How do people with moderate intellectual disability evaluate restrictions in daily care?

Anne Pier Schelte van der Meulen, Elsbeth Frederieke Taminiau, Cees (Cornelis) Marinus Petrus Hertogh & Petri (Petronella) Johanna Catharina Maria Embregts

To cite this article: Anne Pier Schelte van der Meulen, Elsbeth Frederieke Taminiau, Cees (Cornelis) Marinus Petrus Hertogh & Petri (Petronella) Johanna Catharina Maria Embregts (2018) How do people with moderate intellectual disability evaluate restrictions in daily care?, International Journal of Developmental Disabilities, 64:3, 158-165, DOI: 10.1080/20473869.2018.1442182

To link to this article: https://doi.org/10.1080/20473869.2018.1442182

© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

Published online: 08 Jun 2018.

Article views: 176

View Crossmark data

Citing articles: 1 View citing articles
How do people with moderate intellectual disability evaluate restrictions in daily care?

Anne Pier Schelte van der Meulen1,2, Elsbeth Frederieke Taminiau1, Cees (Cornelis) Marinus Petrus Maria Hertogh3, Petri (Petronella) Johanna Catharina Maria Embregts4

1Department of Tranzo, Tilburg University, Tilburg, Netherlands, 2Elver, Organisation for People with Intellectual Disabilities, Arnhem-Wehl, Netherlands, 3Department General Practice & Elderly Care, Chair for Ethics of Care for Frail Elderly, Vrije Universiteit Medical Center, Amsterdam, Netherlands, 4Department of Tranzo, Chair for People with an Intellectual Disability, Tilburg University, Tilburg, Netherlands

Objectives: One of the general articles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) focuses on the right of freedom to make one’s own choices and being aware of the importance for persons with disabilities to obtain independence. People with intellectual disability (ID) are, to a greater or lesser degree, dependent on significant others, such as support staff with respect to decision making. For that reason, the UNCRPD also stresses the relevance of supportive decision making, which should be stimulated by service policies. However, support staff may find it necessary to restrict people with ID to make their own choices, for example to prevent them from harm. Since restrictions should be applied in the interest of people with ID, it is essential to examine their own perception. In this study, we have examined how people with moderate ID themselves perceive and evaluate restrictions in daily care, using a qualitative methodology.

Method: Based on an extensive pilot study, we conducted interviews being close in time and place in which possible restrictions might occur. Additionally, we applied triangulation of sources. After conducting interviews with eight persons with a moderate ID, we examined their clinical files and interviewed their key workers. Qualitative analysis was carried out by two researchers, using an inductive, thematic approach.

Results: Results demonstrate communality between the participating people with ID and their key workers in perception and evaluation of restrictions, in people with ID tending to comply with the applied restrictions. When the participants with ID and their key workers differ in their evaluation of applied restrictions, this appears a value based dissensus.

Conclusion: To ensure that restrictions are applied in the best interest of people with ID, it is essential that staff are attentive to the wishes of people with ID, which might be based on different values. By asking people with ID about their experiences and views of the restrictions imposed on them, we hope to contribute to an ongoing and open dialogue to inform the planning and delivery of services for people with ID based on ‘best interest’ principles.

Keywords moderate intellectual disability, restrictions, perception, triangulation, qualitative research

In the care for people with intellectual disability (ID), a paradigm shift has taken place in the last few decades; the focus on caring for people with ID has changed to a focus on supporting and empowering them to arrange their own lives (Van Gennep 1997; Tideman and Svensson 2015). In line with this paradigm shift, a general article of the Disability Convention focuses on the right of freedom for people with physical and intellectual disabilities to make their own choices (United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006, Article 3.1). People with ID are, to a greater or lesser degree, dependent on significant others, such as family members and/or support staff with respect to decision-making (Antaki et al. 2008, Van Asselt-Goverts et al. 2015). For that reason, the UNCRPD stresses the relevance of supportive decision-making (UNCRPD 2006, Article 12.3; Williams and Porter 2015), which should be stimulated by service policies.

Support staff play an important role in the daily life of people with ID. On the one hand, it is their responsibility to provide people with ID space and freedom to make their own choices, on the other hand, it is also their task to protect people with ID from harm, as a consequence of which they may need to restrict them in making their own choices (Verkerk 2001). Hence, applying restrictions can be part of providing good care, but only insofar as these restrictions are in the interest of people with ID and are decided upon in dialog with them (Ahma et al. 2006; Van Dartel 2007).

Restrictions in care can be described from several perspectives, e.g. from a political, sociological, legal or
ethical perspective (e.g. King et al. 2016; Kultgen 2014). In this study, we follow the definition proposed in Dutch legalization regarding care for people with ID and people with a psychogeriatric disorder (Wetsvoorstel Zorg en Dwang 2017).

This bill lists nine categories of involuntary care, among which well-known restrictions and restraints such as isolation and physical restraint. This study focuses on a special category (Article 2.1.h) in which restrictions are defined as measures ‘to arrange the client’s life in such a way that the client has to do or to stop something’ (Wetsvoorstel Zorg en Dwang 2017, article 2.1.h). This includes, for example, daily restrictions in the use of social media or restrictions in bedtimes. Such restrictions are commonly used in daily care for service users and applied as collective care to all the clients living in the same house or living group (Dörenberg et al. 2013). In case people with ID show protest against these restrictions, these are seen as involuntary care according to the bill. Only in case of serious harm for the person with ID or others, involuntary care is permitted. As stated in the bill, an intellectual disability in itself can never be a legitimate ground to restrict people’s freedom. Only the conduct of the person with ID can lead to the use of ‘involuntary care’.

In an earlier study conducted among support staff, we found that support staff applied restrictions thus defined in different domains of daily life, i.e. eating and drinking, hygiene, social contacts, means of communication and bedtimes. Examples of restrictions thus defined are diet rules to protect people with ID from obesity, or restrictions regarding use of social media to protect them from unwanted or predatory contacts. From their perspective, support staff applied these restrictions to provide safety, structure and clarity for people with moderate ID, although they also experienced moral doubt regarding the application of restrictions in general, and more specific regarding the extent to which restrictions are in the best interests of people with ID (Van der Meulen et al. 2018).

Since restrictions should be applied in dialog with and in the interest of people with ID (Dörenberg et al. 2013), it is essential to examine how people with ID themselves perceive the applied restrictions (UN Chronicle 2004). Exploring their perception and evaluation of restrictions may deepen our understanding of the extent to which people with ID agree or disagree with applied restrictions. Moreover, it may illuminate whether the applied restrictions can be considered in the best interest of service users. Most research in this area concentrates on the perception and evaluation of restrictions by people with mild ID (e.g. Netherlands Institute for Health Service Research (NIVEL) 2013; Heyvaert et al. 2014; Negenman et al. 2014). These studies indicate that people with mild ID do not always agree with restrictions in daily care. Research that includes the perspective of people with severe ID via family members or support staff shows that they believe that people with severe ID have few experiences of restrictions as their intellectual disability causes them to be unaware of the applied restrictions (Hertogh et al. 2015). Studies examining the perception of people with moderate ID on restrictions in daily life are scarce however. Therefore, we have conducted a qualitative study, addressing the research question: How do people with moderate ID perceive and evaluate restrictions applied to them in daily care and to what extent do they agree with these restrictions? Due to the cognitive and communicative abilities of people with moderate ID, we were not able to replicate the methods used to collect qualitative data on the perception of restrictions among people with mild ID. Based on an extensive pilot study we developed a tailored method to include the perspective of people with moderate ID, on which we will report in this paper.

**Method**

**Participants**

After ethical approval by the Ethics Committee of Tilburg University (EC-2015–14), participants were recruited via a care organization for people with ID in The Netherlands. The first inclusion criterion for participation was the level of intelligence, i.e. moderate intellectual disability (IQ 35/40–50/55, American Psychiatric Association 1994). Two health psychologists from the care organization selected all service users with this classification in their clinical files. To exclude people with profound intellectual disability from this study, the ability to verbally communicate in an understandable way was set as a second inclusion criterion (American Psychiatric Association 2013). This ability and an additional verification for not having severe ID were also assessed by the two health care psychologists, based on personal contacts with the service users.

Participants were randomly selected from a pool of 25 people. As an additional check for not including people with mild ID, these participants carried out an IQ test (Wechsler Adult Intelligence Scale (WAIS) 2012) conducted by a health psychologist with no affiliation to this study (Table 1).

According to guidelines of the Ethics Committee of Tilburg University, permission was gained from their legal representatives to allow them to participate in this study; this was done by sending the representatives an

| Client | Gender | Age | IQ | Setting  | Number of years in care organisation |
|--------|--------|-----|----|---------|-------------------------------------|
| 1      | F      | 60  | <55| Residential | 53                                  |
| 2      | M      | 35  | <55| Residential | 14                                  |
| 3      | F      | 33  | <55| Residential | 15                                  |
| 4      | F      | 54  | <55| Residential | 31                                  |
| 5      | F      | 62  | <55| Residential | 4                                   |
| 6      | M      | 47  | <55| Family home | 15                                  |
| 7      | M      | 54  | <55| Family home | 20                                  |
| 8      | M      | 46  | <55| Residential | 0.2                                 |
information and consent letter explaining the background of this research. In the letter, it was explained that all information given by the participants would be made anonymous and treated confidentially and that participants were given the opportunity to end the interview at any moment without providing a reason and without negative consequences. The consent letter also stated that the data would be stored for 10 years, according to the guidelines of Tilburg University. Next, the researcher gave the representatives of the people with ID the opportunity to make inquiries about the study by phone or mail. They were given at least two weeks to decide whether or not they would give the client permission to take part in the study. The people with ID that were given permission to take part were informed about the study by their support staff and personally asked for consent to participate, to which all people with ID agreed. In total, eight people with moderate ID participated in the study.

To gain as much information as possible about the perception of restrictions by people with moderate ID, their support staff were also interviewed. All key workers of the eight participants with ID received an information and consent letter informing them about the study and asking for consent to participate in an interview. In line with the legal representatives of participating people with moderate ID, they were also given two weeks to consider their cooperation; the researcher (APM) phoned them during this period to check whether the aim of the study was clear to them. They all gave their written consent.

Procedure

Because of the paucity of studies in which people with moderate ID are interviewed, first a reliable method to collect data was developed. In a pilot study, we conducted an interview based on five domains of daily life: (1) bedtimes, (2) hygiene, (3) eating, (4) social contacts and (5) means of communications (Van der Meulen et al. 2018). The day was visualized by drawing a simple continuum starting with the morning and ending with the evening. This continuum was used to guide the people with ID through the different life domains and ask them for possible restrictions in each of these domains. In addition, pictures were used representing the particular life domains. However, participants tended to agree to all possible restrictions. Therefore, it remained unclear whether they really understood the questions and to what extent they had provided socially desirable answers.

To promote the reliability and internal validity of our study, we therefore adapted our method of data collection. Firstly, instead of conducting a single interview, we interviewed the client during three specific times a day (in the morning 8.00–8.45 AM, at the beginning of the evening 6.30–7.15 PM, and later in the evening 8.15–8.45 PM) during which restrictions in a particular domain of daily life may occur, such as restrictions in hygiene in the morning, in receiving social visits at the beginning of the evening and at bedtime later in the evening. In addition, these interviews were administered in or nearby the setting these restrictions might occur (see Table 2). In this way, we were not only close in time and place, but we also included the context of the living environment of the person with ID. For example, the interviewer asked the client if he could see the clients’ bathroom at nine o’clock in the morning, asking where and how the client washed him or herself this morning, knowing that the client washes him or herself every morning. Subsequently, the interviewer asked whether there were limitations or restrictions in using the bathroom. Finally, the interviewer asked participants with ID how they evaluated the self-mentioned daily restrictions by inviting them to choose between three possibilities related to each of the five domains: ‘good’, ‘could be better’, ‘not good’. The three possibilities were supported by pictures frequently used in the care organization: a picture with a thumb up (‘good’), a thumb sideways (‘could be better’), and a thumb down (‘not good’). In reaction to the client’s choice, the interviewer (APM) further probed to clarify why the client chose the indicated response option. For instance, ‘Can you tell me more about why you chose “could be better”?’. Prior to conducting the interview, the interviewer did not obtain any information about the participants to limit bias in interpreting their accounts. All interviews were audio-recorded. The participants were offered the possibility of listening to the audio-recorded interviews, which was done by two participants.

Secondly, we adapted the method of data collection by applying triangulation of sources in collecting information (Boland et al. 2008). After conducting the interview with the person with ID, we systematically analyzed the clinical file of that person with respect to information regarding (1) possible applied daily restrictions and (2) the person’s perception of these restrictions. The Ethics Committee of Tilburg University, the board of the care organization as well as the legal representatives provided consent to look at the files of the participants. We then interviewed the key worker of the person with ID regarding the restrictions applied. The interview with the key worker took place within two months of the interview with the person with ID. In line with the interviews with the people with ID, these interviews were based on the five aforementioned domains of daily life. First, key workers were asked what kind of restrictions were applied to the people with ID.

| Domain of daily life | Time of interview | Location |
|---------------------|------------------|----------|
| Bedtimes            | 8:00 AM          | Bedroom  |
|                     | 8:30 PM          | Bedroom  |
| Eating              | 8.30 AM          | Living room |
|                     | 8.30 PM          | Living room |
| Hygiene             | 8:15 AM          | Bathroom |
| Social contacts     | 7:00 PM          | Bedroom  |
| Means of communication | 6.45 PM      | Living room |
|                     | 8.15 PM          | Bedroom  |
and subsequently, they were asked how people with ID perceived and experienced these restrictions according to their own opinion. Information from the clinical file of the person with ID regarding restrictions was mentioned by the interviewer when key workers did not mention this information themselves.

**Analysis**

Qualitative analysis of all interviews and clinical files was carried out by two researchers (APM, ET), using an inductive, thematic approach (Braun and Clarke 2006). The analysis started with the verbatim transcription of the interview with the person with ID, which was then coded inductively by both researchers independently. In case of disagreements, consensus was negotiated. Next, the clinical file of the person with ID was checked by the first author for information regarding daily restrictions. Subsequently, this information was coded by both researchers. Again, consensus was negotiated in case of disagreements. Finally, the interview with support staff was transcribed verbatim, and coded inductively by both researchers independently. Both researchers negotiated consensus in case of disagreements. All analyses were conducted supported by Atlas-Ti (Muhr 2005).

After both researchers (APM, ET) completed two cases (participants 1 and 2), four researchers (APM, ET, PE and CH) explored the data and discussed the themes derived. This process was repeated after three additional cases (participants 3 to 5). At that point, we concluded that the interviews with the latter participants showed the same findings. A possible explanation for these similar results was that all people with ID lived for an extended period of time (from 4 to 53 years) in a residential setting and in time might have become used to the institutional restrictions. In search of possible disconfirming or negative cases, we therefore added three cases (participant 6, 7 and 8): two with respect to another type of care setting within the same organization (i.e. people with ID living in a family–home instead of a residential setting) and one with respect to duration of residency in the same organization (i.e. a person with ID who lived in the care organization for only 2 months). These three cases were analyzed in the same way as the first five cases, and confirmed earlier findings. Therefore, we concluded that data-saturation was achieved (Guest et al. 2006).

**Results**

In analyzing the data inductively, three major themes emerged: (1) communality between people with ID and support staff, (2) mutual benefit, and (3) disagreement by people with moderate ID.

**Communality between people with ID and support staff**

Table 3 lists the five categories in which daily care is provided, the restrictions within these categories the participants are aware of and whether participants agree or disagree with these restrictions. In addition, the table shows which restrictions are applied in these categories of daily life according to their clinical files and according to their key workers. Participants did not experience restrictions in the category social contacts or agreed with them. Participant 8 did not mention restrictions in any category at all.

Participants indicated to experience the restrictions to which they agree as part of their daily lives and do not challenge them. In case participants agree with the restrictions, this agreement is confirmed by their key workers. The following excerpts illustrate the communality between the person with ID and the key worker in perception and evaluation of diet restrictions, starting with a description from a key worker:

Our client is motivated to stick to her diet. It is for her a nice guideline to watch her weight. She surely shows no resistance against her diet.

(Key worker client 3)

The client herself reports:

Client: Staff tell me that I am not allowed to eat too much. I have a special diet.

Interviewer: What do you think of that?

Client: I think it is all right. Every Friday I weigh myself on the scales. I do not like to get too fat.

(Client 3)

Subsequently, in the clinical file of client 3 it is described that ‘the client has a special diet preventing her from obesity’. The clinical file contains no notification of (dis) agreement from the client to this restriction.

The following example, restrictions regarding bedtimes, also demonstrates communality in evaluation...
between the person with ID and the key worker. The key worker describes the client’s bedtime restrictions as part of the daily structure and in line with the client’s wish:

She [the client] asks for structure herself… At eight o’clock the television is turned off and clients get ready for bed. At half past eight she goes to bed. She needs that rest and it is okay for her.

(Key worker client 4)

The client expressed agreement with the restriction in bedtimes:

At half past eight I go to bed. As it starts to get dark I have to sleep. That’s okay. I need my rest.

(Client 4)

Subsequently, the report in the clinical file confirms this bedtime restriction in a very brief way, i.e. ‘fixed bedtimes for client are necessary to provide rest and structure’ (clinical file, client 4). (Dis)agreement from the client to the restriction is not described in the clinical file.

**Mutual benefit**

Participants consider the applied restrictions to be beneficial for themselves and also for others like family members. The restrictions are believed to promote their own and others’ well-being as well as the quality of their relation. Interviewees mention in this respect the following justifications namely (a) promoting their own physical and mental health, e.g. restrictions regarding drinking and eating (I am a diabetic, I have to be cautious with eating, client 6) (b) promoting their safety, e.g. restrictions in using a mobile phone to keep people with ID from doubtful contacts (It is not allowed to have [mobile] contact with boys, for my own safety, client 3) (c) obtaining structure and rest, e.g. restrictions regarding fixed bedtimes (I need my rest, so I go to bed at half past eight, client 4) (d) preventing others from inconvenience, e.g. restrictions in contact with family members (My brother has other things to do, he has a busy life, so I better not phone him, client 2) (e) dealing with organizational reasons, e.g. restrictions in duration of bathing time due to limited work time of support staff (Support staff also need to help others, client 5).

In addition, data indicate that the justifications mentioned by people with moderate ID might be derived from justifications provided by significant others like family members. People with ID explicitly refer to these significant others in mentioning the justifications for the applied restrictions. This is shown in the next two interview fragments in which people with ID describe that the restrictions stem from their parents. People with ID seem to adopt these justifications. In the first fragment, the client justifies a restriction, originating from his mother, in the domain means of communication. The client experiences the limitation in phoning as a restriction, but does accept the restriction imposed by his mother:

I may phone my mother once a week on Tuesday, but I may not phone my brothers. My brother B. has a very busy job... My other brother F. is also very busy with the children. Therefore, my mother has decided that R. [the client speaks of himself in third person] does not make any phone calls to them, unless their children are older or go their own way... or something like that... I like to phone him and I like to talk a lot... My brother B. himself does not phone me... But I cannot blame him for that, because he is very busy with his work, his children and with doing his shopping. And he also needs to play tennis. (Client 2)

The key worker of the client states that the reason why the client is restricted in calling his mother and is prohibited from calling his brothers stems indeed from the mother, but is also supported by support staff. According to the key worker:

The client can rattle for an hour and takes a lot of time of his family members. Therefore the client is only allowed to phone his mother for half an hour a week and is prohibited to phone his brothers.... This decision stems from mother and as support staff we understand this.

(Key worker, client 2)

The clinical file of this client reports, without mentioning a reason that the client ‘is allowed to phone his mother once a week for half an hour’.

A second fragment describes a similar theme; according to the person with moderate ID the justification for the prohibition to possess a mobile phone stems from her mother, which is supported by support staff. The client mentions the following:

Client: No, no, I am not supposed to have a telephone. No, no, that is not allowed. No, I do not have a phone or a mobile phone...

Interviewer: Why is that?

Client: The staff. Uh... and my mother does not like it at all...

Interviewer: Can you tell me why you are not allowed to have a phone?

Client: It is because... it is not allowed for me to have contact with boys for my own safety.

Interviewer: How is it for you not to phone or text boys?

Client: I think that’s okay. It is better not to phone them.

(Client 3)

The key worker of the client states:

Our client can make phone calls in the central living room with assistance of support staff. This is for her own good and for her safety. It is better that she does not have a mobile phone as stated by her mother.

(Key worker client 3)

The clinical file of this client makes no further notification of this restriction.

In both examples, the justifications for the restrictions as provided by parents and which are considered beneficial for people with ID are supported by support staff, and are adopted by the people with ID themselves. Hence, people with ID seem to derive the justifications for restrictions.
from significant others like family members and consider these justifications as beneficial for themselves.

**Disagreement by people with moderate ID**

Besides agreement with applied restrictions which participants show, they also show protest against restrictions. Therefore, we identified disagreement as a third theme. In these latter cases, they verbally utter the wish to alter the restrictions, as mentioned both by participants themselves and their key workers. In response to the expressed wishes to alter the restrictions, support staff indicate the willingness to explain the reasons for the applied restrictions, though the altering of the restriction itself is not mentioned. Hence, the protest from people with ID is recognized, but does not lead to changes in care. Where support staff emphasize the importance of maintaining the health of the people with ID, clients stipulate the importance of respecting their privacy. This is the case in the following example where a client protests against support staff putting her medicine in the bathroom when she is taking a shower:

I do not like it when support staff bring me medicine while I am taking a shower. That is not okay, but they are still doing it. I do not like that. They can put the medicine on the table in my room when I am ready taking a shower. I do not forget to take my medicine. (Client 1)

The key worker of this client provides the following reason for this restriction:

We know that our client does not like it that we enter her bathroom. But for our client it is necessary to take her medicine. If the medicine is placed in her bathroom, she can take them directly after taking a shower. It makes it more clear for the client that the medicine should be taken. (Key worker, client 1)

The clinical file of the client does not provide any description of or restrictions in the way the client has to take her medicine.

In this case, support staff seem to act according to classic medical values as ‘causing no harm’ and beneficence. The participating person with ID however dissents from support staff on the basis of other values, i.e. her dignity and privacy. She does not want to be seen undressed and is confident that she can remember to take her medicine (I do not forget to take my medicine). Support staff on their side focus on the health and safety of the person with ID. They want to exclude the possibility that the person with ID forgets to take her medicine. This emphasis on the health of the person with ID is understandable due to staff’s responsibility to prevent clients from harm, but the perspective of the client, including the wish for privacy and dignity, is in this case ignored.

Another case in which a participant shows protest is illustrated in the next example. The client in this example wishes to have more privacy in the late evening to spend more time on the iPad:

Client: I think the staff are a little bit too strict. They control me when I am using my iPad. I like to use my iPad also after ten o’clock in the evening till I am going to sleep... Interviewer: At what time are you going to sleep? Client: Normally at half past ten... Interviewer: Why is it that you have to stop using the iPad? Client: My keyworker says that the iPad is emitting radiation, which is bad for me... just before sleeping. (Client 6)

The keyworker of this client justifies this restriction as follows:

It is clear that our client wants to spend more time on the iPad in the evening... But research has shown that radiation from an iPad or mobile telephone is harmful for people just before sleeping. It influences the sleeping process. We explained this to our client and therefore we stimulate him to turn off the iPad before sleeping. (Keyworker, client 6)

In this example, clients’ wish to have more privacy to spend more time using his iPad is ignored by his keyworker using a questionable justification based on promoting the health of the client.

**Discussion and conclusion**

This study examined how people with moderate ID perceive and evaluate restrictions applied to them in daily care and to what extent people with ID agree with these restrictions. To that end, we conducted qualitative interviews with people with moderate ID regarding possible restrictions in five domains in daily life. Analyses showed that participants tend to agree with the applied restrictions. Moreover, they explained restrictions are applied for their own well-being, varying from promoting their physical and mental health to stimulating structure, safety and rest in their lives. Hence, participants describe that restrictions might be a justified means to live a structured life and might contribute to the promotion of their well-being. In this sense, participants show commumality with support staff who mention similar justifications for the application of restrictions (Hendriks *et al. 2008*; Kultgen 2014; Van der Meulen *et al. 2018*). However, these findings require some nuances. In their justification, participants mention the same reasons for the application of restrictions as their family members, they might even derive and internalize their justifications from them. On the other hand, support staff adopt the justifications of family members and apply restrictions for the participants which are initiated by family members, like the restriction to phone only once a week with a father or mother. Support staff of this participant are considering wishes of the family over client’s autonomy. At least staff seem to take it for granted that they have to comply with the family’s request for limited phone calls. They are transparent about restrictions for their client, but they are not departing from client’s wishes and are not considering alternatives to permanent restrictions.
Analysis also showed a value based dissensus between support staff and the participants. Support staff seem to be attached to moral values as promoting health and safety of participants, which can conflict with other moral values like the protection of the privacy and dignity, which are important for the participants. In this sense, traditional care values like causing no harm and beneficence seem to oppose other more person centered values like respecting a person’s privacy and dignity. Hence, support staff primarily focus on the health of the client, which is understandable because they have to provide good care, but they seem to lack awareness of the client’s perspective insofar other values than the health and safety of the client are at stake. Therefore, taking into account the perspective of people with ID asks for reflection and a broader moral sensitivity by support staff (Tonkens and Weijers 1999; Klaver and Baart 2011). This moral awareness requires effort, exercise, patience and also sensitivity to more person centered values (Van der Zande et al. 2013). To ensure that restrictions are applied for their well-being, which encompasses more than the physical health of the clients, it is essential that support staff are attentive to the needs and wishes of their clients (Arrey and Copeland 2014) and act as advocates for their clients and considering alternatives to permanent restrictions. By building up a trusting and professional care relationship (Van Heijst 2009, 2011; Embregts 2011) with space for the client’s own perspective, staff are more able to attain to the wishes and needs of people with ID. More attention of support staff to values like privacy and dignity of people with ID can be helpful in this respect.

However, attitude of support staff is difficult to influence compared to knowledge and skills, which can be trained in a more straightforward way (Van Oorsouw et al. 2013). Nevertheless, there are also studies which illustrate that attitude can be trained (Zijlmans et al. 2011; Van Oorsouw et al. 2014); Hermsen and Embregts (2015) plead for reflective practice in social work education and coaching, and formulated guidelines to promote unconditional care in relationships with care receivers (Van Heijst 2009, 2011; Embregts et al. 2015). Based on a care ethical approach, unconditional care focuses on seeing the client as a person, implying that every person needs attention, trust and a feeling of freedom of choice. In this respect, the five accomplishments (Murray and Lakhani 1998) which constitute a value-based framework to provide support to people with ID can be helpful. For professionals to take into account three of these five aspects, i.e. choice, respect, and relationships can result in a more constructive instead of restrictive approach. Engaging into a respectful dialog with people with ID, will enable support staff to decide in partnership to what extent wishes are realizable.

Although this study gives us insight in the perception and evaluation of the participants with moderate ID, the transferability of the findings is possibly limited as the study is conducted within only one care organization. The way daily care is provided as well as the culture might differ between organizations. Therefore, more research is needed among people with moderate ID receiving daily care in different care settings to achieve saturation on a theoretical basis. A second limitation concerns the response categories that were used to evaluate daily care, participants were able to choose between three response categories, i.e. ‘good’ (thumbs up), ‘could be better (thumbs sideways)’, and ‘not good’ (thumbs down). The response category ‘could be better’ was piloted and was found to be an understandable category for participants, but it does not represent a mid-point in terms of language. As a consequence the results should be interpreted with caution. A third limitation concerns the IQ test we conducted. The score derived from the IQ test indicated that participants have an IQ < 55, thereby enabling us to verify that participants did not have a mild intellectual disability (IQ < 55). The test could not discern between moderate and severe ID however. To include people with moderate ID and exclude people with severe ID, we used information from participants’ clinical files in which they were described as clients with moderate ID as well as information provided by two health psychologists of the care organization who diagnosed the clients as people with moderate ID.

The strength of this study is the development of a method for collecting qualitative data among people with moderate ID themselves. Research in which people with moderate ID are interviewed is scarce. Most research is conducted by means of proxies (e.g. support staff or family members) rather than gathering information from people with moderate ID themselves. Our research method provided the possibility for people with moderate ID, who have limited verbal capabilities, to speak for themselves as stated in the UN Chronicle ‘Nothing about us, without us’ (2004). Furthermore, the triangulation of sources obtained an overall and holistic picture of the research objective. In describing the research method in detail, we did try to make an impetus for further research among people with moderate ID.

To conclude, via an extensive, tailored research method, especially designed for people with moderate ID, we investigated the perception and evaluation of restrictions in daily care by people with moderate ID. Results showed that people with moderate ID who participated in our study tend to agree with the restrictions in daily care. They, as well as support staff showed communality in their perception and evaluation of restrictions. However, participants with ID also showed dissent from support staff regarding the application of restrictions, especially when their privacy and dignity was at stake. Therefore, it is advisable that support staff also develop moral sensitivity for these personal values. Finally, people with moderate ID tend to take over the justifications of family members. Further research among family members of people with ID is required to provide more insight in their evaluation of...
restrictions and their influence on support staff who apply these restrictions.

Conflict of interest
No potential conflict of interest was reported by the authors.

Contributors
A.P.S. van der Meulen, E. Taminiau, C.M.P.M. Hertogh and P.J.C.M. Embregts conceived and designed the study, obtained ethics approval, analysed the data and wrote the article in communality. A.P.S. van der Meulen collected the data.

ORCID

Elsbeth Frederieke Taminiau https://orcid.org/0000-0003-1064-9359

References

Abma, T, et al. 2006. Kwaliteitscriteria voor vrijheidsbeperking in de zorg voor mensen met een verstandelijke beperking [Quality standards for restraint of freedom]. Maastricht: University Maastricht.

American Psychiatric Association. 2013. Diagnostic and statistical manual of mental disorders. 4th ed. Washington, DC: American Psychiatric Association.

Antaki, C, et al. 2008. Offering choices to people with intellectual disabilities: An interactional study. Journal of Intellectual Disability Research, 52, 1165–1175.

Arrey, J. and Copeland, S. 2014. ‘You have to care’. Perceptions of promoting autonomy in support settings for adults with intellectual disability. British Journal of Learning Disabilities, 43, 38–48.

Boland, M, et al. 2008. Methodological issues in inclusive intellectual disability research: A health promotion needs assessment of people attending irish disability services. Journal of Applied Research in Intellectual Disabilities, 21, 199–209.

Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77–101.

Dörenberg, V, et al. 2013. Oog voor vrijheid. Kwaliteitscriteria voor vrijheidsbeperking in de zorg voor jongeren en jongvolwassenen met een lichte verstandelijke beperking [Eye for freedom]. Leiden: Hogeschool Leiden.

Embregts, P. 2011. Zien, bewogen worden, in beweging komen. Inaugurele rede [Seeing, being moved, start moving. Inaugural speech]. Tilburg: Tilburg University.

Embregts, P. 2015. Menslevende zorg. Handleiding voor trainers [Professional loving care. guidelines for professionals]. Nijmegen: Acadamy Arnhem en Nijmegen.

Guest, G, et al. 2006. How many interviews are enough? Field Methods, 18, 59–82.

Hendriks, A, Frederiks, B. and Verkerk, M. 2008. Het recht op autonomie in samenhang met goede zorg beziens [The right on autonomy in conjunction with good care]. Tijdschrift voor Gezondheidsrecht, 32, 2–18.

Hermes, M. and Embregts, P. 2015. An explorative study of the place of the ethics of care and reflective practice in social work education and practice. Social Work Education, 34, 815–828.

Hertogh, M, and Embregts, P. 2015. Belevingsonderzoek dwang in de zorg. Twee samenhangende deelstudies [Perception of coercion in care]. Amsterdam/Tilburg: Netherlands; VUMc/Tilburg University.

Heyvaert, M, et al. 2014. Systematic review of restraint interventions for challenging behaviour among persons with intellectual disabilities: Focus on experiences. Journal of Applied Research in Intellectual Disabilities, 28, 61–80.

King, J, et al. 2016. Restrictive practices on refugees in Australia with intellectual disability and challenging behaviours: A family’s story. Advances in Mental Health and Intellectual Disabilities, 10, 222–232.

Klaver, K. and Baart, A. 2011. Attentioneness in care: Towards a theoretical framework. Nursing Ethics, 18, 686–693.

Kuftgen, J. 2014. Professional paternalism. Ethical Theory and Moral Practice, 17, 399–412.

Muhr, T. 3rd ed. 2005. Atlas.ti: The knowledge workbench (version 5.0.66). London: Scilor/Sage.

Murray, G. and Lakhani, S. 1998. The five accomplishments: A framework for obtaining customer feedback in a health service community learning disability team. British Journal of Learning Disabilities, 26, 94–99.

Negenman, A, et al. 2014. De perceptie van vrijheidsbeperkende maatregelen door begeleiders in de residentiële zorg voor jonger en jongvolwassenen met een lichte verstandelijke beperking [Perception of restraining by support staff]. Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen, 40, 147–162.

Netherlands Institute for Health Service Research (NIVEL). 2013. Vrijheidsbeperkende maatregelen in de zorg voor jongeren en jongvolwassenen met een lichte verstandelijke beperking [Restraining measures in the care for youngsters with mild ID]. Available at: <www.nivel.nl> [Accessed June 2017].

Tideman, M. and Svensson, O. 2015. Young people with intellectual disability: The role of self-advocacy in a transformed Swedish welfare system. Qualitative Studies on Health and Well-being [published online] [March 2015]. doi: 10.3402/jhw.v10.25100.

Tonkens, E. and Weijers, I. 1999. Autonomy, solidarity, and self-realization: Policy views of dutch service providers. Mental Retardation, 37, 468–476.

UN, Chronicle 2004. ‘Nothing about us without us’: Recognising the rights of people with disabilities. UN, 41, 4.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2012. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html> [Accessed October 2017].

Van Asselt-Govers, A, et al. 2015. Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. Journal of Intellectual Disability Research, 59, 450–461.

Van Dartel, H. 2007. Goede zorg bij verzet, handleiding bij omgaan met verzet [Good care in case of resistance]. Utrecht: VGN.

Van Gennepe, A. 1997. Paradigmavervroeging in de visie op zorg voor mensen met een verstandelijke handicap [Shift in paradigm]. Maastricht: Universiteit Maastricht.

Van Heijst, A. 2009. Professional loving care and the bearable heaviness of being. In: H. Lindemann, M. Verkerk and M. Walker, eds. Naturalized bioethics, toward responsible knowing and practice. New York, NY: Cambridge University Press, pp. 199–217.

Van Heijst, A. 2011. Professional loving care: An ethical view of the healthcare sector. Leuven: Peeters.

Van der Meulen, A, et al. 2018. Restraints in daily care for people with moderate intellectual disabilities. Nursing Ethics, 25, 54–68.

Van Oorsouw, W, et al. 2013. Evaluating staff training: Taking account of interactions between staff and clients with intellectual disability and challenging behaviour. Journal of Intellectual and Developmental Disability, 38, 356–364.

Van Oorsouw, W, et al. 2014. Writing about stress: The impact of a stress management program on staff accounts of dealing with stress. Journal of Applied Research in Intellectual Disabilities, 70, 236–246.

Van der Zande, M, et al. 2013. Ethical sensitivity in practice: Finding tacit moral knowing. Journal of Advanced Nursing, 70, 68–76.

Verkerk, M. 2001. The care perspective and autonomy. Medicine, Health Care and Philosophy, 4, 289–294.

Wechsler Adult Intelligence Scale (WAIS), 2012. ENSCHEDE: NETHERLANDS: PRINTPARTNERS IPSKAMP.

Wetsvoorstel Zorg en Dwang, 2017. Bill Care and Coercion regarding psychogeriatric clients and clients with an intellectual disability. Available at: <http://www.eerstekamer.nl> [Accessed June 2017].

Williams, V. and Porter, S. 2015. The meaning of ‘choice and control’ for people with intellectual disabilities who are planning their social care or interactions between staff and clients with intellectual disability and support. Journal of Applied Research in Intellectual Disabilities, 30, 97–108.

Zijmans, L, et al. 2011. Training emotional intelligence related to treatment skills of staff working with clients with intellectual disabilities and challenging behaviour. Journal of Intellectual Disability Research, 55, 219–230.