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# Restraint interventions in people with moderate to profound intellectual disabilities: Perspectives of support staff and family members

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## Abstract

**Background:** Due to incompatibilities in communication, it is key that family members and support staff can take the perspective of people with moderate to profound intellectual disabilities (ID) whilst putting aside their own perspectives.

**Method:** Ten vignettes describing types of restraint interventions (RIs) were presented to 20 unique pairs of support staff and family members related to individuals with moderate to profound ID.

**Results:** In taking their own perspective, more than half of the support staff and family members perceived all RIs as involuntary and severe. In contrast, when asked to put themselves in the position of the client/family member, only three RIs were considered involuntary by a majority of support staff and family members.

**Conclusions:** These results indicate that support staff and family members can take into account the perspective of people with moderate to profound ID in the evaluation and consideration of involuntary care.

## 1 | INTRODUCTION

Restraint interventions (RIs) frequently are used in the care of people with intellectual disabilities (ID), mostly in reaction to challenging behaviour (e.g., Allen, Hawkins, & Cooper, 2006; Emerson et al., 2000; McGill, Murphy, & Kelly-Pike, 2009). In line with daily practice, RIs can be broadly defined as all measures—whether verbal, physical, mechanical or medical—that restrict a person's freedom (Dutch Healthcare Inspectorate, 2007). Equally, in the United Kingdom, the Deprivation of Liberty Safeguards is used for a wide range of restrictions, including continuous supervision or control and not being free to leave (Ministry of Justice & Department of Health, 2007). In

many other countries, the focus of RIs is still on chemical and physical restraints (Romijn & Frederiks, 2012). Regardless of the range of RIs, however, their use is contentious (Luiselli, 2009; Schippers, van Nieuwenhuijzen, Frederiks, & Schuengel, in press). According to Heyvaert, Saenen, Maes, and Onghena (2014), this is due to lawfulness (e.g., the use of RIs is only legitimate under certain conditions), effectiveness (e.g., the use of RIs might incite additional challenging behaviours) and ethical issues (e.g., the use of RIs contradicts certain values and ethical standards). Moreover, the use of RIs is controversial because of their intrusive nature and the risk of injury to those receiving as well as those applying RIs (Harris, 1996; Luiselli, 2009; Williams, 2010).

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Underlined by the United Nations' declaration for people with disabilities stressing the right of freedom for people with ID to make their own choices (i.e., being autonomous), there is increased attention to the application of RIs towards people with ID. Based on a literature study, Romijn and Frederiks (2012) reported that the use of RIs is a topic on the political agenda internationally, regulated by the criterion of *ultimum remedium*, implying that RIs "should only be used as a last resort after other, less restrictive interventions have been considered (and rejected)" (p. 131). As such, RIs can be applied to avoid harm or disadvantage for the individual with ID and/or in dialogue with the individual and/or his or her representatives. RIs do undermine autonomy, however, and despite numerous initiatives to reduce RIs, they remain widely used on a global level (Romijn & Frederiks, 2012).

In an attempt to reduce RIs, the term *involuntary care* was introduced in national legislation in the Netherlands through the Care and Coercion Act (in Dutch: Wet zorg en dwang). The Dutch government defines involuntary care as all types of care to which individuals with ID or their representatives have not agreed in a dialogue, or to which individuals with ID show resistance. More specifically, the act entails five categories of involuntary care<sup>1</sup>: (a) the administration of nutrition, moisture or medication for a somatic disorder, (b) the administration of medication that affects the client's behaviour or freedom of movement due to a psychogeriatric or a psychiatric disorder or intellectual disability, (c) the restriction of freedom such as isolation and physical restraint, (d) supervision of the client at a distance (surveillance technology), such as a video camera in the bedroom and (e) preventing individuals with ID from managing their own life so that the client has to do or to stop doing something. The law stipulates no hierarchy in these different forms of involuntary care; the perspective of the client is leading. In this respect, it is relevant to underscore that the novel concept of involuntary care covers the entire continuum from RIs to coercion, with the distinctive criterion being the occurrence of resistance in response to the care provided or before the provision of the care. In other words: if there is resistance or no (prior) agreement to apply one of the five categories of care mentioned in the act, care is involuntary. Consequently, involuntary care might embody daily restrictions that are common practice in most residential facilities, often as part of collective measures for all residents (van der Meulen, Hermsen, & Embregts, 2018).

From an ethics of care perspective, involuntary care is related to autonomy, which can be approached in numerous ways (Bekkema, de Veer, Hertogh, & Francke, 2014). Tronto (1993), for example, underlines a relational concept of autonomy, arguing that one is never independent of others. Elaborating on this perspective, Verkerk (1999, 2001) states that the concept of autonomy cannot be separated from relationships with others. Applying

this thinking to the care for people with ID, both support staff and clients have responsibilities in upholding their relationship and by upholding that relationship, they safeguard the client's autonomy (Verkerk, 1999). This requires responsible, attentive support staff who can listen and empathize with the client's perspective and who can constantly reflect on their acting (Verkerk & Maeckelberghe, 2003). As such, with the introduction of the term involuntary care in Dutch legislation, a paradigm shift is occurring because the perspective of the care user (or representative) is now the starting point in deciding if the provided care is involuntary, in contrast to the term RI, where the focus mostly has been on the occurrence of challenging behaviour of individuals with ID that precedes the use of RIs (Denktank Complexe Zorg, 2012).

With this paradigm shift, it is key to understand what individuals with ID consider involuntary care and to understand their perspective when making decisions about the use of RIs. Some insightful studies have addressed the way individuals with ID experience RIs (e.g., Brown & Beail, 2009; Fish & Culshaw, 2005; Jones & Stenfert Kroese, 2008). In general, people with ID (mostly people with mild ID) receiving RIs experience these interventions negatively (Dörenberg et al., 2018; Heyvaert, Saenen, Maes, & Onghena, 2015). When confronted with RIs, they report, among other things, negative emotions such as fear, stress, anger, anxiety, sadness, a lack of respect towards staff members (e.g., Fish & Culshaw, 2005; Hawkins, Allen, & Jenkins, 2005; Jones & Stenfert Kroese, 2006; Lunsy & Gracey, 2009; Sequeira & Halstead, 2001), and negative physical reactions such as pain and exhaustion (Fish & Culshaw, 2005; Griffith, Hutchinson, & Hastings, 2013; Hawkins et al., 2005; Sequeira & Halstead, 2001). In addition, persons with mild ID report that the use of RIs often is unnecessary, and they suggest first trying alternatives, such as talking about their problems to support staff (Heyvaert et al., 2015). Moreover, the greater the role of support staff in RIs and the more restrictive the RIs are, the more RIs are regarded as unacceptable by individuals with ID (de Bakker, van Nieuwenhuijzen, Negenman, Embregts, & Frederiks, 2014; Cunningham, McDonnell, Easton, & Sturmey, 2003; Jones & Stenfert Kroese, 2008; McDonnell & Sturmey, 2000; Miltenberger & Lumley, 1997). These findings were obtained by asking persons with mild ID how they experienced RIs. Due to incompatibilities in communication, however, gaining insight into how people with moderate to profound ID experience RIs is challenging. In many cases, we are largely dependent on interpreting their behaviour to obtain some insight into the subjective experience of people with moderate to profound ID. Because their nonverbal signs can be interpreted in many ways (Munde, Vlaskamp, Ruijsenaars, & Nakken, 2011), interpretation of the behaviour by significant others (i.e., family members and support staff) is necessary to assign a meaning to it. At the same time, it is of key importance that family members and support staff remain sensitive to the distinction between their own perspective and that of the client/family member. In this study, we therefore focused on the ability of family members and support staff to differentiate between their own perspective regarding RIs and their views on the perspective of their family

<sup>1</sup>At the time this study was conducted (2014–2015), only five categories of involuntary care mechanisms were distinguished in the Care and Coercion Act. The act now entails nine categories (Frederiks, Schippers, Huijs, & Steen, 2017). The four additional categories (e.g. searching a person's clothing or body) are mainly due to alignment with the mental health care area and are less relevant for the ID field.

member/client with moderate to profound ID, based on their interpretation of the behaviour. Decisions regarding the extent to which RIs are perceived as involuntary care then can be made based upon a true dialogue in which the perspectives of all parties are included.

For this study, we developed 10 vignettes based on focus groups held with family members and support staff of people with moderate to profound ID, each describing an example of an RI. Vignettes offer the possibility to examine different groups' interpretations of an "uniform" situation (Barter & Renold, 1999). Moreover, using vignettes, sensitive issues such as RIs can be discussed from a distance, enabling participants to reflect on them without getting too close (Neale, 1999). Using vignettes based on qualitative information on RIs, we could use the same situations to compare the two conditions (the perspective of family members and support staff versus their views on the client's perspective based on their interpretation of the behaviour).

## 2 | METHODS

### 2.1 | Participants

Initially, a total of 25 unique triads were formed, each consisting of one individual with moderate to profound ID, a family member and a support staff member with good knowledge of the client. After checking all files, five individuals with ID were excluded from the study because they did not have the required IQ (i.e., an IQ < 50) or an IQ score was unavailable. Of the 20 remaining individuals with ID, 7 had moderate ID and 13 had severe to profound ID. Because family members and support staff were asked how they would experience RIs both from their own perspective and from the perspective of the person with moderate to profound ID, they (i.e., family members and support staff) were the participants in the study.

The 20 individuals with moderate to profound ID, who formed the centre of the triads with support staff and family members, had a mean age of 46 years (range: 23–74), and 11 were men (55%). In addition to their ID, several individuals had additional psychiatric disorders: six had autism spectrum disorder, two had an attachment disorder, and two were known with a mood disorder. Moreover, numerous individuals displayed one or more forms of challenging behaviour. Ten individuals displayed physical aggression towards persons, nine displayed destructive behaviour towards objects, eight displayed self-injurious behaviour, and five displayed compulsive behaviours. They all lived in residential care facilities which offered care 24 hr a day for individuals with moderate to profound ID who need assistance with personal care or medical needs. On average, they had received support by the present ID service for 26 years (range: 1–68).

Participating support staff were key support workers of the individual with moderate to profound ID and had at least weekly contact. Data available on 15 of the 20 support staff indicated that, on average, they had 15.5 years of work experience in the ID field (range: 6–33 years) and, on average, 14.8 years of

experience working with people with moderate to profound ID (range: 6–33 years). Table 1 shows the characteristics of participating family members and support staff.

### 2.2 | Procedure

After ethical approval of the study by the Ethics Committee of Tilburg University (reg. nr. EC-2014.02a), managers of three ID services in the southern part of the Netherlands selected individuals with moderate to profound ID by consulting psychologists, who selected clients through convenience sampling. Inclusion criteria were age 18 or older, having moderate to profound ID (IQ score < 50), living in a residential facility and having a family member and a support staff member who were willing to participate in the study. In addition, the support staff member and client had to know each other for at least 3 months. After 20 individuals with ID were selected, we contacted the clients' personal support staff members and informed them about the study, both verbally and in writing. After support staff agreed to participate, they provided the names of the clients' legal representatives who then were informed about the study, again both verbally and in writing. All family members and support staff consented to participate. A member of the research team visited each participant at home (in the case of family members) or at their workplace (in the case of support staff). After a brief conversation to put the participant at ease, the researcher introduced 10 vignettes, representing 10 examples of possible involuntary care. The researcher read aloud each vignette and its related questions. The participant verbally answered each question, in most cases saying yes or no, which the researcher then recorded on the questionnaire and afterwards into SPSS. First, participants were asked to respond to all 10 vignettes from their own perspective, that is, to identify

**TABLE 1** Characteristics of the participants of the current study

Characteristic	Support staff (N = 20)	Family members (N = 20)
Gender		
Male	2 (10%)	11 (55%)
Female	18 (90%)	9 (45%)
Age (mean)	39.1	62.3
Range (min–max)	24–60	43–79
Relationship with client		
Parent	n.a.	13 (65%)
Sibling		5 (25%)
Other (e.g., legal representative)		2 (10%)
Length of contact with client		
3–6 months	2 (10%)	n.a.
6 months–1 year	0 (0%)	
1–3 year	5 (25%)	
>3 years	13 (65%)	

to what extent they would consider types of care as involuntary if they were to receive these types of care themselves. Second, they were asked to put themselves in the client's position and to indicate to what extent their family member/client with ID would consider these types of care as involuntary.

## 2.3 | Materials

The construction of the vignettes consisted of three phases. The participants who took part in the construction phase were different from those who took part in the actual study.

### 2.3.1 | Phase 1: Inventory of restrictive measures pertaining to involuntary care in the ID field

The concept of involuntary care covers a diversity of restrictive measures. Therefore, an inventory of restrictive measures in the five categories of involuntary care from the Care and Coercion Act was made specifically for the ID field. We conducted two group discussions with six participants each; one group consisted of support staff and one of family members of individuals with moderate to profound ID. In these discussions, participants were asked to name all restrictive measures in each of the categories of involuntary care that they either had applied to their client or had experienced in the care for their family member.

The results of both group discussions were combined into one list (see Table 2). As can be seen in Table 2, support staff and family members primarily mentioned restrictive measures with respect to (a) restraints of freedom such as isolation and physical restraint (e.g., putting the wheelchair on the brake, closing spaces and placing a screen between service users) and (b) restraints that prevent individuals from managing their own life (e.g., fixed bedtimes, handing in lighters/keys and not allowing clients to have a television/radio/computer in their own room). Phase 1 thus resulted in a list of restrictive measures used in daily practice in the care of people with moderate to profound ID, according to support staff and family members.

### 2.3.2 | Phase 2: Prioritizing restrictive measures

The aim of the second phase was to prioritize the restrictive measures in Table 2 from the perspective of individuals with moderate to profound ID. Phase 1 participants were invited to undertake this prioritization; nine individuals (four family members and five support staff) accepted the invitation and participated in a joint session at the headquarters of the healthcare organization.

They rated the three most severe and the three least severe examples of restrictive measures for each of the five categories of involuntary care from the Dutch Care and Coercion Act. Based on the total scores per restrictive measure, we established an overall ranking. The most and least severe examples of restrictive measures for each category were chosen and processed in the vignettes, resulting in 10 vignettes (see Table 3).

**TABLE 2** Examples of restrictive measures used in daily practice in the care of people with moderate to profound ID, according to support staff and family members

<b>Category 1: Administration of nutrition, moisture, or medication</b>	
Restricting the amount of food	Putting medicine in the food
Restricting the use of tobacco	Administration of nutrition/moisture/medication by squeezing nose
Restricting the choice in food	Pouring hot drink on top of cold milk
Providing food using a stomach probe	Providing food in small pieces
<b>Category 2: Administration of medication that affects behaviour or freedom of movement of service user</b>	
Sedating	Prescription of medication for side effects such as tremors (side effect Dipiperon)
Prescription of an antidepressant	
<b>Category 3: Restraints of freedom such as isolation and physical restraint</b>	
Sending someone to bedroom with/without door locked	Holding someone with coercion
Closing spaces (e.g., bathroom, kitchen, office)	Naming the following: do not scratch, masturbate, etc.
Locking closets (refrigerator, medicine cabinet, file cabinet)	Putting a wicket in front of bedroom door
Putting wheelchair on the brake	Placing a screen between service users
Using belt in the wheelchair/triple chair	Using a leash
Locking doors (front door)	Locking shoes
Fencing the garden, using garden gates, using shutters	Clothes with safety lock
Using side rails and playpen bedbox	Using gloves
Allowing to get outside only with accompaniment	Using nontearable clothes/bedding
Chaining to the playpen with a belt	
<b>Category 4: Restraints to supervise service user at a distance</b>	
Motion detection camera	Listening device
Video camera	Spying
Leaving the door ajar (e.g., bathroom or bedroom)	Using mattress that sounds when someone walks out of bed
<b>Category 5: Restraints that prevent individuals from managing their own life</b>	
Restricting choice in clothing	Bathroom tap on yet bath plug out
Fixing bedtimes	Wearing a helmet
Determining where meals has to be eaten	Not allowing to call parents
Determining where someone may sit/lay down	Handing in lighters/keys

(Continues)

**TABLE 2** (Continued)

Using a Time Timer (e.g., to prevent someone is taking a bath too long)	Restricting choice in watching television/gaming/playing
Using a bib	Not allowing television/radio/computer in own room
Using plastic tableware	Not allowing feet on the table

### 2.3.3 | Phase 3: Formulating questions with respect to the constructed vignettes

The aim of the third phase was to formulate relevant questions with respect to the constructed vignettes in Phase 2 (e.g., “would you consider the described type of care involuntary?”, “would you consider this type of care to be a severe form of involuntary care?” and “how would your client/family member react to this type of care?”). These questions enabled us to explore the participants’ subjective experiences. That is, we provided neither a definition of *involuntary care* nor a description of *severe*. Most questions were closed (yes/no) questions, but for the question regarding the client’s expected behavioural response to involuntary care, six clusters of behaviours were formed that were deemed to cover the most common responses to the types of care described in the vignettes (Embregts, Habraken, Trompenaars, & Negenman, 2015). These clusters were (a) aggressive behaviour towards others, (b) aggressive behaviour towards self, (c) destructive behaviour towards materials, (d) resistance and defiance, (e) compulsive and stereotypical behaviour and (f) avoiding, passive behaviour. These clusters were formulated based on an earlier study consisting of concept-mapping sessions with ID physicians and psychologists, support staff and family members. The aim of these sessions was to gain insight into the behaviour of people with moderate to profound ID that might suggest resistance, making it a case of involuntary care. More details about the process of the concept-mapping sessions can be found in Embregts et al. (2015).

In sum, the phases 1–3 yielded 10 vignettes presented in a questionnaire format. The questionnaire was identical for support staff and family members, with the exception that the term *client* was used in the questionnaire for support staff whereas the term *family member* was used in the questionnaire for family members. The questionnaire started with questions about demographic variables and background data for both the participant (i.e., family member or support staff) and the related individual with moderate to profound ID. Next, we presented the 10 vignettes one by one. For each vignette, we first asked participants if their client/family member with moderate to profound ID had ever experienced the described type of care. Next, we asked the participants, from their own perspective, if they considered the described type of care as involuntary when applied to them, and if so, to rate the severity of this type of care. Subsequently, we invited participants to put themselves in the clients’ position and to indicate from this perspective if

**TABLE 3** The 10 vignettes used in the study as examples of involuntary care

The categories of involuntary care in Care and Coercion Act	Most severe example	Least severe example
Category 1: The administration of nutrition, moisture or medication for somatic disorder	Vignette 1: To make sure that Mrs Jones takes her medicine, the pill is put on a spoon. Support staff squeezes Mrs Jones’ nose so that she opens her mouth	Vignette 2: Mrs Brown’s cup is filled half with cold milk. Hot coffee is then poured on top of the cold milk
Category 2: The administration of medication that affects the behaviour or the freedom of movement	Vignette 3: Martin cries and screams. Support staff don’t succeed in calming him down and choose to sedate him	Vignette 4: The doctor prescribes an antidepressant for Mr Blake because of his restless behaviour
Category 3: Restraints of freedom such as isolation and physical restraint	Vignette 5: Dianne is being chained to the playpen with a belt.	Vignette 6: To prevent Laura from taking food from the cupboard, the doors to the kitchen cupboards are locked
Category 4: Restraints to supervise the client at a distance	Vignette 7: A camera is placed in Mr Wayne’s room	Vignette 8: It was agreed that Edwin’s bedroom door would be left ajar so that support staff can hear and see what he is doing
Category 5: Restraints that prevent individuals with ID from managing their own life	Vignette 9: Support staff decided that Robin’s parents are not allowed to call Robin any more	Vignette 10: Mr Fox is given cutlery, plates and cups made from plastic

the described type of care would be experienced as involuntary. In addition, we asked participants if this type of care was likely to precipitate behaviours related to the six clusters described in Phase 3 by indicating the answer on a Likert-type scale ranging from 1 to 5 (1 = *very unlikely*, 5 = *very likely*).



## 2.4 | Data analysis

The data were entered and analysed using IBM SPSS for Windows (version 22). Descriptive quantitative analyses, such as frequencies and percentages per type of response, were performed for each vignette.

## 3 | RESULTS

According to support staff and family members, their clients/family members with moderate to profound ID have experienced all types of involuntary care described in the vignettes (see Tables 4 and 5).

### 3.1 | Perspective of support staff and family members

When responding to the questions from their own perspective, nearly all support staff and family members considered the care described in seven of 10 vignettes as involuntary and severe (see Tables 4 and 5): squeezing the nose to open the mouth (vignette 1; both 100%), sedating (vignette 3; 100% and 95%, respectively), chaining to the playpen with a belt (vignette 5; both 100%), locking the kitchen cupboards' doors (vignette 6; 100% and 85%, respectively), placing a camera in the bedroom (vignette 7; both 100%), leaving the bedroom door ajar (vignette 8; 85% and 80%, respectively) and not allowing parents to call them (vignette 9; both 100%). In addition, 85% of the family members also considered the prescription of an antidepressant (vignette 4) as involuntary and severe. The remaining two vignettes were considered involuntary as well by all family members and by most of the support staff, but a smaller number of participants judged these vignettes as severe. Pouring hot coffee on top of cold milk (vignette 2) was considered a severe form of involuntary care by 55% of the support staff and 65% of the family members, and using plastic tableware (vignette 10) was considered a severe form of involuntary care by 55% and 63%, respectively.

### 3.2 | Perspective of people with moderate to profound ID as perceived by support staff and family members

When asked to put themselves in the position of the client/family member, most of the support staff and family members considered the described care in three of 10 vignettes as involuntary: squeezing the nose to open the mouth (vignette 1, 100% and 95%, respectively), chaining to the playpen with a belt (vignette 5, both 90%) and not allowing parents to call them (vignette 9, 90% and 70%, respectively). In taking the client's position, most of the support staff (75%) considered sedating (vignette 3) as involuntary, whereas half of the family members (50%) indicated this as involuntary care. In addition, approximately half of the support staff and family members considered locking the kitchen cupboards' doors (vignette 6, 47% and 63%, respectively) and leaving the bedroom door ajar (vignette 8, 45% and 55%, respectively) as involuntary care from the perspective of the client. Moreover, according to a minority of support staff and family members, people

with moderate to severe ID would consider the other types of care as involuntary: pouring hot coffee on top of cold milk (vignette 2, 35% and 30%, respectively), prescription of an antidepressant (vignette 4, 15% and 10%, respectively), placing a camera in the bedroom (vignette 7, 30% and 21%, respectively) and using plastic tableware (vignette 10, 20% and 10%, respectively).

### 3.3 | Reasons for not considering care as involuntary

When participants indicated that people with moderate to profound ID would not consider a type of care described in the vignettes as involuntary, we asked them to provide an explanation. Table 6 displays the explanations for each vignette. According to both support staff and family members, the most important reason for people with moderate to profound ID not to consider care as involuntary was a lack of understanding of the act and the consequences. For example, with respect to the prescription of an antidepressant (vignette 4), one participant indicated, "An antidepressant, it's just a pill to her [the client], she just swallows it, she does not know what it is for." With respect to pouring hot coffee on top of cold milk (vignette 2), a participant stated, "That's the way it is, he [the client] does not understand what is going on and that does not bother him." Moreover, regarding the presence of a camera in the bedroom (vignette 7), according to participants, most people with moderate to profound ID would not notice the device in their bedroom. In not noticing it, they would not be aware of the consequences of a camera. As one participant put it, "She [the client] wouldn't think about it and doesn't understand what it means."

Finally, both support staff and family members pointed out that people with moderate to profound ID might become accustomed to certain structures (e.g., closed doors), and, therefore, previously shown behavioural resistance disappears. For example, with respect to locking the kitchen cupboards' doors (vignette 6), one participant indicated, "When the doors are locked, it gives her [the client] peace of mind." According to participants, clients even might adapt to involuntary care over time. In the words of a participant, "She [the client] has become habituated. She cannot get anything herself anymore. In the past, when she could still open them herself, she would have minded this more."

### 3.4 | Clients' behavioural responses to involuntary care

When participants indicated that people with moderate to profound ID would consider a type of care described in the vignettes as involuntary, we asked them how these persons probably would react to this type of care, choosing from the six clusters of behaviours. Tables 4 and 5 illustrate that all categories were recognized by support staff and family members as possible responses to involuntary care. It should be noted that aggressive behaviour towards others and aggressive behaviours towards self are combined into one cluster in Tables 4 and 5 because both behaviours were seldom reported and rated equally.

**TABLE 4** Results per vignette for support staff (N = 20; \* = 1 missing)

Vignette	1. N (%)	2. N (%)	3. N (%)	4. N (%)	5. N (%)	6. N (%)	7. N (%)	8. N (%)	9. N (%)	10. N (%)
Did your client ever experience this type of care?										
Yes	0 (0%)	15 (75%)	2 (10%)	11 (55%)	4 (20%)	11 (55%)	5 (25%)	10 (50%)	0 (0%)	10 (50%)
No	20 (100%)	5 (25%)	18 (90%)	9 (45%)	16 (80%)	9 (45%)	15 (75%)	10 (50%)	20 (100%)	10 (50%)
Would you consider this type of care involuntary?										
Yes	20 (100%)	18 (90%)	20 (100%)	13 (65%)	20 (100%)	20 (100%)	20 (100%)	20 (100%)	20 (100%)	14 (70%)
No	0 (0%)	2 (10%)	0 (0%)	7 (35%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (30%)
Would you consider this type of care severe?										
Yes	20 (100%)	11 (55%)	20 (100%)	10 (50%)	20 (100%)	20 (100%)	20 (100%)	17 (85%)	20 (100%)	11 (55%)
No	0 (0%)	9 (45%)	0 (0%)	10 (50%)	0 (0%)	0 (0%)	0 (0%)	3 (15%)	0 (0%)	9 (45%)
Would your client consider this type of care involuntary?										
Yes	20 (100%)	7 (35%)	15 (75%)	3 (15%)	18 (90%)	9 (47%)*	6 (30%)	9 (45%)	18 (90%)	4 (20%)
No	0 (0%)	13 (65%)	5 (25%)	17 (85%)	2 (10%)	10 (53%)	14 (70%)	11 (55%)	2 (10%)	16 (80%)
<b>When the client would consider this type of care involuntary, according to support staff, the results below indicate how the client would react</b>										
How would the client react?	(N = 20) M (SD)	(N = 7) M (SD)	(N = 15) M (SD)	(N = 3) M (SD)	(N = 18) M (SD)	(N = 9) M (SD)	(N = 6) M (SD)	(N = 9) M (SD)	(N = 18) M (SD)	(N = 4) M (SD)
Aggression towards others and/or towards self										
	2.85 (1.41)	1.00 (0.00)	2.40 (1.68)	2.33 (2.31)	3.47 (1.55)*	1.72 (1.35)	1.00 (0.00)	1.94 (1.51)	2.08 (1.52)	1.00 (0.00)
Destructive behaviour towards materials										
	3.25 (1.48)	1.00 (0.00)	2.73 (1.79)	2.33 (2.31)	3.65 (1.58)*	3.00 (1.94)	1.67 (1.63)	2.22 (1.86)	2.28 (1.71)	2.75 (2.06)
Resistance and defiance										
	4.75 (0.55)	3.86 (1.35)	4.53 (1.06)	3.67 (2.31)	4.72 (0.58)	3.11 (1.83)	2.67 (1.51)	4.00 (1.73)	3.17 (1.79)	2.75 (2.06)
Compulsory/stereotypical behaviour										
	4.60 (0.50)	3.33 (1.86)*	4.27 (1.39)	3.67 (2.31)	4.67 (0.97)	3.78 (1.48)	3.33 (1.37)	3.56 (1.94)	4.39 (0.70)	3.00 (1.83)
Avoiding, passive behaviour										
	4.26 (1.15)*	2.57 (1.62)	4.07 (1.62)	2.33 (2.31)	3.72 (1.67)	1.44 (1.33)	3.17 (1.84)	1.78 (1.56)	2.67 (1.88)	1.75 (1.50)

Support staff indicated that people with moderate to profound ID most often would show compulsive and stereotypical behaviours or behaviours indicating resistance and defiance. These two types of behaviour also were most frequently reported by family members.

## 4 | DISCUSSION

In this study, we explored whether support staff and family members could differentiate between their own perspective regarding RIs and their views on the perspective of their family member/client with moderate to profound ID, based on their interpretation of the behaviour. In taking their own perspective, all examples of RIs (as described in vignettes) were perceived involuntary and severe by more than half of the support staff and family members. In contrast, when asked to put themselves in the position of the client/family member, most of the support staff and family members considered that three of 10 RI examples would be experienced as involuntary. In addition, approximately half of them considered three additional vignettes as involuntary care from the perspective of the client/family member. Support staff and family members thus hold different points of view regarding involuntary care from their own perspective as compared to that of the client/family member with moderate to profound ID. This would

imply that support staff and family members can make a distinction between their own perspective and their view on the client's perspective, as construed from their interpretation of the behaviour.

We investigated the ability of participants to take the perspective of the client/family member in our study and concluded there was a significant difference between their own perspective and their view on the client's/family member's perspective. These findings are valuable, especially from the viewpoint of best interest decisions. People with moderate to profound ID lack the mental capacity for informed consent, and therefore, others have to decide for them, taking into account their best interest. Most care decisions are best interest decisions, but if resistance is observed in response to a best interest decision (i.e., involuntary care), we at least need to reconsider the decision. Interestingly, support staff and family members considered fewer examples of RIs as involuntary when taking the perspective of the person with ID. Squeezing the nose to open the mouth, chaining to the playpen with a belt and not allowing telephone contact with parents were considered involuntary both from their own and from the client's perspective. However, although pouring hot coffee on top of cold milk, prescribing an antidepressant, placing a camera in the bedroom and using plastic tableware was considered involuntary care by at least half of the support staff and the family members from their own



**TABLE 5** Results per vignette for family members (N = 20; \* = 1 missing; \*\* = 1 respondent removed due to inconsistent response patron in particular vignette)

Vignette	1. N (%)	2. N (%)	3. N (%)	4. N (%)	5. N (%)	6. N (%)	7. N (%)	8. N (%)	9. N (%)	10. N (%)
Did your client ever experience this type of care?										
Yes	3 (15%)	15 (75%)	7 (35%)	7 (35%)	9 (45%)	13 (65%)	6 (32%)	6 (30%)	1 (5%)	7 (37%)
No	17 (85%)	5 (25%)	13 (65%)	13 (65%)	11 (55%)	7 (35%)	13 (68%)	14 (70%)	19 (95%)	13 (63%)
Would you consider this type of care involuntary?										
Yes	20 (100%)	20 (100%)	19 (95%)	17 (85%)	20 (100%)	19 (95%)	19 (100%)	16 (80%)	20 (100%)	20 (100%)
No	0 (0%)	0 (0%)	1 (5%)	3 (15%)	0 (0%)	1 (5%)	0 (0%)	4 (20%)	0 (0%)	0 (0%)
Would you consider this type of care severe?										
Yes	20 (100%)	13 (65%)	19 (95%)	17 (85%)	20 (100%)	17 (85%)	19 (100%)	16 (80%)	20 (100%)	13 (63%)
No	0 (0%)	7 (35%)	1 (5%)	3 (15%)	0 (0%)	3 (15%)	0 (0%)	4 (20%)	0 (0%)	7 (37%)
Would your client consider this type of care involuntary?										
Yes	19 (95%)	6 (30%)	10 (50%)	2 (10%)	18 (90%)	12 (63%)*	4 (21%)**	11 (55%)	14 (70%)	2 (10%)
No	1 (5%)	14 (70%)	10 (50%)	18 (90%)	2 (10%)	7 (37%)	15 (79%)	9 (45%)	6 (30%)	18 (90%)
<b>When the client would consider this type of care involuntary, according to family members, the results below indicate how the client would react</b>										
How would the client react?	(N = 19) M (SD)	(N = 6) M (SD)	(N = 10) M (SD)	(N = 2) M (SD)	(N = 18) M (SD)	(N = 12) M (SD)	(N = 4) M (SD)	(N = 11) M (SD)	(N = 14) M (SD)	(N = 2) M (SD)
Aggression towards others and/or towards self										
	2.39 (1.43)	1.67 (1.64)	3.00 (1.67)	1.00 (0.00)	3.19 (1.67)	1.37 (0.71)	1.00 (0.00)	1.86 (1.31)	2.00 (1.52)	1.00 (0.00)
Destructive behaviour towards materials										
	2.37 (1.71)	1.67 (1.63)	2.80 (1.99)	1.00 (0.00)	3.28 (1.84)	1.75 (1.36)	2.75 (2.06)	2.09 (1.87)	2.29 (1.86)	1.00 (0.00)
Resistance and defiance										
	4.42 (1.07)	4.33 (1.63)	4.50 (1.27)	3.00 (2.83)	4.61 (1.04)	3.17 (1.95)	3.75 (1.89)	4.91 (0.30)	2.93 (1.94)	1.00 (0.00)
Compulsory/stereotypical behaviour										
	3.95 (1.65)	3.00 (2.19)	5.00 (0.00)*	1.00 (0.00)	4.83 (0.51)	2.92 (1.78)	4.50 (1.00)	4.36 (1.29)	3.79 (1.85)	2.50 (2.12)
Avoiding, passive behaviour										
	3.63 (1.74)	4.17 (1.60)	3.00 (2.11)	2.50 (2.12)	3.50 (1.89)	1.50 (1.17)	3.25 (2.06)	1.36 (1.21)	1.85 (1.63)*	2.00 (1.41)

perspective, only a minority of them perceived this as involuntary when taking the perspective of the person with ID. It should be noted that these latter examples of care frequently are used in residential facilities, resulting in support staff and family members perceiving this as normal day care and perhaps overlooking the possible involuntary character of it.

In addition, support staff and family members were invited to provide an explanation when indicating that their client/family member would not consider a type of care as involuntary. The most important explanation provided was the client's/family member's assumed unawareness of the restriction and its consequences. As also described by Niemeijer, Depla, Frederiks, and Hertogh (2015), clients can experience a camera in their bedroom as involuntary only if they understand that others will be able to monitor them at a distance through the camera, and, hence, that they will have limited privacy in their bedrooms. Therefore, according to support staff and family members, the intellectual disability of their client/family members prevents them from experiencing this type of care as involuntary. A second explanation was related to the fact that clients might become accustomed to certain structures (e.g., closing doors), and that because of that, previously shown resistance disappears. In addition, people with ID have learned to be overcompliant

to authority figures, stressing the need to remain aware of the tendency of individuals with ID to adapt to the types of care they receive, regardless of their coercive nature (Marinos et al., 2009; van der Meulen, Taminiau, Hertogh, & Embregts, 2018). Given this tendency, it is important that an RI is implemented after a thorough discussion among all formal (multidisciplinary) and informal network members and only if the intervention is in the person's best interest. In this study, some reasons provided by support staff and family members for not considering care involuntary from the clients' perspective might indicate self-justifications for applying restrictive interventions. In this context, it is essential that support staff and family members are aware of this and act only if the RI is in the person's best interest.

Support staff and family members were asked how their client/family member probably would react to care they would consider involuntary. More specifically, they were asked whether the RIs described in the vignettes were likely to precipitate behaviours they, in part, may be designed to control. Both support staff and family members indicated that people with moderate to profound ID most often would show behaviours indicating resistance and defiance, or compulsive and stereotypical behaviours; aggressive behaviours were seldom reported. Interestingly, although half of the people

Vignette	Support staff	Family members
1	<i>N.a.</i>	<i>N.a.</i> <sup>a</sup>
2	Content is more important (N = 4) Practical (N = 2) Acceptance (N = 1) Not aware (N = 2) More enjoyable (N = 2) Habituation (N = 1) More safe (N = 1)	Not interested (N = 5) Easier to drink (N = 4) Habituation (N = 4) No awareness (N = 1)
3	No awareness (N = 3) Happy with effect (N = 1) Habituation (N = 1)	Not conscious of care given (N = 2) Not able to monitor what is happening (N = 2) Did not understand (N = 1) Not aware (N = 4)
4	No awareness (N = 11) Acceptance (N = 2) Enjoyable (N = 1) Feeling of being helped (N = 1) Trust (N = 1) Interesting (N = 1)	Acceptance (N = 1) No understanding (N = 2) No awareness (N = 14) Habituation (N = 2) Interesting (N = 1)
5	Feeling of safety (N = 1) Gives peace (N = 1)	Safety (N = 2)
6	No awareness (N = 2) Gives peace (N = 1) Outside own experience and perspective (N = 4) Trust in staff (N = 1) Not interested (N = 1) Clarity (N = 1)	Habituation (N = 2) Outside own experience and perspective (N = 4) No awareness (N = 1)
7	No awareness (N = 12) Unable to understand (N = 1) Acceptance (N = 1)	No awareness (N = 12) Not interested (N = 3) Cannot locate the camera (N = 1)
8	Feeling of safety (N = 4) No awareness (N = 1) Enjoyable (N = 4) Bothered by noise (N = 1) Not bothered by (N = 1)	Enjoyable (N = 5) Not interested (N = 2) No awareness (N = 2)
9	No awareness (N = 2)	No awareness (N = 4) Acceptance (N = 1) Unable to understand (N = 1)
10	Eating is more important (N = 7) Feeling of safety (N = 1) No awareness (N = 2) Habituation (N = 2) Not interested (N = 3) More enjoyable (N = 1)	Acceptance (N = 2) Appearance is more important (N = 1) Eating is more important (N = 1) Habituation (N = 1) No awareness (N = 5) Not bothered by (N = 1) Not interested (N = 7)

<sup>a</sup>Although one family member did not consider vignette 1 as involuntary care, this family member did not provide an explanation.

**TABLE 6** Reasons for not considering care involuntary from the clients' perspective, according to support staff and family members

with moderate to profound ID are known for displaying physical aggression towards persons, support staff and family members indicated that other types of behaviours (i.e., compulsive and stereotypical behaviours, or behaviours indicating resistance and defiance) are more likely to be shown as a response to involuntary care. In this respect, it is important to emphasize that, in general, stereotypical behaviour is reported more often than aggressive/destructive behaviour in people with severe levels of ID (Poppes,

van der Putten, & Vlaskamp, 2010). Undoubtedly, this study's findings seem to suggest that RIs may be self-defeating in that they generate oppositional behaviours. This is in line with the suggestion of Heyvaert et al. (2014) that RIs can either provoke additional oppositional behaviours or uphold oppositional behaviours when they function as reinforcement. In a similar vein, Fish and Culshaw (2005) reported that the use of RIs made clients more frustrated and brought back memories of frightening experiences; hence, RIs

may be self-defeating in that they incite additional oppositional behaviours.

Notably, great similarity was found when comparing the responses of support staff with those of family members. This outcome is in line with previous research by de Geus, van Oorsouw, Hendriks, and Embregts (2017), who found resemblances between the perspectives of support staff and family members regarding the quality of life of people with severe to profound ID. These findings are relevant because collaboration between support staff and family members is essential for effective support of people with ID, with a similar view being beneficial for collaboration (Turnbull & Turnbull, 2001). In addition, in the current study, no differences were found between support staff and family members of people with moderate ID and support staff and family members of people with severe to profound levels of ID.

In this study, all participants answered the questions regarding the vignettes based on their own perspective first, before being asked to put themselves in the position of the client/family member. Although it is a strength of the current study to illustrate that people can differentiate between these perspectives, this order also might have biased the responses on the client's perspective. Moreover, someone's response or judgement is based on numerous factors, including background and previous experiences. For example, support staff working with clients showing high levels of challenging behaviours in terms of frequency and severity are more likely to experience negative emotions such as fear and anxiety (Lambrechts, Kuppens, & Maes, 2009). As such, it is conceivable that their judgements differ from those who do not experience these negative emotions. Further research should include such previous experiences as well to explore how respondents come to their judgements. In addition, the debate of overmedication of people with ID for the purposes of control is important with respect to the concept of involuntary care. That is, RIs might not always being used not for safety measures, or for the relief of burdensome symptoms, but also to make life easier for carers and staff. Obviously, this raises ethical questions regarding the use of such RIs. However, the client's response to the administration of medication does not allow us to make any statement about the appropriateness of the medication. As our vignettes focused on the direct responses of clients to the application of care, we encourage future research to address this important issue using other methods. Moreover, it would be interesting for future research to focus also on methods to include signals of people with moderate to profound ID themselves, for example, by observation. Systematic observations are an important assessment method to interpret behaviour and to take the meaning of the individual's behaviour into account (Munde et al., 2011). The use of systematic observations, however, is rather time-consuming and, thus, often not feasible in daily situations (Petry & Maes, 2006).

A strength of this study is that, using vignettes, we were able to compare the two different perspectives regarding the same situations for all participants and to explore how clients/family members probably would react in each vignette situation. Nonetheless, it would

be valuable to also include the actual reactions on involuntary care in real life. Next, in line with the Dutch legislation, we intended to explore what people themselves would describe as severe, without defining the term in advance. For example, from a professional point of view, one might interpret prohibiting cigarettes or coffee as not severe, whereas an individual with ID might interpret it as severe. Nevertheless, whether or not an intervention is defined as severe remains a recurring issue in the debate on involuntary care, and future research should address this issue. Finally, future research should include larger sample sizes with randomly selected participants. This also would provide the possibility to undertake some statistical analysis, such as the McNemar test to determine whether there is a significant difference between the two ratings (self-perspective versus service-user perspective).

To conclude, this study indicates that support staff and family members can provide information on RIs from the perspective of clients/family members who are limited in verbally expressing themselves and that they can differentiate between the two perspectives. That is valuable, as it indicates that they can consider the perspective of people with moderate to profound ID in the evaluation and consideration of involuntary care.

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## CONFLICT OF INTEREST

None.

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