerations about what works best for whom. In this article, *implicit* ideals in care practices formed the starting point for developing a new normative vocabulary for analyzing good care for people with learning disabilities. We link these implicit practices to notions of interdependence and relationality as developed in care ethics, disability studies, and care studies (Pols 2015; Winance 2010).

The setting

We conducted a document study and ethnographic fieldwork in the Netherlands to study care in two ambulant care organizations for people with learning disability that were active in two large cities and one smaller town. The two field workers (Brigitte and Els) took extensive notes from their observations, and recorded, anonymized and transcribed the interviews. Some clients objected to recording, but allowed note taking. Interviews with caregivers lasted about an hour, while interviews with clients were shorter, between 15 to 30 minutes. Interviews were in Dutch, following a set list of topics, and discussed cases encountered during the fieldwork. Experts in the field were engaged through our advisory board. From February to June 2014, the two fieldworkers followed 11 community caregivers on 26 home visits to adult clients with learning disability. The 11 caregivers all had clients with alcohol or drug problems, including one client who was refusing diabetes medication, putting caregivers in a comparable dilemma of wanting to address problems that their client did not perceive. Informal conversations were conducted with other clients and caregivers. Besides interviewing the 11 caregivers, the fieldworkers also interviewed the leader of the team, and one caregiver who they had not followed. In both organizations, fieldworkers attended team meetings and conducted team focus group discussions with their caregiver informants. The groups discussed concerns with alcohol problems, visions on care related to autonomy and caregivers’ own ideals, as well as the dilemmas they experienced. The fieldworkers interviewed eight clients, four at each location. All participants volunteered to participate, and the consent of the clients was requested twice, first by the caregiver, and again by the researcher. Based on the narratives of the

caregivers and our observations of interactions, we constructed 21 case studies of 21 clients with alcohol or drug problems. The material—case study descriptions—was analyzed in a master's thesis (Althoff 2014) and led to a practical guideline for caregivers (Bransen 2015).

At the start of the study, we used autonomy as the sensitizing concept for analysis. We analyzed the meanings caregivers attached to the concept, and the way they used it in care practice. The material was further analyzed for other values in care, in line with our empirical ethics approach. We identified values as they were explicitly phrased or tacitly enacted. This qualitative study did not need ethics approval according to Dutch law, as it does not intervene in patient bodies or pose possible harm. However, because we were dealing with a vulnerable population, we took extra care to approach clients and ensure their consent. When we talked to client informants, we were careful to register any unease expressed either verbally or through body language. Clients could always opt out of a conversation with the researcher, or refuse to see her. The collected material was anonymized, and pseudonyms are used in the text.

Autonomy in the wild: Ideal or matter of fact?

As an ideal, autonomy is prevalent in visions of care for people with intellectual disabilities and has a specific meaning. When asked for their vision on care, the caregivers spoke in one voice:

Brigitte: Does your organization have a particular philosophy of care?

Sonja: Yes, [it is aimed at helping you] to direct your own life. That is the idea, that you can decide most things for yourself. [laughs] It's funny, but the way I work, and what I find very important is that the clients can decide things for themselves. We [caregivers] don't stand above them, but beside them. And as long as it's safe [*verantwoord*, responsible], we'll do what the client wants. So to speak. It's a very good vision, because everyone has the right to live their own life, and even with their learning disability, they can decide what to do. I find that very important.

The quote provides a clear example of the citizenship paradigm as an ideal in care, to be put to practice within the limits of safety and responsibility. Clients should be supported to live the life that they want. However, caregivers struggled to achieve this ideal:

Diane: He [client] overestimates what he can handle. It's gone wrong so often, whenever he gets a job. He wants to work five days a week, and it's fine for three weeks but then it all goes wrong and he loses the job. Whereas, if he worked two days, he could manage it. I'd like to show him that, by asking him questions. But he's really keen to work, and in the end he does what he wants. That's his choice, so, yes. It doesn't work well. [laughs] But I have to say that this last job is going surprisingly well, and that's really nice to see. So it's a dilemma. On the one hand you want to protect him against the failures he has to endure, and on the other hand he's so happy, and you want to give him a chance, to go ahead and try.

Caregivers have learnt to take a step back and give their clients the benefit of the doubt rather than try to prevent the harm they foresee. They grant their clients the opportunity to chase their dreams, and give things a try. This does not mean that they let their clients do whatever they want. They kept an eye on the results and discussed these with the clients. Experiments were possible, but the clients were not left alone. This implied a fine balance, where familiarity and predicted outcomes were balanced against the good of getting the chance to try again.

From our observations of day-to-day care, it was apparent that caregivers not only strived for the *ideal* of autonomy as directing one's own life, but that this ideal was actually *realized*. Autonomy was often a given, a condition under which the caregivers had to work. The clients rented their own apartments and this gave them, literally, the power to shut the door on their well-meaning caregivers. The possibility of being cut out was a concern that kept coming up in the way the caregivers worked in practice.

Field note: Jolanda says that they all have their own apartments. "You can't control what happens in there. You can have nice chats about things, but if someone goes to the supermarket and fills up his fridge with beer, you can't stop that happening." Jolanda then gives an example: It's always give and take with Michael [client]. At any moment he could say, "I don't want any more care. Here's your marching orders."

Clients do govern their own lives. Caregivers have to deal with this, and they were careful not to disrupt their relationship.

Joanna: You see, you have to know how to address Bert [client]. Because if you get too oppressive ... I do set limits, but very carefully, and not that often. That's how you must relate to Bert, otherwise you'll lose him. He closes the door on you, and then he won't let you in again. If that happens you certainly won't help him.

Thus, client autonomy was not only an ideal but also an actual situation, and caregivers have to work with and navigate around this fact. The power of clients who have become citizens is that they can *end* the relationship with their caregivers. Hence, caregivers worked hard on keeping the relationship going, staying in touch with their clients to allow them to give any support at all, even if not ideal and even if really problematic. Before they can even consider the value of “supporting autonomy,” the major challenge for caregivers was to get access to their clients at all.

Autonomy as a competence

Shaped as an ideal of governing one's life, autonomy could pose problems for caregivers, especially when clients did things that caregivers thought were not good for their own well-being. It was apparent that care not only aims at guaranteeing autonomy; caregivers want to achieve a good life for their clients. On that point, caregivers shift their interpretation of autonomy, which they then understand as a competence—something at which one can be good or bad, better or worse. If autonomy is a competence, one can also fail at it. In care, competence is often phrased in terms of the capacity to make decisions. Caregivers repeatedly told us that their clients weren't particularly good at this. Very often they made the wrong decision, in the sense that it did not help them achieve a good life for themselves.

Thera: You see, José [client] went to a dietician for her diabetes, and the dietician didn't understand how it works with people with a learning disability. She said for instance, ‘Do you drink tea?’ ‘Yes, I do’, says José. ‘Do you put sugar in your tea?’ ‘No.’ And then you should stop, next topic. But the dietician said: ‘Well, if you *did* use sugar, I'd advise you to start using sweeteners.’ And José thinks: ‘Sweeteners are better.’ And so she bought sweeteners, whereas it is better to drink tea *without* sweeteners. Or the dietician said: ‘You're allowed to eat a cake every now and then.’ But what is ‘every now and then?’ José never ate cakes, only on birthdays and such. But now she thinks: ‘Ah, I can eat cake! Every now and then I can eat cake.’ And now she buys cake. She eats worse now than before she went to the dietician. [laughs]

We heard several examples of tacit or explicit advice that led exactly to the behavior it tried to prevent. The most dramatic was Roger, who drank alcohol with his pills even though his doctor had explicitly and emphatically forbidden it, and a sticker on the package warned, “Do not use with alcohol.” The same evening Roger had to be admitted to hospital by ambulance, as he had drunk alcohol anyway. It was not clear if the doctor had considered Roger's alcohol problem when prescribing the medicine, or that Roger had ignored the warnings for other reasons. But problems with alcohol or abstract reasoning could put caregivers in real dilemmas.

Thera: See, if you knew that she could decide properly or that she could use her freedom to make a wise decision, then you can make an agreement. Then I'd say to her: ‘Your diabetes can give you problems with your health, your sight can get worse, you'll get low blood pressure, wounds, foot amputation, whatever.’ And if she said: ‘Ok, I'll take that into the bargain, because this is how I want to live.’ Well then, fine. But you can't talk like with her like that because she doesn't understand [the long-term consequences]. That makes it so hard.

Here, the problem is not this client's right to govern her own diabetes regime; she is doing it. But this is exactly where care for self-governance runs into problems. Here, there is a difference between good and bad autonomy, and between good and bad decisions. In both cases individuals govern themselves, but differently in each case. This kind of governance can go wrong. Here, the caregiver's problem becomes clear. Caregivers do not want to wait until their clients ends up with problems that are so bad that the caregiver is legally entitled to force compliance. They want to give support long before this. Moreover, caregivers *rejected* the use of force as it would jeopardize their relationship

with their clients. The clients would close the door on them, or they would go on doing what they liked, but out of sight of the caregivers.

[Caregiver]: Well, people drink or smoke, you have to be realistic. Prohibiting things is of course senseless. If you prohibit things, clients become invisible. They'll keep doing it behind your back. Our strategy is to get it [the abuse] out of the taboo area, and guide it [the use] towards acceptable proportions. That's the strategy.

These situations point to the limits of the ideal of autonomy in care. As an ideal of self-determination, autonomy is often achieved. There is little sense in using force in care, as it is not allowed and does not lead to the desired effects. When autonomy is regarded as a competence, however, clients were deemed to perform badly, particularly when alcohol or drugs clouded their judgment. The care vision based on self-governance gave caregivers no direction here, other than "wait for things to escalate."

From autonomy toward relationships

But this impasse is not where the story ends. Care was also directed at other types of goodness. Caregivers knew what they should strive for, even if they did not clearly articulate or justify their ideas. The dominance of the discourse on autonomy made that difficult. The tacit vision of care we could articulate presented a different logic (Mol 2008), with different values to orient it and different words to discuss it. The basis of this alternative vision is a relational approach rather than one that makes the individual central. How do caregivers work to establish and maintain relations with their clients, between and amongst clients and others? How do they work with the material facilitating infrastructures?

Maintaining the relationship

Lianne: Of course they [clients] can learn. Anyone can learn, and they can too. But maintaining a network? Or a structure in life? In daily life, each day is a test. You need to be able to stick to your structure and your plans. And they can't do that.

The quote shows what this caregiver finds important: having a structure in life, a plan, and a network of relationships. As a first step, much of the caregivers' work consisted of attempts to establish and maintain the relationship between *themselves* and their clients. These formed an important basis on which to build and support relationships with others. The relationship with the caregiver is supposed to be sustainable and resistant to contingent changes in a client's life over time. It needs patience to build this relationship.

Gisela [about her client]: You should be glad if you've built some trust in six months, that you've gained an entrance and maybe picked up on the first little things. It would be exceptional if we got any further than this in six months time.

By building a relationship, caregivers learn to get to know their sometimes unpredictable clients.

Wilma: With Jasper you mustn't emphasize the down side too much. Then he gets stuck, keeps repeating things. Whereas, if you take a positive note, he'll move on. I once commented on him skipping dinner. That he should have so-and-so-many meals a day. The next day he didn't have dinner again. He's a bit of a small child then: yes, yes, yes, sorry, sorry, sorry! He really wants me to be proud of him, and he doesn't want to be told off. That's how I see it. He's scared of rejection. And he's learnt that I'm really glad when he tells me things, that I can support him better like that, because then I know what's going on. And he knows I won't get angry. So then he reports something really hesitantly, like: 'See, Wilma, something went a tiny little bit wrong...' Then I try to respond like: 'Well, isn't that too bad now, how did it happen? Tomorrow is another day, so let's take it from there.'

For any caregiver, it is a matter of learning which approach works best for a given client. Each person has their own traits and habits. Being in a relationship means respecting the autonomy of not just the one party. Positions are negotiated. And although caregivers are flexible, not everything is acceptable. There was clear input from both partners.

Caregivers tried to tweak their clients' behavior when it had a destructive effect on their relations. This meant that caregivers defined the limits as to what *they* would accept from their clients. For example, Roger used to show up at the office drunk, ready to fight his caregivers and swear at them. This was threatening for the staff and destructive to the relationship caregivers had with Roger. The caregivers told him that they would not talk to him when he was drunk and enacted this policy strictly. Rather than damaging the relationship, it allowed flexibility for when Roger was *not* drunk. Establishing clear lines to the relationship meant it was easier to get things done or talk to people. One caregiver used the metaphor of a game.

Lisa: You have to play with people. Not go straight for your target. Try another way as well. You see, I really like Martin, who he is as a person. I don't approve of everything he does, but you have to feel for him a bit. I can tell him straight off: 'Damn it Martin, you can't do this, you can't go off all night and not tell your partner! She waits up all night for you and is scared shitless!' I can say that to him, but that's also because I'm quite relaxed with him, his beers and his hassle. And I do a lot of coaching talks in their relationship as well.

The metaphor of play meant that the move of one player depended on the moves of the other. The challenge was to keep the game going and stop players from dropping out. Rules and positions were not set in stone but are improvised along the way. This involved constant evaluation and adaptation, tinkering⁴ to achieve a "good game." There was give and take, where Lisa was allowed to reprimand Martin, because she also helped care for his relationship with his girlfriend. If either player dropped out, the caregiver attempted to re-engage the client or themselves in the game. The caregivers' creative efforts to craft relationships with clients was their core business. It meant they could address the problems and negotiate the limits.

Building network and infrastructure

Often caregivers used strategies to support a client's network and infrastructure, to ensure they had a job they could manage and felt good about, got on well with their family and friends, had meaningful things to do with their day, and a manageable household.

Thera: I often think we're more preoccupied with setting conditions for life without alcohol abuse rather than going straight for the target and saying: you can only have two beers. That doesn't work at all. You work on the things around it. You try to put their lives back on track, so that people will adapt their drinking in the same go.

For example, the caregivers almost gave up on Roger, the troublesome binge drinker who pushed other people away by swearing at them.

Janna: It was two minutes to blast off, so to speak, or maybe it was already blast off. Nobody saw any more options; it was really, how can we, the team, still coach him? We really didn't see how, especially because of the nuisance he caused where he lived. The idea was, this is really the last chance. We saw that his housing situation wasn't ideal. He shared a flat, lived with other clients. So we got him a small home apart from the others, where he's a bit further away from everyone. It worked well.

The first intervention for this almost "lost cause" was not to target Roger's alcohol use, but to adapt his housing situation. This meant no other people were around to be abused by him when he was drunk. The next step was to help him find a job. By helping him build a better life, working on finding a good fit in terms of material and social embeddedness, the caregivers did not give up on Roger. They built an infrastructure around him, setting out the tracks to sustain a meaningful life.⁵ "Building network" could also apply to the caregivers' professional network. They could call in extra help or particular expertise, for instance, a behavioral expert or a psychiatric or neighborhood nurse. The team delegated Roger to two team members who jointly coordinated their work. They were advised by a psychologist on how to manage his abusive behavior toward other people.

The strategy of building networks and infrastructures proved more fruitful than *reasoning* with clients, although caregivers would keep trying to talk to them.

Case study: Steven is generally very agitated but refuses to take his medication. He smokes cannabis to slow down. His caregiver says he understands this, and it also helps in his contact with Steven. When he had a job he liked, Steven smoked two joints a day and found a good balance. His employer kept an eye on him and they could work well together. But he lost that job due to reorganizations, and got a new one he didn't like. He found it too heavy for his back; he thought the pay was too low, and that he was being taken advantage of. And so he quit. His cannabis use increased dramatically. Due to his drug use, swearing bouts and refusal to take his medication it is difficult to interest employers in him. His caregiver says finding a suitable job is pivotal for Steven. Steven also stresses the importance of a good job, but is suspicious of being underpaid and discriminated against.

The story tells how Steven was kept off drugs through the support of his employer and the positions and routines he obtained through his job. Having a meaningful life reduces the need for alcohol and drugs, the caregivers reason. This is what they learnt from their history with their clients so they started from there. Notwithstanding the ideal of directing one's own life, the most important goal in the caregivers' work is to help clients obtain a satisfactory life, embedded in networks and with as few problems as possible. Achieving this may be situated in influencing others, changing institutions and environment, or adapting their client's response. This is how clients can also help each other.

Case study: Rinus has Down's syndrome. This organization has been coaching him since he was 17, in various housing circumstances. Four years ago, Herman, an old friend and colleague from the social employment organization, moved in with him, following a suggestion from Rinus's caregiver, Stefan. Stefan saw that the two men got along well. Herman is autistic. Herman and Rinus both work. Rinus had a drinking problem in the past, which was ignored in his previous accommodation. He turned to healthy living after a heart attack. Two years ago, when he moved into his present address, Rinus began to drink too much, and then would fight with the staff. When I [BA] talked to him, he said he drank one glass every other day. It's not an issue any more under Stefan's supervision. It helps that Herman positively detests alcohol, due to bad experiences in his past. Stefan encourages the two men to manage things between them. And they do. Rinus and Herman cook together. Herman takes care of Rinus's medication, helped by the overview put on paper by the thrombosis service, and goes to the dietician with him. The staff support practical matters like finances and the mail. Stefan supervises the consultations with the dietician. Stefan is happy with the way things have turned out.

The three men have established a balanced situation in which each person's tasks are clear. The situation does not foreground autonomy, self-governance or individual decisions, but shows that an intricate relational and infrastructural network has been put into place. The caregiver has not withdrawn, but takes his part of the tasks (finances and mail); he helps orchestrate the relations between both men and keep them going. The caregiver gets something in return: job satisfaction.

Care for substance use

One problem in providing effective care for alcohol or drug taking is the specialist nature of treatment in the Netherlands (and elsewhere, McLaughlin et al. 2007). Autonomy plays an important role because care is organized by a specialist, tertiary service that requires patients to visit the caregivers, and at the time of the study, there was no outreach such as community care teams. This limited the accessibility of the service, and if clients did not perceive a problem, they would not go.

The caregivers reported on the effect of the ideal of autonomy in the treatment of problematic drug or alcohol use. The care services start from the idea that people should be *motivated* to stop using alcohol or drugs. If clients are not motivated, the reasoning goes, then treatment will not succeed. The stronger the addiction, the stronger the effects of withdrawal, the more motivation the client needs. Although the Vision Document on Care for Addiction (GGZ Nederland 2013) advises assertive intervention and motivational training, this did not seem to be applied for the clients we studied.

Jan: That's the problem with [addiction care organization]. They're very much, if you [client] don't want to do it, we can't do it for you. You [client] have to be motivated, otherwise we can't do anything for you. And that is where it ends for them. Or they say, it has to go completely wrong first. Otherwise they'll never get motivated.

Care for addiction did not engage clients in any form of play. No caregivers came knocking on doors, or tried to develop methods to engage a particular client.

Petra: The method focuses on gaining insight, making agreements, and the clients' own motivation... When I see how hard it is for us to keep a relationship going, then I understand why Sjors doesn't want to go to [addiction care organization]. The clients have to go to them, but we always go to the clients.

Other ways of organizing care for addiction, coordinated with the work of the care team, seems well-advised to reach such clients. However, it does mean that organizational barriers need to be overcome.

Conclusion

Our analysis traced the concerns with autonomy as the concept took root in care for people with learning disability in the Netherlands. These concerns are not uniquely Dutch, but relate to wider concerns around the notion of autonomy in relation to alcohol use (Clarke and Wilson 1999). We have shown that coercion and restriction have very little utility, either because they do not lead to the desired result or because there are no power relations in place, other than those present for any citizen (the police, the law). Also, coercive measures are counterproductive to the core task caregivers have set themselves: to maintain relationships with their clients.

The notion of autonomy focuses attention on individual clients, who should be enabled to govern their own lives, but may not be good decision-makers. This often leads to an impasse when caregivers and clients have different ideas about what should happen. A care vision based on autonomy does not cover the role of the caregiver or others with whom the client has to live. As this vision excludes the caregiver (see also Ootes et al. 2013; Pols 2006), like the citizenship paradigm, it does not provide much direction for what caregivers should achieve, other than to support the self-governance of their clients. It did not work well, either because self-governance was already achieved or it provided no foothold for action when caregivers saw problems that clients did not perceive.

A care vision that includes caregivers requires a relational understanding of life and care. This has long been the message of care ethics that departs from the interdependence of people on one another, and the crucial activity of caring (Tronto 1993; Walker 1997). In this relational perspective we could see that caregivers, clients and others are constantly interfering with one another's autonomy (as we all are). They influence each another, disagree about things, try to persuade others to see things their way, and have different ideas about what is best to do in a particular situation. Desires may not be feasible without cooperation. There are limits to what one can arrange by oneself. The environment sets limits as well, or it forms infrastructures to enable new possibilities.

In care situations, interdependency means that it is not the caregivers' job to avoid hindering people from enacting autonomy, but to support them to achieve a good life. Caregivers become part of the network of their clients. As players in a serious game with each individual in the network, they have to stay in touch, keep knocking on doors and adapt their approach to fit each person. The other may act in unpredictable ways, and each person will have limits and conditions, or idiosyncratic ways of responding. Things can be tried, tested and adapted, and infrastructures for a good life can be built. The caregivers tried to keep the game going, tried to include enough players to keep the playing field stable. Between "doing nothing" and "applying coercion," there were many options for action. But "many options" did not guarantee immediate success. It took time and effort, persistence and dedication to get to know one another, and to accept that one's influence as a caregiver was limited. This was the caregivers' concrete way of "discouraging substance use." They did not tackle use directly, but tried to "work around" it. "Discouraging" meant offering a better alternative.

"Doing something for someone else" is often seen as a threat to autonomy. Autonomous people are often assumed to be better off doing things for themselves. Our analysis shows that caring for others is a way of establishing and maintaining relations. We met managers who sacrificed social activities such as cooking or shopping together, as that would be overprotective and "pamper"

clients. In a relational perspective, however, social networks should be cherished and facilitated because they make people part of a community that is meaningful to them. In many ways, it is more meaningful to find support than try to achieve any task alone. The two clients who organized their daily lives between them were supervised from a distance. Together they divided the work that needed to be done.

What does a meaningful life look like? From the caregivers, we learnt that it is a life embedded in relations that are meaningful to the individual, and engaging in meaningful activities. Some stability through supportive infrastructures proved crucial. Care for people with learning disability then benefits from and adds to the society in which they live in the sense that it provides opportunities for work, friendship, and meaningful activity. This vision is not about the quality of decisions or guaranteeing self-governance, but about what to achieve and how to achieve it. It treats people with learning disability as relational citizens, who have become part of society through their successful relations with others (Ootes et al. 2013; Pols 2006, 2016).

Notes

1. This is effected through the “law of participation” (participatiewet). See https://www.rijksoverheid.nl/onderwerpen/participatiewet?utm_campaign=sea-t-subsidies-a-participatiewet&utm_term=participatiewet&gclid=Cj0KEQIAAtMSzBRDs7fvDosLZmpoBEiQADzG1vIJ1oTRt9515z22gAmVtxymT1pK1810ohxUo-6X7KdwaAjFw8P8HAQ
2. The interpretation of autonomy in these terms is strikingly consistent in this field, whereas there is more variation in long term psychiatry (Ootes et al. 2010; Pols 2006, 2015).
3. At the time of writing the Dutch parliament had agreed to the new law *Zorg en Dwang* (care and coercion) for people with learning disability or dementia.
4. On tinkering, see Mol, Moser, and Pols (2010), chapter 1.
5. See for care infrastructures: (Danholt and Langstrup 2012; Langstrup 2013).

Acknowledgments

We want to thank the clients and caregivers for allowing us a glimpse into their lives and work. We are grateful to the support committee for this research: Evelien Tonkens, Joris van Erp, Dirk Verstegen, Jolanda Douma, and Xavier Moonen. We thank our colleagues for comments on earlier drafts of this article: Annelieke Driessen, Kristine Krause, Laura Vermeulen, Ariane D’Hoop, Tanja Ahlin, Emil Baek, Anja Hiddinga, Eileen Moyer, Hilje van der Horst, Wakana Kyoto, Tone Seppola-Edwardsen, Silke Hoppe, and Dick Willems. We thank Barbara DaRoit for her critical reading of Brigitte Althoff’s thesis.

Funding

This research was made possible by a grant (no. 731010003) from ZONMW, Ethiek and Gezondheid.

Notes on contributors

Jeannette Pols is Socrates Professor of Social Theory, Humanism and Materialities in the Health, Care and the Body Program, Department of Anthropology at the University of Amsterdam. She works as Associate Professor and Principal Investigator in the Section of Medical Ethics, Department of General Practice of the Academic Medical Centre in Amsterdam. She is the author of *Care at a Distance: On the Closeness of Technology* (2012), and a co-editor of *Care in Practice. On Tinkering in Clinics, Homes and Farms* (2010).

Brigitte Althoff is associated with the Department of Anthropology in Amsterdam. She did her master’s degree in Medical Anthropology and Sociology at the University of Amsterdam. For her master’s thesis, she collaborated on the research reported in this article.

Els Bransen is a research associate at the Trimbos Institute, Netherlands Institute of Mental Health and Addiction, Utrecht. She supports the development of guidelines to treat mental health problems of people with mild to borderline intellectual disabilities in the Netherlands.

References

- Althoff, B.
2014 Spelen verboden? Een zoektocht naar de balans tussen zorg en autonomie in de ambulante zorg voor volwassen cliënten met een licht verstandelijke beperking die alcohol en/of drugs gebruiken. Master thesis, Medische Antropologie en Sociologie, University of Amsterdam.
- Bransen, E.
2015 Waar bemoei ik me mee? Handreiking voor begeleiders van mensen met een lichte verstandelijke beperking die alcohol of drugs gebruiken. Trimbos-instituut, ed. Utrecht, The Netherlands: Trimbos-instituut.
- Bransen, E., H. Schipper, and J. Blekman
2009 Middelengebruik door jongeren met een licht verstandelijke handicap. *Verslaving* 5(4):37–49.
- Clarke, J. J. and D. N. Wilson
1999 Alcohol problems and learning disability. *Journal of Learning Disability Research* 43(2):135–139.
- CRPD, United Nations
2006 Convention on the Rights of Persons with Disabilities. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Danholt, P. and H. Langstrup
2012 Medication as infrastructure: Decentering self-care. *Culture Unbound: Journal of Current Cultural Research* 4(3):513–532.
- Flynn, E. and A. Arstein-Kerslake
2014 Legislating personhood: Realising the right to support in exercising legal capacity. *International Journal of Law in Context* 10(01):81–104.
- Foster, C.
2009 *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law*. Portland, OR: Hart Publishing.
- Frederiks, B. J. M., R. H. van Hooren, and X. M. H. Moonen
2009 Nieuwe kansen voor het burgerschapspaaradigma: Een pedagogische, ethische en juridische beschouwing. *Nederlands Tijdschrift voor de zorg aan mensen met verstandelijke beperkingen* 35(1):3–30.
- Gennep, A. T. G.
1997 Paradigma-verschuiving in de zorg voor mensen met een verstandelijke handicap. *Tijdschrift voor orthopedagogiek* 36(5):189–201.
- GGZ Nederland
2013 Een visie op verslaving en verslavingszorg: Focus op preventie en herstel. Amersfoort, The Netherlands: GGZ Nederland.
- Goffman, E.
1968 *Asylums: Essays On the Social Situation of Mental Patients and other Inmates*. New York: Anchor Books.
- Hutchinson, P. and J. Lord
2001 Empowerment: De instelling uit, de samenleving in. Lecture for conference 'Over grenzen. Een reis van zorg naar ondersteuning in de samenleving'. Stichting Perspectief en Odyssee Maatschappelijke Ontwikkeling, Ede, September 12–15.
- Kaal, H. L., M. M. J. van Ooyen-Houben, S. Ganpat, and E. Wits
2009 Een Complex Probleem: Passende zorg voor verslaafde justitiabelen met co-morbide psychiatrische problematiek en een lichte verstandelijke handicap. Report for Wetenschappelijk Onderzoek- en Documentatiecentrum (WODC), Ministry of Justice and Safety. Available at: <https://repository.tudelft.nl/view/wodc/uuid:27201076-1819-42e2-afad-3b635c211841/>
- Langstrup, H.
2013 Chronic care infrastructures and the home. *Sociology of Health and Illness* 35(7):1008–1022.
- Mackenzie, C. and N. Stoljar
2000 *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford, UK: Oxford University Press.
- Mainline, working group Mild Intellectual disabilities (werkgroep LVB)
2013 Visie: middelengebruik door licht verstandelijk beperkten (LVB) in de maatschappelijke opvang (MO). Report from werkgroep LVB en middelengebruik in de Maatschappelijke opvang, supervised by Mainline. Available at: <http://docplayer.nl/1655219-Visie-middelengebruik-door-licht-verstandelijk-beperkten-lvb-in-de-maatschappelijke-opvang-mo.html>
- Manthorpe, J.
1995 People with learning difficulties: Alcohol and ordinary lives. In *Alcohol Problems in the Community*. L. Harrison, ed. Pp. 98–114. London: Routledge.
- Marlatt, G. A. and K. Witkiewitz
2010 Update on harm-reduction policy and intervention research. *Annual Review of Clinical Psychology* 6:591–606.

- McLaughlin, D. F., L. Taggart, B. Quinn, and V. Milligan
2007 The experiences of professionals who care for people with learning disability who have substance-related problems. *Journal of Substance Use* 12(2):133–143.
- Meininger, H. P.
2001 Autonomy and professional responsibility in care for persons with learning disabilities. *Nursing Philosophy* 2(3):240–250.
- Mol, A.
2008 *The Logic of Care*. London: Routledge.
- _____.
2010 Care and its values. Good food in the nursing home. *In Care in Practice: On Tinkering in Clinics, Homes and Farms*. A. Mol, I. Moser, and J. Pols, eds. Pp. 215–234. Bielefeld, Germany: Transcript Verlag.
- _____.
2012 *The Body Multiple*. Durham, NC: Duke University Press.
- Moonen, X.
2015 Is inclusie van mensen met een verstandelijke beperking vanzelfsprekend? Lectorale Rede. Available at: <https://www.zuyd.nl/onderzoek/lectoraten/inclusie-van-mensen-met-een-verstandelijke-beperking/over-de-lector>
- Ootes, S., J. Pols, E. Tonkens, and D. Willems
2010 Bridging boundaries: The concept of ‘citizenship’ as a boundary object in mental healthcare. *Medische Antropologie* 22(2):375–388.
- _____.
2013 Opening the gift: Social inclusion, professional codes and gift-giving in long-term mental healthcare. *Culture, Medicine and Psychiatry* 37(1):131–147.
- Pols, J.
2005 Enacting appreciations: Beyond the patient perspective. *Health Care Analysis* 13(3):203–221.
- _____.
2006 Washing the citizen: Washing, cleanliness and citizenship in mental health care. *Culture, Medicine and Psychiatry* 30(1):77–104.
- _____.
2015 Towards an empirical ethics in care: Relations with technologies in health care. *Medicine, Health Care and Philosophy* 18(1):81–90.
- _____.
2016 Analyzing social spaces: Relational citizenship for patients leaving mental health care institutions. *Medical Anthropology* 35(2):177–192.
- Renders F. A. and H. P. Meininger
2011 Afscheid van het burgerschapsparadigma? *NTZ-Nederlands Tijdschrift voor de Zorg aan Verstandelijk Gehandicapten* 37(3):147.
- Roe, G.
2005 Harm reduction as paradigm: Is better than bad good enough? The origins of harm reduction. *Critical Public Health* 15(3):243–250.
- Simpson, M. K.
1998 Just say ‘no’? Alcohol and people with learning difficulties. *Disability & Society* 13(4):541–555.
- Stevens, A.
2011 Drug policy, harm and human rights: A rationalist approach. *International Journal of Drug Policy* 22(3):233–238.
- Taggart, L., D. McLaughlin, B. Quinn, and C. McFarlane
2007 Listening to people with learning disabilities who misuse alcohol and drugs. *Health and Social Care in the Community* 15(4):360–368.
- Tenneij, N. and H. Koot
2006 *Doelgroep in beeld: Een nauwkeurige omschrijving van mensen met een lichte verstandelijke beperking en meervoudige complexe problematiek*. Den Dolder, The Netherlands: De Borg.
- Thévenot, L.
2001 Pragmatic Regimes Governing the Engagement with the World. *In The Practice Turn in Contemporary Theory*. T. R. Schatzki, K. Knorr-Cetina, and E. von Savigny, eds. Pp. 56–73. London and New York: Routledge.
- Tonkens, E. and I. Weijers
1999 Autonomy, solidarity, and self-realization: Policy views of Dutch service providers. *Mental Retardation* 37(6):468–476.
- Tronto, J. C.
1993 *Moral Boundaries: A Political Argument for an Ethic of Care*. New York and London: Routledge.

- Van Der Nagel, J., M. Kiewik, J. Buitelaar, and C. De Jong
 2011 Staff perspectives of substance use and misuse among adults with learning disabilities enrolled in Dutch disability services. *Journal of Policy and Practice in Learning Disabilities* 8:143–149.
- Van Genneep, A. T. G.
 2000 *Emancipatie van de zwaksten in de samenleving: over paradigma's van verstandelijke handicap*. Meppel, The Netherlands: Boom Koninklijke Uitgevers.
- Vereniging Gehandicaptenzorg Nederland
 2007 *Kwaliteitskader Gehandicaptenzorg; Visiedocument*. Utrecht, The Netherlands: Vereniging Gehandicaptenzorg Nederland.
- Walker, M. U.
 1997 *Moral Understandings: A Feminist Study in Ethics*. Oxford, UK: Oxford University Press.
- Wilde, M. de
 2015 *Brave New Neighbourhood: Affective Citizenship in Dutch Territorial Governance*. PhD thesis, University of Amsterdam, Amsterdam Institute for Social Science Research. Available at: <http://dare.uva.nl/search?metis.record.id=476731>
- Willems, D.
 2010 Varieties of goodness in high-tech home care. In *Care in Practice: On Tinkering in Clinics, Homes and Farms*. A. Mol, I. Moser, and J. Pols, eds. Pp. 257–276. Bielefeld, Germany: Transcript Verlag.
- Willems D. and J. Pols
 2010 Goodness! The empirical turn in health care ethics. *Medische Antropologie* 22(1):161–170.
- Winance, M.
 2010 Care and disability. Practices of experimenting, tinkering with, and arranging people and technical aids. In *Care in Practice: On Tinkering in Clinics, Homes and Farms*. A. Mol, I. Moser, and J. Pols, eds. Pp. 93–117. Bielefeld, Germany: Transcript Verlag.
- Woittiez, I. B., L. Putman, E. Eggink, and M. Ras
 2014 *Zorg beter begrepen: Verklaringen voor de groeiende vraag naar zorg voor mensen met een verstandelijke beperking*. Den Haag, The Netherlands: Sociaal en Cultureel Planbureau.