




Perspective of relatives on restrictions applied to their family members with moderate intellectual disability

Anne Pier S. Van der Meulen¹ , Elsbeth F. Taminiau¹ ,
Cees M. P. M. Hertogh²  and Petri J. C. M. Embregts¹

¹Tilburg University, Tranzo, Tilburg, Netherlands; ²Department of General Practice & Eldery Care Medicine, Amsterdam UMC, Amsterdam, Netherlands

The application of restrictions plays a great part in daily support of people with moderate intellectual disability (ID). In this study we examine the evaluation of relatives of restrictions applied to their family members with moderate ID. Relatives are key and permanent figures in the lives of people with moderate intellectual disability. Moreover, relatives in their role as representatives are authorized to make decisions in case people with moderate ID are not able to oversee the consequences of their actions. To explore relatives' evaluation of restrictions, we conducted semi-structured interviews with 10 relatives. Qualitative analysis was carried out using a thematic approach. We found that respondents consider restrictions necessary when they promote physical well-being, safety and indistinctive, 'normal', appearance of their family members with ID. In applying these restrictions a 'rules are rules' and a 'tailor-made rules' approach can be discerned. The 'tailor-made approach' provides space for dialogue with people with moderate ID. In this dialogue the criteria of proportionality, effectiveness, and subsidiarity are helpful. In using these criteria, the application of a restriction has to be in proportion, has to lead to the desired effect, and, finally, should be as unintrusive as possible for the person concerned. As such, it is recommended that, in dialogue, support staff, people with moderate ID themselves, and their relatives seek ways to examine what kinds of restrictions are justified for people with moderate ID.

Keywords Intellectual disability, restrictions, ethics, justifications, dialogue

Introduction

In the care for people with moderate intellectual disability ID (IQ 35/40–50/55, APA 1994), the current focus lies on supporting them to live their own lives and to make their own choices without restricting them. This focus is in line with the UN convention, which stipulates 'the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (UN 2006, article 1). In line, the Dutch Care and Coercion Act (2018) also promotes freedom of choice for people with ID. The Act states that, in addition to severe restrictions, like isolation or being forced to take medication, less severe restrictions, such as restricting people with ID in using means of communication or the amount of food-intake, can also be considered as

involuntary care (article 2.1 h). In this study, the focus will be on these 'less severe' restrictions applied in the daily lives of people with moderate ID living in a residential setting. According to their support staff, daily life restrictions are applied in the domains of eating and drinking, hygiene, social contacts, means of communication, and bedtimes (Van der Meulen *et al.* 2018a). Examples of these restrictions are the constraint to take a daily shower (domain hygiene) or restrictions concerning staying up at night (domain of bedtimes). Support staff explain that these restrictions are applied to contribute to physical well-being, safety or structure for people with moderate ID. Hence, restrictions in daily care have to be applied in a careful and conscientious way. The perspective of people with moderate ID themselves is key in this respect. In a previous study the present authors found people with moderate ID living in a residential setting themselves to confirm the existence of daily life restrictions. Taking into account that their responses might be socially desirable, people

Correspondence to Anne Pier Van der Meulen, Tilburg University, Tranzo, Tilburg, Netherlands. Email: A.P.S.vdrMeulen@uvt.nl

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with moderate ID generally show agreement with these restrictions, indicating that these restrictions contribute to their own physical well-being, safety and structure, and prevent others from inconvenience. However, when a disruption in their privacy or infringement of their dignity is at stake, they show disagreement (Van der Meulen *et al.* 2018b). In evaluating these daily life restrictions, people with moderate ID attach great value to the view of their relatives, which seems to be guide for their own opinion-making (Van der Meulen *et al.* 2018b).

Relatives indeed play an important role in the lives of people with moderate ID during their whole lifespan. Social networks of people with (moderate) ID are often small and restricted to their relatives and support staff, on whom they are strongly dependent for social and emotional support (Giesbers *et al.*, Lippold and Burns 2009). Although there is a wide range of individual profiles within the group of people with moderate ID, they all have more or less severe problems with conceptual and rational thinking and adaptive behavior (APA 2013). These limitations result in a compromised capacity to reflect on the implications of their actions and decisions with respect to their own and others' well-being. Therefore, relatives are often legally authorized to make decisions on behalf of their family member with moderate ID (Care and Coercion Act 2018). As such, they have a key role with respect to the application of restrictions in the lives of people with moderate ID, as both the guide in decision-making for people with moderate ID and from a legal perspective. Since restrictions should only be applied in the interest of people with moderate ID (Dörenberg *et al.* 2013), relatives have the responsibility to carefully balance the extent to which their family members with moderate ID can be provided with the freedom to make their own choices when it comes to the decision to apply restrictions to protect their family members from harm. Conflicts may arise between what is considered 'best-interest care' by relatives and the desires and preferred choices of people with moderate ID themselves. According to care ethics, in this possible tension between the self-determination of people with moderate ID and their protection from harm, the well-being of people with moderate ID should be the guide, and the solidarity of relatives to promote the well-being of people with ID is required (Tonkens and Weijers 1999, Verkerk 2001a). Hence, in addition to the perspective of support staff and people with moderate ID themselves, it is of great importance to investigate how relatives evaluate daily life restrictions of family members with a moderate ID living in a residential setting. To the present authors' knowledge, studies conducted on this topic so far focus on more *severe* restrictions such as fixation and separation as applied to people with moderate ID *and challenging behavior* (see, e.g. Elford

et al. 2010, Heyvaert *et al.* 2015). In these studies, relatives describe the application of restrictions as an attempt to strike a balance between providing freedom and safety for their family members with ID (Elford *et al.* 2010). The present research question is more focused on these 'less severe' and more subtle restrictions applied in daily life of people with moderate ID: How do relatives of people with moderate ID evaluate restrictions in daily care for their family members with moderate ID living in a residential setting? This study focuses on relatives who are often parent(s) or sibling(s) of the person with ID in their role as legal representatives, and with whom they often have close emotional ties (VGN 2017).

Method

Respondents

Permission to interview relatives of people with moderate ID was granted by the Ethical Review Board of Tilburg University, the Netherlands (EC-2016.44). In addition, the care organization where the family members with moderate ID reside also granted permission for this study. Participating relatives received an information and consent letter, explaining the aim and background of the study. In the information and consent letter, researchers explained that all information given by the respondents would be made anonymous and treated confidentially. Next, the researcher explained in the information letter that the interviews would be audio-recorded and that respondents were free to end the interview at any moment without negative consequences. Furthermore, in the consent letter it was stated that the data would be stored safely for 15 years according to the guidelines of Tilburg University. The respondents were selected by purposive sampling (Palys 2008). Potential participants were selected in consultation with the health psychologists working at the care organization at which the relatives with moderate ID reside. Because of their insight into the social network of their clients with moderate ID, the health psychologists were able to indicate potential participants meeting our (purposive) sampling criteria (see Analysis for more detailed information about the sampling procedure). In all, 15 relatives were asked to participate in this study. Five relatives, including relatively older and younger potential respondents, were not willing to participate and did not provide a clear explanation for their refusal (e.g. 'I think it is better that you ask someone else for your research'). According to the process of recruitment they did not have to mention any reasons for refusal

Procedure

Semi-structured interviews were conducted in which the interviewer asked relatives to provide information on the restrictions applied to their family member with

Table 1. Demographic characteristics of relatives of people with moderate ID.

Respondent	Age of respondent	Age of person with ID	Relation to person with ID	Profession
1	68	66	Brother	Manager
2	60	34	Mother	Teacher
3	63	53	Brother	Teacher
4	62	30	Father	Engineer
5	44	15	Mother	Care worker
6	51	49	Sister	Care worker
7	79	35	Mother	Housewife
8	63	39	Father	Construction worker
9	44	53	Sister	Secretary
10	56	62	Sister	Entrepreneur

moderate ID during daily care and to subsequently share their perspective on these restrictions. Prior to the interview, the interviewer had checked the clinical file of the person with ID for restrictions in daily care for which the care organization and relatives had given permission. Checking the clinical file was done to be able to include restrictions in the interview when the respondents themselves did not mention these particular restrictions. In these cases, the character of the interview altered from a nondirective to a directive semi-structured interview (the interview guide is provided in Appendix 1). In the interview, the interpretation of what was meant by daily life restrictions was left open to the respondents, although in the information letter a few examples were mentioned regarding bedtime restrictions for people with moderate ID and restrictions regarding social media, for the purpose of facilitating the dialogue between interviewer and respondent. Prior to data collection, pilot interviews were held with two relatives (other than the 10 participating relatives). Based on this pilot, a few vocabulary changes were made for the sake of clarity and uniformity. After this, the interview guide proved to be useful for an open dialogue about the evaluation of daily life restrictions.

Analysis

Qualitative analysis of all interviews was carried out during the phase of data collection to provide the researchers the opportunity to use increasing insights in each consecutive phase of data collection. The interviews were inductively coded by using a thematic approach (Braun and Clarke 2006), supported by Atlas-ti software (Muhur 2005). The first four interviews were independently coded by two researchers. Inter-coder agreement was determined by checking all codes of both researchers (Miles *et al.* 2014), resulting in an agreement level of 95%. Next, all four researchers involved (APM, ET, CH, PE) discussed these findings. The following interviews were coded by one researcher (APM) and systematically checked for quality, e.g. for bias, by a second researcher (ET) in line with guidelines for qualitative research (Miles *et al.* 2014, p. 312). Each interview was analyzed prior to recruiting the following participant and conducting the next interview. In

this way, the researchers were able to sample consecutive respondents purposively based on data gathered from the previously conducted interviews. In discussing the first four interviews, the research team decided to include two younger respondents since the research population till then consisted of respondents only in the age range of 62–68 years. Belonging to another generation, younger relatives might have a different view on restrictions applied to their family members with moderate ID. With six interviews conducted and analyzed, the research team discussed that younger relatives in the range of 44–56 years of age were indeed more critical of the application of restrictions to their family members with moderate ID. Since all six respondents had a higher education level or worked themselves in caring for people with ID, it was then decided to approach two respondents with professions for which no higher education is required and who had no occupation related to caring for people with ID. Eight interviews were then conducted, and after the analysis of these eight interviews by three researchers (APM, ET, PE), it was concluded that information from respondents with a lower education level or with no profession related to caring for people with ID did not yield new findings. Therefore, it was decided to include two more siblings younger than 60 years of age to obtain balance in the number of participating parents and siblings and to obtain better balance in the age of respondents (i.e. six respondents older than 60 and four respondents younger than 60). After the analysis of all 10 interviews with the research team, no new themes emerged; therefore, it was decided that data saturation was achieved (Table 1).

Findings

In analyzing the data, three themes were identified. First, it was found that relatives mention several justifications for applying restrictions to their family members with moderate ID. Subsequently, it was found that relatives use two different styles to apply restrictions, i.e. the style ‘rules are rules’ (restrictions just have to be followed) and the style ‘rules have to be tailor-made’ (restrictions need to be individually adjusted to their family member with moderate ID).

Table 2. Styles and strategies of applying restrictions according to relatives of people with moderate ID.

Styles	Strategies
'rules are rules': restrictions just have to be followed by their family members with moderate ID	Mentioning negative consequences Offering two alternatives which are both acceptable to the relative Using the argument of a competent authority Being firm in keeping to the restrictions
'rules have to be tailor-made': restrictions are to be adjusted to their family members with moderate ID	Dialogue between support staff, relatives and people with moderate ID

Justifications

In their evaluation of daily life restrictions for their family members with moderate ID, all respondents stipulate that the application of restrictions may be necessary to promote the well-being of their family members. These restrictions are applied by support staff as well as by the respondents themselves. Respondents state that due to their intellectual disability, their family members with moderate ID may lack the awareness and judgment of what is the best thing to do or what is in their best interest. In this respect, restrictions can be helpful to guide their family members with moderate ID in the 'right direction'. The following justifications for applying restrictions were discerned. Respondents endorse restrictions if they promote:

- The physical well-being of their family members with moderate ID.

In this respect, restrictions to maintain good health as well as restrictions to prevent family members with moderate ID from becoming obese are mentioned. Examples are restrictions related to the frequency of physical exercise (e.g. daily exercise of half an hour on the home-trainer) or dietary restrictions (e.g. the restriction not to eat unhealthy food or restrictions with respect to the amount of food intake). For example, a father of a 39-year-old daughter mentions the following dietary restriction:

'To avoid that [names] becomes obese, she is allowed to eat two slices of bread in the morning and two for lunch. Support staff do check this accurately.' (Respondent 8)

Respondents are concerned about the physical condition of their family members, since this is perceived as being vulnerable. In restricting their family members from eating too much and to oblige them to exercise, respondents try to prevent their family members with moderate ID developing physical complaints.

- The safety of family members with moderate ID.

Respondents mention restrictions aimed at protecting their family members with moderate ID from dangerous situations in which they could get injured (e.g. the restriction not to be allowed to ride a bike alone) or restrictions concerning social contacts with unfamiliar

people with the (perceived) risk of abuse. A mother of a 35-year-old daughter with ID describes her fear about her daughter having contact with unknown individuals:

'I just do not want that she visits places where we do not know the people. In case people make unwilling advances to her I always say, "They have to keep their hands off you."' (Respondent 7)

Analysis indicated that fear for what might happen to their family member was motivated by either concrete dismal experiences in the past or by the mere thoughts of possible risks.

- A 'normal' indistinctive appearance of their family members with moderate ID.

According to respondents, their family members with moderate ID have to wear clean clothes, and the combination of clothes has to be suitable and result in a 'normal', indistinctive, appearance to make their relative fit into the daily street scene. In the following example, a respondent describes his difficulties with the way his brother likes to clothe himself:

'I do not want to give my brother too much freedom in choosing his own clothes. He had periods in which he wore three or four sweaters combined with some t-shirts at the same time. That was not normal. I think it was a way to attract attention.' (Respondent 3)

Respondents indicate that they do not like it when family members with moderate ID receive attention because of unusual clothes. They are not so much worried about the teasing or humiliation of their relative with moderate ID, but they in particular stress the attention-seeking attitude of their relative, which is abnormal in their eyes (Table 2).

Styles of applying restrictions

All respondents stipulate the importance of applying restrictions to their family members with moderate ID. In applying restrictions, two styles were identified:

- 'Rules are rules'

Some of the respondents (nos. 1, 2, 3, 4, 7, and 8) indicate that restrictions just have to be followed in all cases, even when their family members with moderate

ID might wish to alter these restrictions. In cases when their family members with moderate ID protest, these respondents seek ways to maintain the restrictions. To realize this, they contact the support staff in order to be involved in the process of caring for their family member with ID. Analysis showed four strategies in which respondents deal with daily life restrictions or urge support staff to deal with daily life restrictions in cases where their family members with moderate ID protest:

- Explaining the background of the restriction and mentioning the negative consequences in case their family member with moderate ID does not follow the restrictions. For example: ‘If you eat too much, you will get obese and then you cannot walk anymore.’ (Respondent 8)
- Offering two alternatives that are perceived as acceptable by the respondent. For example, ‘Do you want to buy this t-shirt or the other one?’ (Respondent 2)
- Using an argument of a competent authority to persuade the person with moderate ID. For example: ‘The dentist has said that you have to put in your dental prosthesis.’ (Respondent 3)
- Being firm in adhering to the restrictions without adapting them. For example:

‘My son has to wear his new shoes instead of the old, shabby ones. He may protest as long as he wants, but he will wear his new shoes.’ (Respondent 4)

It is the opinion of these respondents that support staff, who apply the restrictions in the context of the service provider, should stick to the restrictions. In general, respondents have the feeling that staff are aligned with them and are firm in applying the restrictions without adapting them. However, the adage ‘rules are rules’ is not always endorsed by support staff. For example, the brother of a 53-year-old client expresses his indignation about the permissive attitude of support staff:

‘I am not satisfied with the fact that support staff give in too easily. As an example, my brother is missing a front tooth. Therefore, he has received a dental prosthesis. From the beginning, the staff was not motivated to encourage my brother to put in his dental prosthesis. Staff say to me, ‘if he does not want to, he just does not have to put it in.’ Staff are so permissive.’ (Respondent 3)

In these cases, respondents state that support staff are not strict enough in applying and maintaining the restrictions that they consider important.

- *Tailor-made rules*

In contrast to the style ‘rules are rules,’ other respondents (nos. 5, 6, 9, and 10) mention that in some cases, restrictions must be adapted. According to these respondents, adaption of restrictions is desirable in cases where organizational or medical protocols lead to static, inflexible care. In residential settings, restrictions can be applied to all clients as a form of collective care (Dörenberg *et al.* 2013). Respondents stipulate that in

these cases, they want to have a say in the rulemaking process and in the application of restrictions. Not the prescribed protocol, but the interest of their family member with ID should be the guide. These respondents want to be involved in the care of their family member with moderate ID. The desired dialogue between support staff, relatives, and family members with moderate ID should result in tailor-made rules for their family members with moderate ID. Instead of fixed restrictions or protocols, these respondents prefer personalized restrictions, which requires a certain form of flexibility from support staff and the care organization.

The following example shows a lack of dialogue about restrictions between support staff and a mother of a 15-year-old son. This mother was confronted with a restriction regarding the sitting posture of her son, following a medical protocol, about which she was not informed.

‘The restriction is that my son has to sit in a special chair in a special way to prevent him from developing an incorrect sitting posture. But our son is 15 years old, very lively, and he already has to sit three times a day at the table for his meals. Moreover, he throws the cushions off his special chair. Then I ask myself: “Why did they not consult us as parents about this restriction?”’ (Respondent 5)

The next example expresses a respondent’s indignation at the fact that his family member with ID was obliged to visit the cinema:

‘My brother does not like to go to the movies. He has been scared of staying in dark places since he was young. A while ago he had to join the whole group of clients and go to the cinema due to the organizational restriction that every client joins common activities. There they let him stay alone in the foyer during the whole movie. Afterwards I accidentally heard the entire story. At such moments I think to myself, “What is going on here?” ... Why not consult with me? I want to be part of it.’ (Respondent 3)

These examples make clear that these respondents ask to be engaged in the dialogue about rulemaking. According to these respondents, there may be reasons to adapt the restrictions and make them more tailor-made based on the idea that the well-being of the client is promoted by personalized care.

Discussion

In this study, we qualitatively examined relatives’ perspectives on the restrictions applied in the daily care of their family member with moderate ID. All respondents indicated that the application of restrictions in the daily life of their family members with moderate ID are justified since they promote their physical well-being, safety, or a ‘normal’ indistinctive appearance. Mostly relatively younger respondents (ranging from 44–56 years) emphasize the importance of adjusting restrictions to make them tailor-made for their family members with moderate ID, while relatively older

respondents (ranging from 60–78 years) focus on the mere maintenance of restrictions in applying a so-called ‘rules are rules’ style. In applying a ‘rules are rules’ style various strategies are included, differing from a soft urging to a strong urging and coercion (Verkerk 2001b). In interpreting the findings we use Verkerk’s framework. She defines soft urging as an urging that is visible in persuading and convincing people. A strong urging emphasizes the negative consequence of not following a restriction, e.g. ‘If you do not follow the restriction, then this will be the unpleasant consequence.’ Coercion does not leave any space for freedom for the person concerned as that person is forced to follow the restriction. In our study, respondents who hold the adage ‘rules are rules’ use urging, mentioning negative consequences if family members do not obey the restrictions. Also, they use coercion on their family members by forcing them to keep to the restrictions, without adapting them. In these cases, there is no way out for their family members with ID, i.e. they have to follow the restriction.

In our (previously) conducted studies, professionals (Van der Meulen *et al.* 2018a), people with a moderate ID themselves (Van der Meulen *et al.* 2018b), and their relatives indicate that restrictions in daily care are applied, and they simply provide the same explanations, i.e. restrictions contribute to clients’ physical well-being, their safety, and daily life structure. Relatives, however, provide in our study an additional rationale in indicating that restrictions should also be applied to promote an indistinctive appearance for their family member with moderate ID.

Knowing that there might be morally acceptable justifications to apply restrictions (Care and Coercion Act 2018), people with moderate ID who are at serious risk of becoming a victim of sexual harassment may be persuaded not to contact unknown or unfamiliar individuals. Morally much more complicated is the use of coercion in cases where people with moderate ID are not willing to wear ‘normal’ and decent clothing or a cosmetic dental prosthesis for reasons of appearance. If there is no indication that wearing non-ordinary clothing leads to danger or harm for the person with ID (such as sexual abuse), the justification to restrict the person with ID by coercion seems questionable in terms of power dynamics. This is surely the case in the examples of family members with moderate ID who are obliged to wear neat shoes or a dental prosthesis. Care which is considered in the ‘best interest’ by relatives might be in conflict with clients’ own perceptions. In these cases, relatives’ wishes not to attract the public’s attention, which they perceive as uncomfortable, might outbalance the sense of accomplishment that persons with moderate ID experience in putting together an outfit or choosing which shoes to wear. Since this freedom to make one’s own choices and execute them

accordingly enhances experienced self-determination (Verdugo *et al.* 2012), an open dialogue with respect to best interest care is of great importance in decision-making with respect to applying or maintaining restrictions (Taylor *et al.* 2019, UNCORPD 2012, Article 12.3, Williams and Porter 2017). Perhaps consultations about the individual support plan (Herps *et al.* 2016) offers a good point from which to start a dialogue between support staff, people with moderate ID, and their relatives about restrictions.

Furthermore, for a justified application of restrictions, the criteria of proportionality, effectiveness, and subsidiarity can be helpful (Berghmans 1992, Dörenberg *et al.* 2013). In using these criteria, the application of a restriction should be in proportion, should lead to the desired effect, and, finally, should be as unintrusive as possible for the person concerned. As such, it is recommended that via dialogue support staff, people with ID themselves, and their relatives seek ways to examine what kinds of restrictions are in proportion, effective, and as unintrusive as possible for people with ID. This recommendation especially counts for support staff who collaborate with relatives who are in favor of the ‘rules are rules’ style. According to NICE guidelines, people with ID need to be invited to discuss their preferences in order to individualize their care. It must be ensured that care and support for people with intellectual disabilities is tailored to their needs, strengths, and preferences and is not determined solely by their level of intellectual disability (NICE 2019). This means that in the case that restrictions are necessary for the well-being of the family member with ID based on the promotion of safety and physical well-being, they have to be ‘tailor-made’.

With respect to possible patronization in deciding for the persons concerned what is best interest care, we should also critically reflect on our own procedure in recruiting participants for this study. Health psychologists of the care organization helped us to recruit relatives, but in this process of recruitment we only informed their family members with moderate ID. We did not ask them for permission to interview their relatives or to check their clinical files. In interpreting the findings of this study, another limitation should be taken into account; the sample size (10 respondents) was small and based on one particular care organization. For this reason, the findings of this study, as is the case in most qualitative studies (Verschuren and Doorewaard 2010), cannot represent a greater number of relatives of people with moderate ID. This study did not focus on frequencies, however, but on the exemplary character of the issues discussed (Hertogh *et al.* 2004). Therefore, via purposive sampling, the researchers stepwise selected respondents who differed in age and education level in order to achieve a wide range of variation in respondents. Post-validation of our results

with the respondents would have further strengthened trustworthiness of our findings, however.

The strength of this study is the focus on the relatives of people with moderate ID and without challenging behavior with regard to daily life restrictions, which, as far as the authors know, was lacking in the current literature. Because of their significant role in the lives of their family members with moderate ID, insight into relatives' perspectives of daily life is pivotal in stimulating clients' self-determination.

Conclusion

Relatives of people with moderate ID living in a residential setting indicate that applying restrictions in daily care for their relatives is necessary to promote their well-being. Because of the dependency of people with moderate ID on their relatives, these relatives should carefully balance (a perceived) avoidance of harm by applying restrictions on the one hand and stimulations of self-determination of their family member on the other. It is recommended that best interest care for people with moderate ID, which could also entail the application of restrictions, is decided upon in a conversation between people with moderate ID themselves, their support staff, and their relatives.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Anne Pier S. Van der Meulen  <http://orcid.org/0000-0002-3447-2634>

Elsbeth F. Taminiau  <http://orcid.org/0000-0003-1064-9359>

Cees M. P. M. Hertogh  <http://orcid.org/0000-0003-3081-1245>

References

- American Psychiatric Association (APA). 1994. *Diagnostic and statistical manual of mental disorders*. 4th ed. Washington, D.C.: American Psychiatric Association.
- American Psychiatric Association (APA). 2013. *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, D.C.: American Psychiatric Association.
- Berghmans, R. 1992. *Om bestwil: Paternalisme in de psychiatrie: een gezondheidsethische studie [In own interest: Paternalism in psychiatry]*. Amsterdam, Netherlands: Thesis Publishers.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Care and Coercion Act. 2018. *Wet zorg en dwang psychogeriatrische en verstandelijk gehandicapte cliënten [Care and Coercion Act for people with psycho-geriatric disorders and intellectual disabilities]* [Viewed 15 January 2018]. Available at: <http://www.eerstekamer.nl>.
- Dörenberg, V., Embregts, P., VAN Nieuwenhuijzen, M. and Frederiks, B. 2013. *Oog voor vrijheid. Kwaliteitscriteria voor vrijheidsbeperking in de zorg voor jongeren en jongvolwassenen met een lichte verstandelijke beperking [Eye for freedom]*. Leiden, Netherlands: Hogeschool Leiden.
- Elförd, H., Beail, N. and Clarke, Z. 2010. A very fine line: Parents' experiences of using restraint with their adult son/daughter with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 23, 75–84.
- Herps, M., Buntinx, W., Schalock, R., Breukelen, G., and Curfs, L. 2016. Individual support plans of people with intellectual disabilities in residential services: Content analysis of goals and resources in relation to client characteristics. *Journal of Intellectual Disability Research*, 60, 254–262.
- Hertogh, C., The, A., Miesen, B. and Eefsting, J. 2004. Truth telling and truthfulness in the care for patients with advanced dementia: An ethnographic study in Dutch nursing homes. *Social Science & Medicine*, 59, 685–1693.
- Heyvaert, M., Saenen, L., Maes, B. and Onghena, P. 2015. Systematic review of restraint interventions for challenging behavior among persons with intellectual disabilities: Focus on experiences. *Journal of Applied Research in Intellectual Disabilities*, 28, 61–80.
- Lippold, T. and Burns, J. 2009. Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53, 463–473.
- Miles, M., Huberman, A. and Saldana, J. 2014. *Qualitative data analysis: a methods sourcebook*. 3rd ed. Los Angeles: Sage.
- Muhr, T. 2005. *Atlas.ti: the knowledge workbench (version 5.0.66)*. 3rd ed. London: Scolari/Sage.
- National Institute for Health and Care Excellence (NICE). 2019. *NICE guidance, overarching principles [Vewed 20 September 2019]*. Available at: <http://www.nice.org.uk>.
- Palys, T. 2008. Purposive sampling. In: L. Given, ed. *The Sage encyclopedia of qualitative research methods*. Los Angeles: Sage Publications, pp. 697–698.
- Taylor, W., Cobigo, V. and Ouellette-Kuntz, H. 2019. A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32, 1116–1128.
- Tonkens, E. and Weijers, I. 1999. Autonomy, solidarity, and self-realization: Policy views of Dutch service providers. *Mental Retardation*, 37, 468–476.
- United Nations (UN). 2006. Disability convention: Convention on the rights of persons with disability [Viewed 15 January 2017]. Available at: <http://www.un.org/disabilities/convention>.
- United Nations Convention on the Rights of Persons with Disabilities (UNCORPD) 2012. [Viewed October 2018]. Available at: <http://www.un.org/development/>.
- van der Meulen, A., Hermsen, M. and Embregts, P. 2018a. Restraints in daily care for people with moderate intellectual disabilities. *Nursing Ethics*, 25, 54–68.
- van der Meulen, A., Taminiau, E., Hertogh, C. and Embregts, P. 2018b. How do people with moderate intellectual disability evaluate restrictions in daily care? *International Journal of Developmental Disabilities*, 64, 158–165.
- Verdugo, M., Navas, P., Gomez, L. and Schalock, R. 2012. The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 11, 1036–1045.
- Verkerk, M. 2001a. The care perspective and autonomy. *Medicine, Health Care, and Philosophy*, 4, 289–294.
- Verkerk, M. 2001b. Over drang als goed zorgen. Een zorgethische beschouwing [Urge as a measure for good care]. *Tijdschrift Voor Geneeskunde en Ethiek [Journal of Medicine and Ethics]*, 11, 101–106.
- Verschuren, P. and Doorewaard, H. 2010. *Designing a research project*. 2nd ed. Den Haag: Eleven International Publishing.
- Vereniging Gehandicaptenzorg Nederland (VGN). 2017. *Algemene voorwaarden zorg en dienstverlening WLZ [General conditions care and provision of service WLZ]*. Available at: <http://legacy.vgn.nl/> [Viewed June 2018].
- Williams, V. and Porter, S. 2017. The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 30, 97–108.

Appendix A. Interview guide

Welcome	Word of welcome/aim of the interview
Daily Care	1. Can you tell me how you experience the daily care offered to your relative? 2. What do you in general think of the daily care offered to your relative?
Restrictions	1. Do you know whether restrictions in daily care are applied to your relative? <i>If restrictions are applied, for each restriction consider the following questions:</i> 2a. Which restriction is applied to your relative? 2b. Do you know the reason for the applied restriction? 2c. Is your relative consulted about this restriction? 2d. Does your relative show resistance to the restriction? 2e. Do you as a relative agree or disagree with the restriction? Can you explain this? 2f. If you disagree with the restriction, do you feel the freedom to criticize it? 2g. How does your relative experience the restriction in your view?
Relation to support staff	1. How do you experience your relation to the support staff of your relative? 2. How do you experience your relation to other staff members of the care organization? 3. Do you feel free to express criticism? Can you explain this?
<i>In the case that restrictions have not been mentioned till now</i> Restrictions as described in the clinical file	In the clinical file of your relative the following restriction are mentioned. For each restriction consider the following questions: 1. Do you recognize this restriction? 2a. Do you know the reason for the applied restriction? 2b. Is your relative consulted about this restriction? 2c. Does your relative show resistance to the restriction? 2d. Do you as a relative agree or disagree with the restriction? Can you explain this? 2e. If you disagree with the restriction, do you feel free to express your criticism? 2f. How does your relative experience the restriction according to you?
Remaining questions	Are there any other issues regarding the application of restrictions which you like to mention?
Completion	I would like to thank you for your contribution to this interview. If you wish, you can receive an elaboration of this interview.