

# How Professionals Tinker With Ethical Tensions Collectively When Fostering Service User Autonomy: An Ethnographic Study In Long-term Care

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## Research article

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# Abstract

**Background:** The value of patient autonomy has become central in healthcare. However, care practices involve a plurality of possibly conflicting values. These values often transgress the borders of the individual professional-client relationship as they involve family members, other professionals and community organizations. Good care should acknowledge this complexity, which requires a collective handling of the tensions between values. To better understand this process, we draw on Mol (2008, 2010) by developing the notion of collective tinkering.

**Methods:** Through ethnographic study in two teams in community housing services for people with intellectual disability and serious mental illness, we analyze how professionals tinker collectively. This research design enables in-depth analysis of care practices as they unfold in their situated context. Data were gathered by means of participant observation, interviews and focus groups with professionals, service users, peer support workers and family members.

**Results:** Collective tinkering is analyzed 1) within teams of professionals working together with family members; 2) between professionals from different organizations providing care for the same client; and 3) in organizing practices for a collective of clients. Collective tinkering involves assembling values into a care practice, attentively experimenting with these care practices and adjusting care accordingly within a collective of those involved in care for a particular client or collective of clients. When collective tinkering does not occur, the stakeholders excluded from the tinkering (e.g. clients or family members) may experience poor quality of care.

**Conclusion:** Collective tinkering differs from 'individual' tinkering between professionals and clients in several ways. First, by including stakeholders involved with the client, collective tinkering adds values and ontologies important in dealing with the situation and aids the creative process of inventing and experimenting with the care practices that assemble these values. Second, collective tinkering needs organizational structures beyond direct professional-client contacts. Structures that provide the time and space for the wider collective involved in care to come together, reflect and co-design care practices. The results also show that collective tinkering runs the risk of excluding clients in negotiating value tensions. Including clients should be carefully considered when structuring collective tinkering.

## Background

“Jesse receives support for independent living, he lives in a studio apartment with kitchen and bathroom in a building he shares with four other service users. Jesse used to study art and live in a student home but became homeless during a first episode of psychosis. His symptoms have diminished with the use of medication and Jesse is in a process of finding a vocation. His mother is an important part of his support network. He stays with her during the week as this is closer to where he follows his education in computer programming. Jesse likes to spend evenings reading and drawing, while having a glass of wine or a beer. His room is covered with paintbrushes, dirty laundry, dishes and cigarette butts. His support workers visit him a few times a week or he goes to their office nearby. They used to come and help him tidy up his room weekly. However, one professional convinced the team Jesse likes having his room a bit messy and is uncomfortable with support workers invading his personal space when helping him tidy up. In order to respect his self-determination, they better let him be the way he likes it. Therefor the team decided they no longer help him tidy up, apart from small nudges, for instance reminding him if he is going to spend a week at his mother’s house it might reduce smell if he takes out his trash before. His mother however worries this unhygienic situation might affect his health negatively and considers this a form of negligence as Jesse is not helped in learning to take care of his household.”

The care relationship is an important part of quality of long-term care. While the determinants of the quality of the care relationship have been described, the ethical dimension of what constitutes a good care relationship is often overlooked [1,2]. Addressing the ethical dimension is specifically prudent in relation to tensions between the value of autonomy and other values. The value of autonomy has gained prominence and reducing inequality between patients and professionals is increasingly seen as an important aspect of good care as is also described in the vignette above. Clients for instance are involved in care planning [3-6], are supported to manage activities of daily living and participate in the community [7-9] and moved from institutional settings to supported independent living [10-12]. This focus on autonomy has made the care relationship more complex as professionals experience tensions with other values such as preventing harm [13-17].

When considering the wider collective of stakeholders involved in long-term care beyond the client-provider relationship these complexities multiply. For instance, involving family members in long-term care is another important aspect of quality of care [18, 19]. However, value tensions aggravate when professionals, clients and family members have different views on good care in the context of fostering autonomy, such as the support team and Jesse’s mother in the vignette above [15, 20]. Moreover, clients often receive care from a multitude of health and social services including supported living, sheltered work and leisure activities [21, 22]. As providing integrated care is important, value tensions between professionals of these different organizations may further impact quality of care. For instance, when professionals working at the day center feel a client should be motivated to limit alcohol consumption in the evening as it affects his motivation and mood during the day, professionals at the supported living facility might feel drinking alcohol is part of peoples’ self-determination.

Insight into how professionals handle value tensions within these collectives provides directions for improving quality of care. However, this insight is currently lacking. The concept of ‘tinkering’ [23] enables an understanding of how professionals handle value tensions and enact good care. In this paper we develop the concept of ‘collective tinkering’ to gain insight into how value tensions are handled

collectively: within teams of professionals, with family members and between professionals from different organizations. We do so through an ethnographic study into how professionals handle tensions between values within collectives in community housing services.

Community housing services are an interesting case for understanding collective tinkering. First, care provision in these settings is very much a collective process. Professionals must work in teams, with family members and other care/community organizations. For instance, clients visit day centers or (sheltered) job facilities, receive treatments from specialized services or encounter other professionals in the neighborhood such as local police officers [12]. Second, autonomy has become an important value for community housing services, creating tension with other values. For instance, service users may enact their self-determination by not engaging in activities deemed important for living an independent lifestyle by professionals [15]. Our study develops a notion of tinkering as a collective practice. This way, we contribute to theories on the ethics of care that do justice to the complexity of care practice [23]. Practical benefits include insights for professionals, managers and policy makers into how to improve quality of care given the complexity of care work that values patient autonomy.

### **Tinkering good care**

The concept of tinkering has been introduced by Mol to describe how professionals enact good care in practice [23, 24]. According to Mol et al. [23] good care emerges out of practices and is not given before the act. It has to be established along the way. Care situations involve a plurality of values and tensions between them are handled in practice through attentive experimentation. This is a process of attuning to unfolding tensions and shifting problems in practice combined with a continuing process of trying different things in order to adapt. This is an ongoing practice as situations are in constant flux [23]. In the case of Jesse described in the vignette above, professionals handled the value tension they encountered with preventing harm from living in an unhygienic environment and Jesse's self-determination by inventing a new care practice of nudging instead of helping him tidy-up. This can be seen as part of a tinkering approach.

This 'tinkering approach' to ethics aligns with the ethics of care [23] and has benefits over more traditional principle-based ethics [25]. The added value of the tinkering approach lies in its focus on values and realities in the plural. It serves as an analytical tool for understanding the tensions and controversies in difficult social situations, directing attention to the actions of both human and non-human actors. Care practices are often characterized by constant flux. With patients and contexts ever changing, different values and tensions are brought to the fore. The tinkering approach lets us focus on how values are continuously and dynamically enacted. As opposed to the more traditional principle-based approach to ethics, it sees values as situated instead of universal. Tensions experienced by professionals are deliberated in day-to-day language instead of in terms of abstract principles. The tinkering approach focuses on what works in practice over solving dilemma's through stepped-based deliberation [23-26].

Tinkering brings together two aspects of handling value tensions: (1) a discursive aspect where different values are brought together into a certain ordering of reality in a given, specific, local practice; (2) a

practice of handling value tensions through attentive experimentation. As clients and context are ever in flux, tinkering is an ongoing process of attuning to unfolding tensions and shifting problems combined with trying different things out in order to adapt. As values and ontologies are seen as unfolding in situated practices, it is up to the participants involved to carefully reflect on which values and ontologies are at stake, which arrangements are possible, experiment with these care practices, attune to their effects and adjust. This situational, material and practice-oriented reading of value tensions shifts the focus to the inherent multiplicity of values and the handling of inter-value tensions in practice. It focuses on the consequences of value practices in relation to the entities that come into being – e.g. what kind of patient arises out of situated tinkering – thus studying the ontological politics of such practices [23, 24, 26].

Tinkering is sometimes criticized for not showing which local arrangements reflect ‘better’ care because it does not provide a normative stance from which to delineate the bad from the good [27]. However, looking at the relationships and specifically the quality of interactions between those involved does give ground for delineating better from poor quality of care. Interaction quality depends on whether different values and ontologies of those involved in the care relationship are articulated and negotiated and if care practices are crafted accordingly. It also depends on whether the effects of care practices are evaluated and constantly adapted to the changing context. The question is then whether and to what extent the relationality of tinkering is embedded within the care process [27].

While tinkering is posed as a relational concept that can be used to understand complex care practices, including all relations important to providing care, it is mostly used to analyze the micro-relationships between professional and client. Despite some exceptions, there is little focus on the wider network of care relations, including teams of professionals, informal caregivers and other health/social care providers [17, 23, 24]. Complexities and dynamics in such settings abound, as well as the need to handle tensions between different values and ontologies. As care is increasingly a collective effort, handling tensions between values and ontologies has become part of collectivity. Who is part of this collectivity is defined in practice as those involved in the care of a particular client. This may include family members and professionals from other organizations but also managers at the organizational level as their policies co-constitute care. This raises the question how collective tinkering works to achieve good care. Current studies do not elaborate on how collective tinkering works in practice or develop this notion theoretically. Our study takes up this challenge by conducting ethnographic fieldwork in community housing services for people with serious mental illness or intellectual disabilities.

## Methods

### *Study design and setting*

The ethnographic study took place in a Dutch community service organization that cares for people with psychiatric illness or intellectual disability. Autonomy-related values such as strengthening an independent lifestyle, self-determination and community participation are inscribed in its mission statement and history. The fieldwork was conducted in two teams caring for people with serious mental

illness (care team 1) and intellectual disabilities (care team 2). Both had social workers and peer support workers (expert-by-experience) who provided care in three types of housing arrangements: supported housing in a group home or satellite home and supported independent living.

The study employed a participatory ethnographic design. Ethnography allows in-depth insight into care practices as they unfold. The data collection method included participant observation, interviews and focus groups. Adding aspects of participatory action research to the study design improves quality, relevance and usefulness of the findings [28]. The participatory element of the study design included an advisory group consisting of two managers on the organizational level of the care organization; a professional; a project leader from a patient advocacy organization and an expert-by-experience. This advisory group met three times during the study to discuss study design, informed consent procedure; recruitment strategies; topic list of interviews and focus groups and analysis of the findings. Moreover, professionals and service users were involved in the analysis of findings through the focus groups.

### ***Recruitment of teams and interviewees***

Participant observation took place in two teams. This was a convenience sample in which teams were selected to include diversity in terms of housing arrangements, providing both supported housing and supported independent living and in terms of client population including a team caring for people with serious mental illness and a team caring for people with intellectual disabilities. To obtain variation in the sample, teams were excluded when they provided care to specific client populations such as autism spectrum disorders, elderly, the recently homeless or people with severe substance dependence as a primary diagnosis. In order to recruit teams, the research team held two presentations about the research to a group of managers who each are responsible for several teams. Two managers expressed their interest to partake in the study as they were interested to engage their team members in reflection on the ethics of the care relationship. They each suggested one of their teams to partake in the research.

Interviews were held with professionals, service users and family members. All respondents for the interviews were recruited using a convenience sample. Within each team all professionals were asked to partake in an interview. In the first team two declined, one because she was due to leave the team in the coming month, the other did not voice her reason for declining. In the second team no team member declined, but one team member was not interviewed as she left the team during the fieldwork. Professionals at other organizational levels could reflect on complex situations beyond the two included teams. These interviews included the managers of both teams; three managers on the organizational level and two team coaches providing support to these and other teams who experienced complex situations. Professionals all had a background in social work.

For recruiting service users, effort was made to include a variety of service users in terms of independence and infliction by symptoms. In the second team all service users were invited to participate in an interview. The researcher made an effort to make participating in an interview accessible to service users by acquainting them first during daily informal coffee moments before asking them to partake in the interview; by being responsive to the time schedules and mood of service users and by chopping up

the interview in smaller moments of conversation when this fitted service users' needs [29]. Twelve service users agreed to an interview and eight declined. Reasons stated were not liking to talk in general or specifically to 'strangers' or barely coping with doing daily tasks and fearing an interview would be too demanding. In the first team recruiting service users for an interview proved most demanding. The team had decided it would violate service user privacy and diminish their care relationship if the researcher would approach service users directly. Therefore it was decided that professionals would ask service users if the researcher could reach out to make an appointment for an interview or tag along during a care meeting for purpose of observation and after acquainting the service user come back for an interview. Four service users were included through this recruitment strategy. Many service users however declined. Professionals stated reasons such as service users' not wanting to talk to a stranger or having told their story too often and not seeing the purpose of telling it again. Moreover, professionals stated that with some of their service users even posing the question had negatively affected their fragile care relationship with these service users. As a second strategy for recruitment the researcher visited the weekly coffee meetings, acquainting the attending service users and asking them for an interview. Four of the regular attendees agreed. Three declined for reasons related to trust or being too busy with settling down after recently having moved. As these two recruitment strategies may have led to selection bias, selecting only those clients who were more social or less afflicted by symptoms to participate in the research, additional interviews were held with experts by experience. These worked as peer-support workers in teams providing supported housing or supported independent living and could share care practices they had witnessed. This way experiences of clients for whom the interview was not possible could be included as they were shared and reflected on by the experts-by-experience. Experts-by-experience of this specific organization were recruited firstly through an add on a Facebook group directed at recovery-oriented care, were many experts-by-experience were present and secondly through snowballing. After these interviews, saturation was reached. Service users were diagnosed with Schizophrenia; Major Depression; Personality Disorders; Autism spectrum disorders or had intellectual disability. All service users were over 18 years old.

Family members were invited for an interview after service users agreed they could be contacted by the researcher. In the first team three clients agreed their family members could be contacted. All three family members agreed to an interview. In the second team six service users agreed for a family member to be interviewed. Two family members declined stating they were too busy combining their job, their family and providing informal care to the service user. Reasons for service users not wanting a family member to be contacted for an interview included family being too busy, feeling the informal care is already burdensome to the family member, not having good contact or not wanting to involve family members in any way in care as they had divergent views. As saturation was not reached after these interviews three family support workers were interviewed. These were family members of service users themselves and worked at the organization to support other family members of service users. They could reflect on both their own experiences and those of other family members they had encountered. Family members and family support workers were mothers, fathers, siblings or siblings in law.

### ***Participant observation***

Participant observation enabled the researcher to observe care practices as they unfolded. The fieldwork took place over six months, three months in each team, 12 visits totaling 19 hours for the first team and 12 visits totaling 65 hours for the second. The first author observed shift handover meetings when all clients were briefly discussed (team 2); bi-weekly team meetings (both teams); coffee moments for clients (both teams); meals (team 2); care moments (both teams); informal discussions between professionals in the office (both teams); and activities in the dayroom of the communal house (team 2). Extensive field notes were made shortly after each observation. Sensitizing concepts guiding the observations included: 'value tensions related to fostering autonomy and community participation' [30]. The difference of hours spent in each team and type of situations observed reflects a difference in the way care is organized in these two teams. The first team organized care in an individualized way. They had no frequently used communal spaces where the researcher could just 'hang out', establish rapport with clients and observe care practices. Instead, the researcher had to accompany professionals when they provided care, which meant clients had to agree with the researcher's presence before rapport could be established. Clients often declined which resulted in limited opportunity for participant observation. This was strikingly different in the second team where the researcher had plenty of chances to meet clients informally and observe care moments in the communal day rooms, during many coffee moments and at communal meals. This challenge for data collection through participant observation in team 1 was partly resolved by interviewing peer support workers (experts-by-experience). As these people worked in different teams, they could elaborate on complex situations they had witnessed, serving as co-ethnographers in situations that did not cater for the researcher's presence.

### ***Interviews***

In depth- interviews were conducted to gain insight into the complexities of fostering autonomy and community participation. Table 1 presents an overview of participants.

Interviewees functioned as co-ethnographers [26] by describing situations that did not cater for the researcher's presence where various values needed to be tinkered with. Interviews were held face-to-face, in a meeting room of the care organization or in the residence of a client or family member, depending on the preference of the participant. The topic list was developed for this particular study (see supplementary file). The topic list was similar for all respondents and opened with 'What do you find important in the care relationships you are involved in?' Each mentioned value was prompted for narrative exploration of situations in which the value was easily put into practice or proved complex when different values were in tension. When autonomy related values were not named spontaneously, these were prompted by the researcher after spending elaborate time exploring the situations brought up by the interviewees. Interviews were audio recorded and transcribed verbatim. Interviews lasted between 25 minutes and 90 minutes with a median of between 45 and 55 minutes. Five clients and one professional did not want to record their interview. In these cases extensive notes were taken during the interview which were elaborated on shortly after.

### ***Focus groups***

For purpose of member check and data enrichment, five focus groups with service users, professionals and family peer support workers (see Table 2) were held.

For these focus groups vignettes (five to eight per group) were developed describing the complex situations containing value conflicts derived from participant observation. These vignettes were developed by the first author through thematic analysis and contained anonymized quotes from interviews or notes from the participant observations for each subtheme, edited into one coherent narrative. For purpose of researcher triangulation and peer deliberation these vignettes were refined through discussions between the authors and in two meetings with the advisory group. These refined vignettes served as input for the focus groups. The focus groups were chaired by the first author in collaboration with a project leader from the collaborating patient advocacy organization. Focus groups lasted between 93 minutes and 154 minutes. Each vignette was read aloud by a chair or participant of the focus group. The chairs then prompted reflection on these vignettes by questions such as: 'Is the situation in the vignette familiar to you, or not?'; 'What important experiences in the care relationships you are involved in are missing in these vignettes?'. For service users and professionals all participants of the interviews were invited. In focus groups with service users, special effort was made to make participating accessible to them. Focus groups were held in a familiar setting, in the living room of the group homes. Participants of the interviews were invited by the researcher with whom service users were familiar with by the participant observation and interview and invitation was followed-up by the professionals. Joining the focus group was flexible as service users could decide to join last minute. Prior to the focus groups an informal social event (coffee, tea & and cake baked by one of the participating service users in team 1 and a communal meal in team 2) was organized to familiarize the service users with the chairs and to informally address reserves in partaking in the focus group service users might have. Reasons for declining for professionals included having left the team or not being able to combine attending the focus group with other duties. Reasons for declining for service users were not liking to talk in a group; not being allowed to partake by one's voices or fearing not being able to express oneself. As most interviewed family members had expressed their reluctance in joining a focus group due to time restrains, this focus group was organized with family peer support workers only during one of their monthly peer-to-peer coaching sessions. The focus groups resulted in yet further refinement of the analysis.

### ***Data analysis***

The various complexities described by respondents and observed during fieldwork were analyzed thematically. The first round of inductive coding was guided by three questions: (1) which values do different stakeholders find important for good care; (2) when values are put into practice, which situations are complicated by tensions between values and ontologies; (3) how do stakeholders tinker with the tensions?

After the first round, it struck the researchers that tinkering not only involved service users and professionals but was a collective process including individual service users, professionals, family members and other community organizations. This became the focus of a second round of coding,

guided by two questions: 1) who is involved or excluded in tinkering; 2) how is collective tinkering shaped by the organizational context of the care team? Open coding guided by these questions, was followed by a round of axial coding and selective coding using constant comparative method [31]. Coding was done in Atlas-ti. All names used in this document are pseudonyms in order to protect respondents anonymity.

## Results

In this section we analyze tinkering as a collective practice, focusing on three types of collectives: (1) a care team including clients and family members; (2), a care team including clients, family members and other care/community organizations; and (3) a collective of clients for whom care arrangements are created. Each theme discusses tinkering in a complex situation that occurred in both teams, that various team members mentioned, and that focus group participants recognized as complex.

### Tinkering in teams including family members

A complex situation highlighted by many professionals is when clients neglect to do the grocery shopping they feel is required. One example of tinkering within a team is the case of John (all names are changed). John has an intellectual disability and has suffered psychotic episodes. He lives in an apartment owned by a social housing company a few blocks away from the communal home and office of the care professionals. John has a weekly grocery allowance. Responsible for his own money and meals, John gains self-determination and practices with an independent lifestyle. Impulsively, however, he often buys expensive takeaways or flowers for his girlfriend, leaving him without money to buy food at the end of the week. This then puts professionals in a difficult situation as they also want to prevent the harm of John not eating properly.

John's contact moments are provided by the team members scheduled for that day. The team needs to work collectively to align their approach, for when he comes to the care unit to ask for food because he is out of money. John's sister is also involved as he asks if he can eat at her place. The sister doesn't mind having John over but wants him to learn how to take care of himself. This situation requires the team, with the sister, to arrange the values of self-determination and independence while preventing the harm of not having food. Their collective tinkering involves chatting in the team on shift, at shift transition meetings as well as formal discussions of cases at bi-weekly team meetings. This structure fosters team communication *about* clients, it does not include clients or family members. Family involvement depends on the efforts of individual professionals. One of John's professionals keeps in touch with the sister, frequently discussing his situation on the phone and asking for her input.

Needing to find a way to arrange these values, the team experimented on doing the grocery shopping with John. The practice was then consolidated in John's care plan and the schedule that structures the professionals' daily tasks.

"We see him every week. Then he gets his grocery allowance, signs for it and we do the food shopping together, for the whole week. He's really good at it, always buys healthy products, and he's a super cook. In

his case you present the organization's rules with sort of white lie. You tell him, we need to come along because we need your receipt for the bookkeeping. Every now and then it goes well, maybe twice in a row, and then we say, go on your own, but then it goes wrong again and on Sunday he'll turn up at the care unit because he's run out of food and wants to eat with us or asks for bread. Well then, you take over again, make him go shopping with you but you only follow him, you needn't do a thing. Just the fact you're there limits him in his self-determination because he feels he has to do things right."

This is not a one-time decision but an iterative process, evaluated and adjusted when necessary. Professionals experiment with what John can do by himself, attentively observing what happens and adjusting their actions accordingly. However, this arrangement creates tension with other values, of being honest with John – why they go grocery shopping with him – and of helping him sustain the positive self-identity of a 'big man' capable of handling his own housekeeping. The ontology worked up about John is of someone capable of making healthy choices and cooking for himself but hindered by poor impulse control. The values and ontology are then assembled in the care practice of presenting grocery shopping to John with a white lie: they tell him the care organization demands receipts from clients under curation.

In John's case different values and ontologies are assembled in one care practice. The case of Jesse (team 1), however, shows that collective tinkering does not always happen, which impacts the quality of care. In this case the client neglects his house. It is contrasted with the case of Max, cared for by team 2, who does the same but collective tinkering within the team does happen.

In Jesse's case- as is described in the introduction- the values of preventing harm by having a hygienic household, promoting an independent lifestyle, self-determination and attuning to Jesses vulnerabilities are in tension. The problems for Max are much the same as Jesse's. He lives in a 10m<sup>2</sup> room in the communal house, bordering the living room. His room is crowded as he moved in from a big apartment and brought along all his precious possessions. The only free walking space in the room, surrounding his bed, is full of dirty dishes and laundry, trash and cigarette ash.

In both cases, team members differ on how they work up the reality of who the client is, and which values should be prioritized. In Max's case, some team members see his unhygienic living conditions as due to personal incompetence. Others see Max as someone able, but not willing. These different ontologies evoke different values in caring for Max. If Max is incompetent, good care involves helping him clean. If Max is competent but unwilling, helping him would hinder his goals to live independently one day. The team agrees that living in neglect will pose harm to Max. Something has to change. The team organizes his care collectively. Daily tasks, such as reminding Max to clean his room, are put on an agenda that the professionals who happen to work that shift execute. The team discusses Max's case at the twice daily handover meeting between shifts or at their bi-weekly meetings.

This is different for Jesse as team 1 has limited structures in place to discuss clients. Clients are cared for individually, with one or two caretakers making appointments with the client. This team has no meetings between shifts, where they discuss all clients, only monthly meetings where they discuss only

those clients who the professionals have put on the agenda. In Jesse's case, some professionals in the team stress the value of self-determination, pointing out that Jesse might not share the norms of having a tidy house that other team members might have, and that the entire team should abide by how Jesse wants to live. Other team members emphasize the value of preventing harm from living in unhygienic conditions. Although the team discusses Jesse's case, they do not negotiate on the different values. The professionals favoring the value of self-determination simply convince the others that good care for Jesse means following his wishes. The team decides to stop helping him clean his room.

"So I have this client who everyone finds really smelly and difficult. And they have a point, he is a bit stinky. When it comes to cleaning, he just lets things go. So I try to tell the team that we're not talking about 'Mr. Stinky', we're talking about Jesse, who's just like... like... anyone else and a very smart guy. But Jesse says: 'I don't like things clean and tidy.' We have to know that, we have to understand how it works for him, and we shouldn't go there every Friday and make him feel uncomfortable by cleaning up his place."

Instead his care professionals do sometimes nudge him to clean his room. For instance, by reminding him his laundry will start smelling bad if he doesn't launder it soon. This however seems to have limited effect in terms of the state of Jesse's house and thereby only limitedly attends to the tension between the value of self-determination and other values such as preventing harm from living in neglect. Not attending to this ongoing value tension stops the team from inventing experiments that would assemble the different values and create 'better' care. Moreover, the team excludes the views of Jesse's mother from the conversation. She contacts the professionals several times, expressing her concern about the possible harm of living in neglect and feels that the approach chosen does not foster an independent lifestyle. While the professional holds an ontology of Jesse as someone capable of deciding for himself on his household, mother's ontology is different. She does not see him as fully capable. Instead, she pictures him as being too hindered by his symptoms to accept help in cleaning.

"At one point I thought, this room is filthy. The professionals kept pointing to his autonomy. I said, 'The situation is out of control and he was offered help, so will someone from [care organization] please help Jesse clean his room.' Well, Jesse didn't want that. Because you're touching his stuff, I get it. But they could have taken a structured approach. It would've benefited him, being able to do his own cleaning in due course. [...] Of course he'd say no. That's part of his schizophrenia, to say no to that sort of thing. It fits the diagnosis. Just say no [...]. But you start thinking, it must go wrong sometime, he'll either get food poisoning or some other nasty disease."

The team did not take the mother's view into account in their decision on how to care for Jesse. This not only limits their creativity in crafting care practices that arrange the differing values, it leaves the mother feeling that Jesse is not receiving good care.

In contrast, team members realized that for Max, emphasizing the value of self-determination and leaving him in neglect simply does not work as it evokes ongoing tension with the value of preventing harm. This tension fosters a creative experimentation process to find ways to not interfere with Max's autonomy yet

improve his hygiene. They follow these experiments closely and invent new ones when they do not work. Failed experiments include reminding Max to clean his room, telling him the consequences of not cleaning and to thoroughly cleaning his room themselves when he is on holiday. Some interventions disturbed Max, and none led to cleaner conditions in the long run. The team then decided to arrange for a professional to come help him every other week. This seemed to have a better effect and even Max was content. As he explained to me when we were eating a jelly pie he had made, he now feels he has more 'living space'.

Even though in Max's case it looks like collaborative tinkering created 'better care', this is not the end of the story. While team members agreed on the assemblage of values in the experiment, they still held different ontologies on who Max is. Some felt that Max should get ongoing help as clearly, he could not keep his room tidy on his own. Others felt that helping him clean risked keeping him lazy and would stop him from being able to do his own housekeeping in due time. For these team members the tension between the values of preventing harm and developing independence persist. This ongoing tension might motivate the team collective to invent new experiments negotiating these values in the future.

As in Johns' case, both Jesse and Max were left out of the team's collective tinkering process. While some ontologies and values put forward may have been influenced by conversations with Max and Jesse, they were not involved in assembling the care practice. Team members decided on what represents value for clients and who they make themselves up to be, in ways that may not altogether align with clients' own views. In Jesse's case, where care is crafted on the single value of self-determination, his view on housekeeping seems dominant. In terms of tinkering, however, this is not 'good care'. Jesse was left out of the decision to exclude the values of independent lifestyle and preventing harm from his care practice. The teams barely considered material arrangements that co-constitute the tensions between values and ontologies. This is especially clear in Max's case. He points to the importance of material arrangements in constituting his situation. Interviewed, Max felt that his 'neglect' was caused by not having enough space to keep all his valuables because he had moved in from a larger apartment. As far as he was concerned, he is not lazy, because he does valuable work as a DJ on his own online radio station. He prefers the privacy of his room above sitting in the communal areas but due to the limited space he cannot work anywhere else than in bed. If the team had considered Max's values, his definition of himself and the material arrangement, it might have fostered the development of care practices that better fit his needs.

In conclusion, tinkering collectively with both professional teams and family members brings together a multitude of values and ontologies and that creates tensions. When tensions are attuned to, teams and family members may invent care practices that assemble the various values and ontologies. Attentively following and adjusting the experiments may lead to providing good care. Collective tinkering requires a consideration of material arrangements and depends on structures that permit team members to discuss clients together. Both care teams 1 and 2 lack the structure to tinker collectively with family members, which makes family involvement highly dependent on the efforts of team members. Opposed to tinkering in professional – client relationships, clients are seldom involved in nor structured into collective tinkering.

## *Tinkering in teams including other care/community organizations*

The second type of collective tinkering we analyzed takes place between team members and other care and community organizations. Clients receive care from many organizations, for instance day centers, (sheltered) job facilities and obtain specialist treatment in mental health services.

A complex situation both teams encounter is when clients make friends with people who manipulate them into criminal activities. This then requires collective tinkering with a wide range of organizations, including other care organizations, local police and the municipality. Both teams had cases in which clients were manipulated into money laundry or growing marihuana in their homes. In care team 2 this situation involved John. John wanted friends and let a few 'cool men' befriend him. They often spent time in his home and one of the men even slept on his couch. John's sister found out about this and suspected possible harm. She questioned the good intentions of the men and wondered if John really desired this situation or if he was simple not capable of refusing the men. She contacted the care professional who took her concern seriously.

*"He's looking for friends, of course, but they're not always the right friends. [...] Once I wanted to come over and he said, 'No, you can't,' and he was so stressed. I found his response very strange. So I went on asking about it and finally he said there were men in his house who didn't want to leave. So I told the professional, who took it very seriously and looked into it straight away. And it turned out that there were indeed men living in his house who were homeless themselves. So there too you have this question of self-determination. But how far do you let the situation go? [...] Those men were just taking advantage. John didn't know how to solve the problem. And he didn't ask for help because he thinks of himself as, let's say, a 'big man' who should solve his own problems. I get that too, but naturally the solution is to ask for help. He finds that hard."*

The professional found out that John had given the men access to his bank account and they were money laundering, depositing criminally obtained money and withdrawing it in cash on John's bankcard. They also put several mobile telephone subscriptions on John's account. John collaborated in this as the men offered him a few Euros in return, making John feel he was one of the 'big men' which is what he wanted. Different values were in tension here. John's bank account facilitated self-determination on spending some of his money and fostered an independent lifestyle because he could do some of his own shopping. After some deliberation, the care team and John's sister decided that the situation posed too great of risk for John and they crafted a care arrangement for his money to be kept under curation.

Later on, John wanted to fix up his house, but not having a lot of money he posted an ad on Facebook asking who might want to help him. A few men replied. So far John's situation follows the autonomy-related value of community participation. One of the men didn't have anywhere to live and proposed living with John while he worked on his house. One of the team members learned of this and suspected potential harm. A professional with a good relationship with John tried to find out more about the situation and learned the names and home village of the men. He contacted a care professional he knew in that village to get information about the men. This care professional knew the men and suspected they

wanted to use John's house to grow marihuana. This unfolding tension then required assembling the values at stake: John's self-determination versus preventing John from the harm of complicity in criminal activity. John's ontology of himself also needed to be part of the negotiation, or at least the professionals' representation of it. As John was perceived to see himself as 'a big man' he would not easily accept that these men were not his friends but were using him. The professionals from the different care organizations did not want to harm Johns' self-esteem by trying to convince him that he was being used. Thus, they crafted a care practice assembling the values and ontologies. The care professional who knew the men would inform them that John's care organization had eyes on them and the police would be called if they pursued criminal activities. The experiment worked: the men stopped seeing John and John had his house to himself again, which sadly was not fixed up but left rather decrepit. This incident made another tension clear. As John lived a few blocks away from the care unit and rented his own house from the social housing company, his care workers had little oversight. This material arrangement contributed to the professionals being quite late in picking up the potential harmful situation and were limited in their interventions as they were not allowed to enter the house, change the lock or set rules about who could come in. These values were assembled in a new material arrangement by moving John closer to the care office into a unit owned by the care organization. This also required the involvement of a wider collective of stakeholders, such as the manager agreeing to the move and the care organization providing one of their houses. For John, having friends and being one of the 'big boys' was also an important value at stake which, however, this new care arrangement did not address so much.

In conclusion, as people move to community settings and participate more in the community, this enlarges the potential care network with other people and other organizations. Material arrangements also co-constitute care practice. This requires professionals to work collectively in networks and take the material arrangements into consideration. To provide good care, tinkering transgresses the borders of the assisted-housing service. However, daily care practices are not structured for this type of collective tinkering. Whether or not it happens, and who is involved, depends on the quality of the professionals' relationships with others in the care network and the personal efforts made by individual professionals.

### ***Tinkering for a collective of clients***

Collective tinkering not only happens in relation to individual clients. When creating care practices for a collective of clients, values and ontologies also require negotiation. This may also involve other layers in the care organization beyond the team, such as managers working on an organizational level. A complex situation both teams mentioned centers on clients' loneliness. One care practice addressing loneliness for a collective of clients involves organizing 'coffee moments'. Here again different values and ontologies need to be negotiated. On the one hand, coffee moments are seen as potentially limiting community participation, as clients are then less inclined to seek social contact in the community. On the other hand, coffee moments are seen as providing a place for peer support in a safe space, where stigma is limited. Here the values of community participation and providing peer support are in tension. Meanwhile, multiple ontologies of clients are evoked: as clients capable of engaging in social relations in the

community and as vulnerable clients needing a safe space to foster social contact. One professional in the first team voices these tensions:

*“Some professionals believe in group stuff, while I believe in the individual approach. Group sessions are nice, having coffee once in a while [...] and catching up with others. Like on Sundays when the activity centers are closed. But don’t have coffee moments for the sake of having them, every day a cup of coffee. They should go to an activity center, or a cafe. Then they’ll meet new people and join the community. When they ended up in the healthcare system, they were cut off by society. And now they are allowed back in again. So let them try, for God’s sake. Don’t arrange things in-house if it’s not needed otherwise they’ll never meet other people, be in the community.”*

The two teams assembled these tensions differently, resulting in different arrangements for the coffee moments. Care team 1 organizes coffee moments on Sundays only, as this is when most community options for socializing are closed. This is reflected in the material aspects of this arrangement. The space where the coffee moments take place is not inviting. It looks like a conference room and is in fact the same space where team meetings take place. In care team 2, the value of offering peer support in a stigma-free environment resonates more with the team members, as is expressed by the following quote.

*“It is important to facilitate [...] those coffee moments. You could call that inward-looking. But Ryan, with snot in his hair and Emma, who stinks, they’re not going to be invited into people’s homes. But they do come to these coffee moments. And so you bring them together. Nobody here ever says, ‘Did you notice how badly Emma smelled? Or how filthy Ryan is?’”*

Care team 2 arranges coffee moments twice a day in the communal living space of one of the houses where residents live together. This material arrangement adds to the homely sphere. Clients who receive care from this team but live independently are welcome too. This way of organizing coffee moments was under threat as managers on the organization level introduced a policy to arrange housing in such a way that every client has ‘their own front door’. This policy was introduced to materialize the value of living an independent lifestyle. Due to this policy, care team 2 was in the middle of re-organizing the housing situation. Service users were moved one-by-one to their own apartment, each with their own kitchen and living space. This rearrangement led to the demise of the coffee moments as this new set-up offered limited space for organizing communal moments. Social contact for service users was also reduced as clients could now more easily decide for themselves to stop socializing with their neighboring service users, as they no longer shared a house and occasional coffee moments were no longer in their own home. This example makes clear not only that professionals need to adapt care practice for a collective of clients but also that collective-client practices are enabled or limited by other layers in the care organization, such as managers.

The new context required inventing new experiments in assembling the values of promoting well-being through social contact, self-determination and independent living. The value of preventing harm was also part of this assemblage as professionals feared lonely clients would be more prone to engage with people who could take advantage of them (see the example of John). The team experimented with

connecting service users to community organizations that arrange 'buddy contact'. Although the team felt this was not the best way to facilitate social contact, the corporate 'own-front-door' policy for service users limited their ability to provide the social contact they wanted, through regular, easily accessible coffee moments. Here, the team and organization managers undertook no collective tinkering, no experimenting with other material arrangements to assemble the values of providing social contact and fostering an independent lifestyle.

In sum, teams tinker collectively in creating care practices for the client collective. These arrangements need to handle the tensions between values and ontologies by assembling them differently and adjusting them to the ever-changing contexts. Here other stakeholders, such as managers may be implicated. Adding to previous points on the lack of structure for collective tinkering, this case shows that teams may have limited means in tinkering with organization-wide policies that impact care practices.

## Discussion

National care policies placing patient autonomy to the fore are translated into organizational values that have consequences for care practices. In this paper we took a tinkering approach to understand how this policy change creates value tensions in practice and how professionals deal with these tensions. Our investigation of care practices makes clear that fostering client autonomy requires much work from professionals, family members and clients alike. Part of this work involves negotiating autonomy-related values with other values, such as preventing harm, and assembling all the values in care practices. Meanwhile, different ontologies of clients are evoked, which also requires negotiation in care practices. Materiality influences care practices which, as we saw in the case of the coffee moments, for example, also becomes part of negotiating and assembling. As clients and contexts change, and tensions between values and ontologies are never fully settled, good care requires ongoing experimentation.

This view on good care has been captured in the concept of 'tinkering' [23]. This paper elaborates on this theory of good care by focusing on the collective aspects of tinkering. This is particularly prudent in care that moves beyond the individual professional-client relationship by involving other team members, family members and other care- and community organizations.

Collective tinkering differs from 'individual' tinkering between professionals and clients in several ways. First, by including stakeholders involved with the client, collective tinkering adds values and ontologies important in dealing with the situation and aids the creative process of inventing and experimenting with the care practices that assemble these values. Different views on ontologies or values within a collective may continue even when a care practice is negotiated. This creates tensions that might drive a collective to keep experimenting with other ways of caring, possibly inventing even 'better' care. When tinkering is not a collective process, for instance when team members are not engaged or family members are not involved, as is shown in the case of Jesse, these stakeholders might feel that the quality of the provided care is poor, given that their values are not assembled in the care practice.

Second, collective tinkering needs organizational structures beyond direct professional-client contacts. Structures that provide the time and space for the wider collective involved in care to come together, reflect and shape care practices. Teams often have these structures, in regular team meetings, for instance. But having structures in place does not suffice as tinkering requires professionals to feel safe enough to express doubts and dilemmas, actively deliberate on different values and ontologies, assemble these in care practices and keep on evaluating and changing care practices to come to a better assemblage of values or to tune into changing clients or contexts. Such structures seem to be lacking for collective tinkering with family members, other layers of the care organization or professionals working in other community organizations. This lack makes this kind of collective tinkering dependent on the efforts and networks of individual professionals. As Rutz and de Bont [32] show in the case of youth inspectors, structures that permit collective deliberation to handle complexities improve the quality of compromises.

One backlash of collective tinkering is no or a marginal role for clients, resulting in care that does not include their ontologies of themselves or the values they prioritize. While clients and professionals may tinker in their personal care moments, clients are not present when teams of professionals, family members or other organizations assemble different values and ontologies into care practices. Partly, this lack of client involvement in collective tinkering might be understandable in the context of community housing services. When situations become especially complex, clients often seem hindered by their competence or symptoms, at least in the eyes of family or professionals, and are thus deemed unable to maintain a coherent view of the potentially harmful consequences of their actions (e.g. John inviting criminally-minded men into his house). Research shows in other cases that clients are only minimally involved when their physical state hinders their ability to let themselves be heard [23] or when they are deemed limited in their competency to decide what is good for them [17]. Involving clients with disabilities in tinkering is certainly not impossible, although it requires professionals to emphasize clients' experience-based expertise over their perceived incompetency [33]. A heuristic framework of how clients are negatively affected by care aimed at promoting autonomy might sensitize professionals to clients' concerns, thereby aiding professional in including client's perspectives in tinkering [reference to be added after review].

Moreover, for clients to voice an opinion of 'good care' in a group of professionals and be an equal partner in deliberating the different values might be quite demanding for clients with intellectual disabilities or serious mental illness and for professionals too. The challenge is to create space and means for tinkering together. This can be done through developing or implementing reflection spaces where clients, family members and professionals are stimulated to reflect on handling value tension and co-design care practices together [reference to be added after review].

## **Limitations**

Care organized in the community provides challenges for ethnographic work. As care is organized more in an individualistic manner with individual care moments and limited (use of) communal spaces this limits possibility for establishing the rapport needed to engage service-users in interviews or for participant

observation. These limitations where be partly resolved by engaging experts-by-experience as co-ethnographer having them describe and reflect on care moments that do not cater for the researchers' presence [24].

This paper conceptualized care through thinking with complexity. However, each way of thinking with complexity involves reductions [26]. Some reductions are worth mentioning. Care for people with intellectual disability or serious mental illness has its own specifics, as do different teams, different neighborhoods, different care organizations etc. These specifics were not elaborated on in this paper. Moreover, in this paper a notion of 'collaborative tinkering' was developed based on ethnographic work in community housing services. This provided elaborative data on handling value tensions collectively between team members and between clients, family members and professionals. Handling value tensions between professionals of different care organizations was also included in the data but only from the perspectives of the professionals in the community housings service. Professionals from other services for instance day centers, or specialized health services might experience other tensions in assembling values in care practices with professionals from community housing services. However, our analysis has contributed to understanding how values such as autonomy change care practices and how professionals can provide good care by collectively tinkering with these values. The points made about collective tinkering may be valuable for all these contexts in improving care practices.

## **Conclusion**

In sum, 'good collective tinkering' requires inclusiveness of all stakeholders, including clients themselves. However, including clients might prove complex and requires additional work. Collective tinkering needs structures through which all the stakeholders involved in a complex situation – the care team, family, clients, managers and professionals of other organizations – can share a time and a space that enables them to negotiate and assemble values and ontologies in care practices, attune to the effects of these practices and adjust accordingly. Future studies could further our insight into 'collective tinkering' by first analyzing ways in which teams can be facilitated to use the time and space available in team meetings for collective tinkering. Secondly, the question of how to include clients in collective tinkering requires further research. Thirdly, research should focus on the way collective tinkering with family members, managers and professionals of other organizations can be structured. Enriching the notion of 'collective tinkering' provides insight into how the quality of the care relationship can be improved when the value of autonomy is in tension with other values and professionals have to collaborate with patients, family members and professionals from other organizations to provide integrated and continues care.

## **Abbreviations**

ID Intellectual Disability

SMI Serious Mental Illness

## **Declarations**

### ***Ethics approval and consent to participate***

The ethical board of the Erasmus MC (Medisch Ethische Toetsings Commissie, METC) judged the study not in need of ethical approval under Dutch law (MEC-2017-122). Participants were asked for their informed consent and signed informed consent forms. Transcripts were anonymized. Names used in this article are pseudonyms. Participants were aware that they could withdraw their consent to participate in the study at any time.

### ***Consent for publication***

Not applicable.

### ***Availability of data and materials***

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to them containing information that could compromise research participant privacy and consent.

### ***Competing interests***

The authors declare that they have no competing interests.

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### ***Authors' contributions***

Acquisition: HvB & RB; Design of the research: MH, HvB and RB; Analysis and interpretation of data: All authors; MH has drafted the work, HvB, MC and RB have substantively revised it. All authors have approved the submitted version. All authors have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

### ***Acknowledgements***

[to be added after review]

## **References**

1. Scheffelaar A, Bos N, Hendriks M, van Dulmen S, Luijkx K. Determinants of the quality of care relationships in long-term care: a systematic review. *BMC Health Serv Res.* 2018; 18(903).

2. Scheffelaar A, Hendriks M, Bos N, Luijkx K, van Dulmen S. Determinants of the quality of care relationships in long-term care: a participatory study. *BMC Health Serv Res.* 2019; 19(389).
3. Anthony WA, Ellison ML, Rogers ES, Mizock L, Lyass A. Implementing and Evaluating Goal Setting in a Statewide Psychiatric Rehabilitation Program. *Rehabilitation counseling bulletin.* 2013;57(4):228–37.
4. Claes C, Van Hove G, Vandevelde S, Van Loon J, Schalock RL. Person-Centered Planning: Analysis of Research and Effectiveness. *Int J Dev Disabil.* 2010;48(6):432–53.
5. Davies C, Fattori F, O'Donnell D, Donnelly S, Ní Shé É, Shea MO, et al. What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review. *BMC Health Serv Res.* 2019; 960(19).
6. Klausen RK, Hansen Blix B, Karlsson M, Haugsgjerd S, Fagerjord Lorem G. Shared decision making from the service users' perspective: A narrative study from community mental health centers in northern Norway. *Soc Work Ment Health.* 2017;15(3):354–71.
7. Dean EE, Fisher KW, Shogren KA, Wehmeyer ML. Participation and Intellectual Disability: A Review of the Literature. *Intellect Dev Disabil.* 2016;54(6):427–39.
8. Farkas M, Anthony WA. Psychiatric rehabilitation interventions: A review. *Int Rev Psychiatry.* 2010;22(2):114–29.
9. Salzmänn-Erikson M. An Integrative Review of What Contributes to Personal Recovery in Psychiatric Disabilities. *Issues Ment Health Nurs.* 2013;34(3):185–91.
10. de Heer-Wunderink C, Visser E, Caro-Nienhuis A, Systema S, Wiersma D. Supported Housing and Supported Independent Living in the Netherlands, with a Comparison with England. *Community Ment Health J.* 2012;48::321–7.
11. McPherson P, Krotofil J, Killaspy H. Mental health supported accommodation services: a systematic review of mental health and psychosocial outcomes. *BMC Psychiatry.* 2018;18(1):128.
12. Bredewold F, Hermus M, Trappenburg M. 'Living in the community' the pros and cons: A systematic literature review of the impact of deinstitutionalisation on people with intellectual and psychiatric disabilities. *J Soc Work.* 2018;20(1):83–116.
13. Broer T, Anna P, Nieboer AP, Bal R. Quest for client autonomy in improving long-term mental health care. *Int J Ment Health Nurs.* 2010;19:385–93.
14. Femdal I, Knutsen RI. Dependence and resistance in community mental health care—Negotiations of user participation between staff and users. *J Psychiatr Ment Health Nurs.* 2017;24:600–9.
15. Heerings M, van de Bovenkamp H, Cardol M, Bal R. Ethical Dilemmas of Participation of Service Users with Serious Mental Illness: A Thematic Synthesis. *Issues Ment Health Nurs.* 2020;41(4):283–95.
16. Jingree T. Duty of Care, Safety, Normalisation and the Mental Capacity Act: A Discourse Analysis of Staff Arguments about Facilitating Choices for People with Learning Disabilities in UK Services. *J Community Appl Soc Psychol.* 2015;25:138–52.

17. Pols J, Althoff B, Bransen E. The Limits of Autonomy: Ideals in Care for People with Learning Disabilities. *Disabilities Med Anthropol.* 2017;36:772–85.
18. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. *BMC Health Serv Res.* 2017; 349(17).
19. Curryer B, Stancliffe RJ, Dew A, Wiese MY. Choice and Control Within Family Relationships: The Lived Experience of Adults With Intellectual Disability. *Intellect Dev Disabil.* 2018;56(3):188–201.
20. Jingree T, Finlay WML. 'It's got so politically correct now': parents' talk about empowering individuals with learning disabilities. *Sociol Health Illn.* 2012;34(3):412–28.
21. Alonso-Sardón M, Iglesias-de-Sena H, Fernández-Martín LC, Mirón-Canelo JA. Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability? *BMC Health Serv Res.* 2019; 63(19).
22. Biringier E, Hartveit M, Sundfør B, Ruud T, Borg M. Continuity of care as experienced by mental health service users - a qualitative study. *BMC Health Serv Res.* 2017; 763(17).
23. Mol A, Moser I, Pols J. *Care in practice: on tinkering in clinics, homes and farms.* Bielefeld: Transcript; 2010.
24. Mol A. *The logic of care: health and the problem of patient choice.* London: Routledge; 2008.
25. Beauchamp TL, Childress JF. *Principles of biomedical ethics.* 7th ed. New York: Oxford University Press; 2013.
26. Mol A. *The body multiple: ontology in medical practice.* Durham: Duke University Press; 2002.
27. Mol A, Moser I, Piras EM, Tirrini M, Pols J, Zanutto A. Care in practice. On normativity, concepts, and boundaries. *Tecnoscienza: Italian Journal of Science Technology Studies.* 2011;2:73–86.
28. Kindon S, Pain R, Kesby M, editors. *Participatory Action Research: Connecting People, Participation and Place.* 1st ed. London: Routledge; 2007.
29. Digby R, Lee S, Williams A. Interviewing people with dementia in hospital: recommendations for researchers. *J Clin Nurs.* 2016;25:1156–65.
30. Bowen GA. Grounded theory and sensitizing concepts. *Int J Qual Methods.* 2006; 5(3).
31. Boeije H. A purposeful approach to the constraint comparative method in the analysis of qualitative interviews. *Qual Quant.* 2002;36:391–409.
32. Rutz S, de Bont A. Collective Discretionary Room: How Inspectors Decide with Providers and Citizens. In: Van de Walle S, Raaphorst N, editors. *Inspectors and Enforcement at the Front Line of Government.* London: Palgrave Macmillan; 2013.
33. Cardol M, Rijken M, van SLantman-De Valk. H. Attitudes and dilemmas of caregivers supporting people with intellectual disabilities who have diabetes. *Patient Educ Couns.* 2013;87:383–8.
34. Mol AM, Law J. Complexities, an introduction. In: *Complexity in Science, Technology and Medicine.* Durham: Duke University Press; 2002.

# Tables

Table 1  
Interviews

		Care team 1	Care team 2
		Serious mental illness	Intellectual disabilities
		<i>N</i>	<i>N</i>
<i>Interviews</i>	<i>Service users</i>	8	12
	<i>Peer support workers</i>	8*	
	<i>Family members</i>	3	4
	<i>Family support workers</i>	3**	
	<i>Professionals</i>	8	10
	<i>Team coaches</i>	2**	
	<i>Team managers</i>	1	1
	<i>Managers on the organizational level</i>	3**	

\* In multiple teams; \*\* not in a team

Table 2  
Focus groups

	Care team 1 participants	Care team 2 participants
	Serious mental illness (SMI)	Intellectual disabilities (ID)
<i>Service users</i>	5	5
<i>Professionals</i>	8	9
<i>Family peer support</i>	6 (both SMI and ID, not in a team)	

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