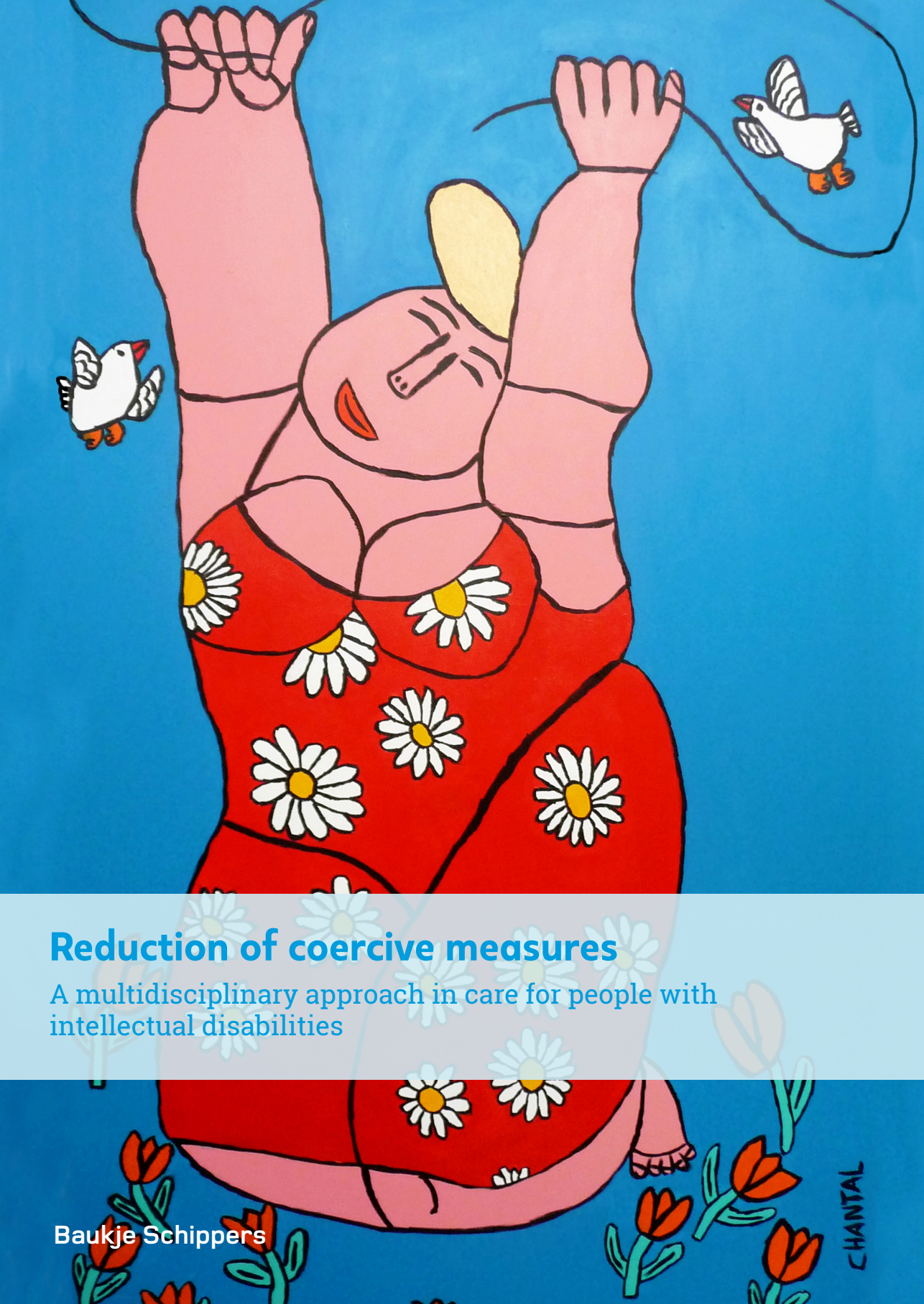

Reduction of coercive measures

A multidisciplinary approach in care for people with intellectual disabilities

Baukje Schippers

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Colofoon

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Reduction of coercive measures

A multidisciplinary approach in care for people with intellectual disabilities

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Chapter 1

General introduction

Depending on their needs, people with intellectual disabilities use long-term care within their own homes, at day care centers, or within residential 24-hour care centers. There are an estimated 135,000 people with intellectual disabilities in the Netherlands, 76,000 of whom use residential care (Schipper, 2014). In the context of residential care, people with intellectual disabilities are often subjected to coercive measures (Fitton & Jones, 2018; Romijn & Frederiks, 2012). In its broadest definition, coercive measures refer to any specific form of care by which the individual person is restricted (Romijn & Frederiks, 2012). Coercive measures as defined in this way include a variety of care practices such as confining persons to their room, tying persons down, locking doors and cupboards, sedating persons, and excluding people from group activities and restriction of access to phones and computers (Dörenberg et al., 2018). The adoption of a broad definition of coercive measures marks a shift in public and professional focus from specific, concrete practices, such as physical fixation or seclusion by means of confinement, towards the abstract notion of subjecting people to coercion in the context of care. This progression is taking place in parallel with the development of the normalization paradigm. The principle of normalization has been gaining influence on practice since 1969 (Van Gennep, 1997), calling for society as a whole to approach people with intellectual disabilities as full citizens with full rights. Everyday life of people with intellectual disabilities should take place as close as possible to the mainstream of society (Van der Meulen, Hermsen, & Embregts, 2018; Van Gennep, 1997). Normalization should not only apply to the topographical and social sphere where everyday life takes place, but also to the sphere of exercising rights and enjoying freedom. Self-determination has also been included in common conceptions of quality of life of people with disabilities (Schalock et al., 2002). As a result of the wide acceptance of the normalization principle, it is upon everyone involved in providing care for people with intellectual disabilities to work towards the reduction and minimization of the use of coercive measures (Frederiks, 2007; Van der Meulen et al., 2018).

A collective acknowledgment of the special vulnerability of people with disabilities to infringement on the universal right of people on self-determination can be found in the UN Convention on the Rights of Persons with Disabilities. The convention explicitly prescribes signatory nations to respect self-determination and to take measures to support persons with disabilities to exercise their rights (United Nations, 2006). To implement the convention, nations have been reviewing and renewing their laws and regulations. In the Netherlands, this has led to the drafting of the Care and Coercion law, which sets requirements for more diligence by healthcare organizations in the use of coercive measures (Romijn & Frederiks, 2012). While it may appear from the lawmaking process in the Netherlands and elsewhere that there is wide consensus regarding the value of self-determination for the quality of life of people with disabilities and the undesirability of measures that can restrict freedom, these coercive measures are still regularly applied and reduction takes place arbitrarily and inconsistently (Schreiner, Crafton, & Sevin, 2004; Williams, 2010; Williams & Grosset, 2011). Empirical research on the use of coercive measures in practice and the effect of methods to reduce their application may contribute to increasing the impact of newly formulated principles and laws.

Criticism on the use of coercive measures and hence the need to adapt legislation and regulations have been reinforced by incidents in the Netherlands and elsewhere that involved very far-reaching and disproportionate coercive measures. At the end of the 1980s, Dutch society was shocked by the images of a young woman with intellectual disability who was tied to a wall without wearing any clothes. The societal and political debate that followed increased awareness of the rights of people with intellectual disabilities (Denktank Complexe Zorg, 2012). However, more recent examples showed that practice around coercive measures is still fraught with dilemmas. In 2011, the media showed footage of an 18-year-old man with an intellectual disability who had been trained to tie himself to a wall upon signal from the care staff. He spent his time almost exclusively indoors. For several years, the care organization had tried unsuccessfully to develop a care plan that would both ensure the physical safety of

their client, care staff, and the facility as well as allow the resident to achieve quality of life (Frederiks, 2011). In addition, in 2013, a woman died during physical restraint performed by four care staff (Frederiks & Moonen, 2013). In these specific cases, professionals perhaps concluded that restrictions and infringement on self-determination were needed in order to provide care. Support for these professionals, and indirectly for their clients, should therefore assume complex, interwoven factors that probably require a combination of disciplines to disentangle (Frederiks & Moonen, 2013).

What do we know about the use of coercive measures

Coercive measures are part of daily care for people with intellectual disabilities. Various national and international scientific studies and reports confirmed that coercive measures occur in almost all locations in the care of people with intellectual disabilities. Figures resulting from studies that have established the occurrence of coercive measures within a period of up to more than one year ranged from 11% to 78% (Fitton & Jones, 2018), indicating almost completely uncertainty about the real rate. Nevertheless, even when the lower bound of prevalence figures is accepted as reflecting reality, both residents and staff are on a regular basis confronted with the application of coercive measures. It is important to note that published prevalence rates are based on a subset of coercive measures, applied for short periods of time to prevent residents and staff from acute danger, such as physical or mechanical restraint or locked seclusion (Matson & Boisjoli, 2009). Little is currently known about coercive measures that are applied over a longer period of time and about measures that are not directly visible, such as social restrictions (Dörenberg et al., 2018). Prevalence rates based on the broad definition of coercive measures are likely higher than currently known figures. Uncertainty of information on the use of coercive measures affects not only scientific developments but also the activities of the organizations themselves. On the basis of a reliable estimate of the use of coercive measures, strategies can be developed to reduce the use of these measures. Therefore, in order to obtain accurate information on the use of coercive measures, more knowledge is needed on the reliable registration of these coercive measures in daily practice.

Reliable registration of coercive measures opens up opportunities to study associated factors. In combination, incidence rates and associated factors can guide efforts towards reduction (Huckshorn, 2004) and help to set priorities. Coercive measures are often applied to avert dangerous situations arising from challenging behavior by residents (Heyvaert, Saenen, Maes, & Onghena, 2015). However, associations between challenging behavior and coercive measures are inconsistent (Lundström, Antonsson, Karlsson, & Graneheim, 2011; Scheirs et al., 2012). This may be explained by some studies choosing to focus only to those restraints used for responding to challenging behavior (McGill, Murphy, & Kelly-Pike, 2009; Scheir, Blok, Tolhoek, Aouat, & Glimmerveen, 2012) while others take a broader approach. In addition to challenging behavior, other resident related factors, such as an autistic spectrum disorder, gender, age, and speech impairments (Lundström et al., 2011; McGill et al., 2009) are also associated with the application of coercive measures. In addition to these static factors, complex dynamic interactions between support staff members and residents are also bound to determine application of coercive measures. Therefore, the application, and also the reduction, of coercive measures depend on an interactive set of factors at different levels. Not only challenging or otherwise risky behavior will lead to coercive measures, but also the care context with direct care staff and other managing and specialist staff are bound to be important.

Rights and law and regulations

The right to self-determination is codified in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006), which indicates that the ultimate outcome of support is autonomy and independence. Autonomy refers to making one's own choices and shaping one's own life. However, the convention indicates that there is a close relationship between autonomy and support. Autonomy is determined by the capabilities of the person with a disability and can only be achieved if a person has an unreserved right to good care (Frederiks, 2007). It turns out that in several countries this right is guaranteed in legislation by means of the ultimum remedium principle (Deveau & McDonell, 2009; Romijn & Frederiks, 2012), meaning

that coercive measures should only be used as a last resort after less intrusive alternatives have been examined. Coercive measures are therefore always to be subjected to scrutiny, as new alternatives may be developed and tried. In addition, the harm that is avoided by coercive measures may not always outweigh the physical and emotional harm that is caused by the coercive measures themselves (Heyvaert et al., 2015).

In the Netherlands, the Psychiatric Hospitals (Compulsory Admissions) Act (Wet Bopz) from 1992 regulates the enforcement of these rights. The law describes a series of measures that may be applied without consideration of the consent of the persons subject to these measures to prevent or avert danger. Also, the law sets out a number of criteria which have to be met when applying coercive measures. In 2020 this law is succeeded by the Care and Coercion Act (Staatsblad 2018, 36), which tightens up criteria under which a care provider may intervene without permission in the life of a client. This act will apply a broad interpretation of coercive care, which includes any measure which a care organization's clients or their legal representatives object or resist against. Organizations will have to adapt their policies to the new act, including the maintenance of a current record of coercive measures and multidisciplinary decision-making on the level of individual residents. The present study took place in the context of these shifts in the legal protection of people with intellectual disabilities with regard to the registration of coercive measures by support staff and professionals.

Care without coercive measures

The use of coercive measures is an issue in all forms of care for people with disabilities. Nevertheless, the question of how to find a solution for the reduction of coercive measures seems to be the most complex and urgent in facilities where 24/7- care is provided (Bowring, Totsika, Hastings, Toogood, & Griffith, 2017; Cooper et al., 2009). In residential care multiple persons with disabilities live in group homes. The daily care is carried out by a team of support staff and is characterized by rules, written care plans, and limits to the amount of individual attention. In addition, residential care is sought when less intensive

and complex forms of care fail to meet the needs of people with disabilities. Complex care often brings risks, for example the risk of injury as a result of severe challenging behavior. If other attempts to prevent or limit this behavior have failed, coercive measures are used to limit the risks of this behavior against.

The need to reduce coercive measures is clear and various initiatives have been taken to reduce coercive measures. The main focus is on safe and sustainable control of risky behavior in the form of the implementation of alternatives to coercive measures (Van Wouwe & Van der Weerd, 2015). The introduction of alternative methods for risk control can be accompanied by organization-wide programs that focus on the elimination of coercive measures. In the Netherlands several initiatives were started and implemented during the past decennium aimed at reducing the use of specific forms of coercive measures, such as a bed belt used for mechanical restraint during times of unrest (Denktank Complexe Zorg, 2012; Romijn & Frederiks, 2012). In addition, organizations are encouraged by the Health Care Inspectorate and the sector association (in Dutch: Vereniging Gehandicaptenzorg Nederland (VGN) to develop and implement policies that reduce the use of coercive measures (Romijn & Frederiks, 2012). However, the phasing out of coercive measures does not yet take place structurally and consistently. Implementation of new working methods in health care that attempt to change the ways in which organizations or teams have adapted to internal or external threats will meet resistance (May, 2013). If coercive measures would be banned at the organization level, care staff and clients are bound to experience insecurity. Support staff, professionals, and residents and their representatives need to know whether it is safe to abandon coercive measures that were put in place to ensure safety (Luiselli, 2009; Williams, 2009). In addition to the safety aspect, it is well known that innovations in healthcare practice are complex and extensive because they almost always consist of changes in several interrelated behaviors of several people working together (May, 2013). Behavior and actions of healthcare employees arise and continue to exist in interaction between these persons. The more complex a process of change is, the more thinking, control, and coordination of different parts of the organization it requires.

In addition to best practice examples, some evidence-based knowledge is available. The body of scientific knowledge can be subdivided into roughly three approaches. The first approach finds solutions for individual residents for the reduction of coercive measures, the second approach is aimed at teaching the team of support staff members to deal with risky and challenging behavior without using coercive measures, and the third approach is an organization-wide approach in which interventions are made within the various organizational units in order to structurally and systematically reduce coercive measures.

In the first approach, risky challenging behavior is often addressed by means of a behavioral interventions, for example by using behavior modification techniques (Williams, 2010). An overview of studies (Williams, 2010) shows positive results in which residents are taught behaviors as an alternative to risky behaviors, eliminating the need for coercive measures. It is also known that coercive measures themselves can provoke and reinforce risky behavior (Matson & Boisjoli, 2009). By means of training alternative behavior and planned reduction of coercive measures, the vicious cycle of behavior and coercive measures can be broken. The results are encouraging (Williams, 2010), even though, however, the sample sizes have been small and it is therefore unclear to what extent results are generalizable. It is difficult to know how often interventions do not deliver the expected results (these may not have been published; Kilgus, Riley-Tillman, & Kratochwill, 2016), what factors contribute to the success of the intervention, and how long the result will last (Luiselli, 2009).

In addition, methods are used to intervene at the level of support staff. These are often varied training courses in which, for example, the team is taught about psychopathology that underlies certain behavior or about dealing with problem behavior by means of techniques in which they reflect on their own behavior (Williams, 2010). Training support staff is common practice in healthcare organizations. Studies (Schreiner et al.,2004; Williams, 2010; Williams & Grosset, 2011) show encouraging results. However, studies often were limited as there was no control group, and possible success factors

were not identified (Williams, 2010). Some approaches combine the above methods with an intervention focusing on the organization (Schreiner et al., 2004; Williams, 2010; Williams & Grosset, 2011). Within these multicomponent approach structural interventions focuses on multiple levels simultaneously. Interventions at the level of residents involve individual treatment, interventions at the level of the teams which provide direct care includes training of professionals, and interventions at the level of organizations are characterized by policies and regulations on the reduction of coercive measures (Schreiner et al., 2004; Williams & Grosset, 2011). Results from studies of the effects of these interventions are promising. However, sample sizes were small and studies were mostly conducted using an A-B design, showing weak control for internal validity.

Despite these encouraging initiatives and results, clients and support staff members continue to be confronted regularly with coercive measures (Fitton & Jones, 2018; Heyvaert et al., 2015). To change care practices, researchers have recommended to intervene at multiple interlocking systems levels (Huckshorn 2004; Luiselli, 2009; Schreiner et al., 2004; Williams & Grosset, 2011). It is unclear how feasible it is to modify ingrained patterns, which include or lead to the use of coercive measures, in professional care for people with disabilities. From the perspective of Normalization Process Theory (May, Johnson, & Finch, 2016), the patterns that need to be changed involve several interrelated practices of people working together, such as support staff, residents and professionals. Patterns of action are formed, are reinforced, and continue to exist within these interactions. It is as yet unclear to what extent effects of interventions focused on single interactions or problems can be extended to a complex of interactions involving multiple residents and units. To be effective a multidisciplinary approach is needed which intervenes at multiple levels, including changing the policy and management of the healthcare organization, training support staff, and intervening with individual residents. This study focuses on the use and reduction of coercive measures in residential care within a Dutch health care organization with national coverage, using a multilevel systems approach.

Dissertation outline

The dissertation describes in the different chapters the use of and reduction of coercive measures in one large care organization for people with intellectual disabilities.

The second chapter describes to what extent a comprehensive daily registration of coercive measures being applied is reliable and feasible. Reliability of registrations of a standardized list of coercive measures of 269 residents living in 55 units was tested against trained observers and informants. Results were validated by a panel of stakeholders. In addition, the implementation of a mandatory routine registration system was investigated by comparing registration of coercive measures to residents' care records.

Within the framework of the new Dutch Care and Coercion Act that enters into force in 2020 and that emphasizes, among other things, the registration of coercive measures by care organizations, the third chapter sets out a qualitative study into the registration of coercive measures on the basis of legal requirements of the Care and Coercion Act. Reflections from experts and the field of practice regarding correctness, feasibility, and significance for the legal protection of people with intellectual disabilities are described.

With data on the use of coercive measures resulting from the registrations by support staff, the fourth chapter examines if the factors challenging behavior, communicative adaptive behavior, attachment behavior, support staff's attributions, and self-efficacy were associated with the use of coercive measures concerning 209 residents living in 41 units.

Finally, the available information on the use of coercive measures provided input for an efficacy study described in the fifth chapter. The efficacy of a multi component program on the reduction of coercive measures applied to 107 residents living in 41 units was studied. The program focused on increasing awareness and registration at the organizational level, multidisciplinary consulting at the residential care unit level, and multidisciplinary intervention at the resident level.

Chapter 2

Feasibility and reliability of full registration of restraints in care for people with intellectual disabilities: A study on reliability and implementation

This chapter has been published as:
Schippers, B., Frederiks, B.J.M., Van Nieuwenhuijzen, M.,& Schuengel, C. (2018). Feasibility and reliability of full registration of restraints in care for people with intellectual disabilities: A study on reliability and implementation *Journal of Policy and Practice in Intellectual Disabilities, 15,* 202-213 doi: 10.1111/jppi.12252

Abstract

Background

Policies limit the use of coercive measures as a measure of last resort to protect people from danger. Whether this is successful can only be determined with registration of the use of coercive measures.

Specific aims

The reliability of 57 standardized coercive measures was tested. In addition, implementation was investigated of improved registration in a residential care setting.

Method

This mixed method study within a residential care organization for people with intellectual disabilities in The Netherlands included 55 living units and 269 residents. Reliability of 57 standardized coercive measures was tested against other informants (a colleague and trained outside observer) and results were validated by a panel of stakeholders. Second, the implementation of a mandatory routine registration system was investigated by comparing registration of coercive measures to personal files of 30 residents.

Findings

Registration of coercive measures yielded reliable data for at least 25 out of 57 types of coercive measures. The second part of the study showed widely varying explanations of unreliable data by stakeholders, including knowledge and awareness of coercive measures of support staff and the influence of contextual factors on the encoding of coercive measures. After implementation, 46% of the coercive measures were registered in the registration system.

Discussion

Comprehensive registration of coercive measures by staff neither appeared feasible nor yielded reliable data. Clearly, multidisciplinary discussion among support staff and professionals is needed to decide whether care practices are restrictive or not. Further research should focus on how these considerations can lead to a reliable and meaningful registration.

Introduction

The use of coercive measures in care for people with Intellectual Disabilities (ID) has come under intensified scrutiny. Not only is the effectiveness of coercive measures against risky behavior called into question (Harris, 1996), their use also runs counter to important values, such as respect for self-determination and human rights (Chan, LeBel, & Webber, 2012; Heyvaert, Saenen, Maes, & Onghena, 2014). An important expression of consensus about this is the UN convention of human rights for people with disabilities, which prescribes and elaborates respect for self-determination (United Nations, 2006). Policies in several countries now emphasize the use of coercive measures only as a last resort to prevent persons with ID harming themselves or others. Romijn and Frederiks (2012) have pointed at gaps between policy and practice. Given that policies in several countries still allow coercive measures use in care for people with ID (Gaskin, McVilly, & McGillivray, 2013; Matson & Boisjoli, 2009), describing the prevalence may help to identify the areas and settings that would require more support in finding alternatives (Huckshorn, 2004; Romijn & Frederiks, 2012). However, prevalence estimates vary widely (Romijn & Frederiks, 2012), probably due to practical and definitional issues (Frederiks, Schippers, Huijs, & Steen, 2017; Chapter 3 of this dissertation). The effects of changes in policy and practice are therefore hard to assess and it is difficult to know how practice can be supported better (Huckshorn, 2004).

In the Netherlands the Health Care Inspectorate (Dutch Health Care Inspectorate, 2008) insists on full registration of coercive measures, in their broadest definition of every measure that is restrictive in a specific situation (Frederiks et al., 2017). The proposal for the upcoming Care and Coercion Act (Staatsblad, 2018, 36) makes such registration obligatory. In the absence of evidence based national guidelines for reliable registrations, the field employs a wide variety of often incomparable instruments that operationalize the broad definitions in laws and regulations. Research on reliability and feasibility of a full registration of coercive measures use in 24-hour care by support staff members and professionals might therefore

not only contribute to better registrations but also to data that can be combined and compared, providing better guidance for efforts focused on reducing the use of coercive measures.

Webber et al. (2011) indicated several difficulties in the registration of coercive measure in their analysis of reports of mechanical and chemical restraint and seclusion made by support staff over a 12-month period in the State of Victoria, Australia. They concluded that the utility of support staff reports was hampered by their confusion over definitions of coercive measures, limitations to the types of measures that were reported, and by the absence of important information such as frequency of use. Matson and Boisjoli (2009) reported a wide variation in prevalence numbers among the studies they reviewed, from 14% to 53%. The studies differed with respect to the time frame investigated (3 months versus 1 month), and the sample sizes (300-500). They proposed that standardized definitions could lead to more information on actual reliability of measurements of the use of coercive measures. To be useful, these standardized definitions should include qualitative aspects, such as the aim of a specific measure or the context in which a specific measure is applied. Qualitative aspects complicate the design of reliable registrations, however.

Niemeijer, Depla, Frederiks, Franke, and Hertogh (2014) studied the use of surveillance technology and found that support staff members weighed safety as more important than self-determination. As coercive measures often serve multiple purposes, this priority for security might also influence the extent to which workers recognize that a particular measure limits the possibilities for residents to do what they want. Staff may assume that residents find the goal of security as important as they do, and therefore would view coercive measures to be aligned with the implied will of residents to be safe. Also, differences of opinion on the right to self-determination among professionals can cause confusion in determining coercive measures. Whenever a resident resists the use of a coercive measure and staff ignores this resistance, the right of self-determination is in peril. However, some residents, as a consequence of their disabilities, are not able to show resistance or, as a consequence of prolonged use of coercive measures, have resigned themselves to the measure.

In sum, further research on registrations is needed to improve policy and practice around the use of coercive measures. One of the subjects to be studied is whether recording of the use of coercive measures can be standardized and sufficiently robust while incorporating the context and the purpose of the potential coercive measure. Firstly, this study aims at establishing reliability of registrations of coercive measures, and secondly it determines whether registration of coercive measures by support staff and professionals in a routine registration system is comprehensive and feasible. The study followed a flexible design (Dellinger & Leech, 2007) in which intermediate research outcomes on psychometric properties of the initial instrument were validated by reflections by stakeholders in order to arrive at a registration that was both reliable and meaningful, and thus would have the highest chance of successful implementation. The first part of the study focused on the reliability of each of the measures that were identified based on a broad definition of coercive measures, as these measures are taken by support staff over the course of a 24 hours period of providing residential care for residents. Reliability was tested by comparing recordings by different members of the care staff team and by comparing recordings between care staff members and observations made by trained, independent observers. The second part of the study focused on the implications of the findings regarding the reliability with which coercive measures could be recorded in two ways. First, findings concerning reliability were discussed in a stakeholder panel of which results were used for the implementation of a mandatory routine registration system. Testing the success of the implementation of the registration system was the next step in the second part of the study. The question was to what extent the new routine recording of coercive measures yielded data that corresponded with the coercive measures as described and approved in the residents' electronic personal plan.

Method

Study setting

The present study was performed within one care organization for people with ID in the Netherlands that serves approximately 9,500 residents. Type of care is diverse. It includes support for living with intellectual and physical disabilities as well as treatment for additional psychiatric problems, challenging behavior, and health problems, and concerns a wide range in age and level of intellectual disability. This broad scope of support is delivered in residential facilities on areas designed as parks owned by the institution or in districts of villages and cities, through support at home, or within day-care centers or outpatient clinics in residential 24/7h care. The study was conducted alongside the implementation of a new policy of coercive measure reduction and registration.

Part one – reliability study

Participants

The study focused on residential care and therefore care units (n = 55) were randomly selected from a total of 566 24-hour care units. Units, in which on average six residents lived, could be included if they provided care for at least four residents. Units were spread throughout the Netherlands and were located within parks or districts of villages and cities.

Procedure

The study was approved by the Ethics Committee of the faculty of Psychology and Education, Vrije Universiteit Amsterdam. Residents or their representatives and support staff were approached for their participation. Residents or, in case of incapacity, their representatives, received an information letter and were asked to return the informed consent form. Capacity of a resident to decide to participate in the study or not was set by consultation of caregivers, legal representatives and sometimes by the residents themselves. When no form was received within three weeks the first author or a research assistant contacted them by phone to provide further explanation. 269 residents or

representatives gave consent (53%). Support staff members received information about the study by email and were asked to participate as well. When staff members did not confirm participation or expressed questions, further explanation was given by researchers by phone or site visit. When support staff members who did not wish to participate in the study were present during a shift that was selected to be registered and observed, the shift was registered by a colleague or the shift was coded as missing data. Support staff received an explanation by email on how they could register coercive measures with a digital list of coercive measures designed for the project. The email was sent to one support staff member per unit and they were asked to discuss it with all staff members in the care unit and to afterwards confirm that the assignment was well understood, or to request additional email or phone consult until full comprehension was reached. Whenever there was no response or support staff expressed questions, further explanation was given by phone.

To obtain a registration of coercive measures which covered care 24 hours a day, support staff was asked to register applied coercive measures per shift and per resident during a period of one month. Independent research assistants, further called independent observers, recorded coercive measures as well in 28 shifts. These shifts were randomly selected out of all shifts between 7am and 10pm during the period in which registration was performed by the support staff members. Between 10pm and 7am no support staff was at the site but need for care was monitored through surveillance technology such as devices to listen in a resident's room or unit and the use of cameras. Whenever a resident needed support during the night a support staff member was available to visit the unit and provide support. Additional coercive measures during the night were reported. Most coercive measures that were applied at or before 10pm mostly lasted until 7am, and were registered by support staff that was present at the unit from 7am the next morning.

Also a second support staff member was asked to register coercive measures, in order to obtain registrations from two support staff members during the same shift. One support staff member from every unit at which two or more persons were present at the unit

during one shift was asked to register 10 shifts independently of his or her colleague. Shifts were not randomly selected but chosen based on the presence of the staff member who was asked to maintain an independent registration.

All independent observers were trained to recognize and register coercive measures using registration standardized list (see instruments). The training consisted of exposure to coercive measures in different situations by using images and learning the terms or phrases used by support staff to indicate the use of coercive measures. All observed coercive measures were registered, irrespective of the purported aims or the presence or absence of resident resistance. This four hour training was provided once by the first author of this paper.

Instruments

Previous to this study, the health care organization had little experience with the registration of coercive measures; the use of a registration system was limited and inconsistent. There were no standardized definitions of coercive measures nor an unequivocal guideline of which coercive measures should be registered.

Therefore, a list of 57 coercive measures was developed, based on studies on coercive measures (Dörenberg et al., 2018; Matson & Boisjoli, 2009; Williams, 2010), reports of the Dutch Health Care Inspectorate (2007, 2008, and 2012) and input of the coercive measure committees of the health care organization, who monitor and improve quality of care concerning the use of coercive measures. Coercive measure was defined as every measure that is restrictive in a specific situation, which was in accordance with the Dutch Healthcare Inspectorate and the Care and Coercion Act (Staatsblad, 2018, 36). The list of coercive measures is shown in Appendix A. Examples are 'Physical restraints (parts of the body being held down)', 'Mechanical restraint of feet and legs', 'Camera/video surveillance (either within resident's private room and/or in communal part(s) of the building)' and an example of restrictions in movement of resident is 'Locking the outer doors'. The list was administered electronically through the care organization's intranet. Per coercive measure the options were 'applied' (coded 1) or 'not applied' (default; coded 0). Registration had to be done at the end

of a work shift; recorded registration could not be changed afterwards. Independent observers and second support staff members used a printed copy of the registration list. They had to tick at one of the options 'applied' or 'not applied'.

Statistical analysis

In order to determine the reliability of registration of coercive measures the inter-rater agreement between the support staff member and both the observer and the second support staff member was examined by calculating Cohen's Kappa. Variables were set up by date and time of shift, unit and person who registered, one of the support staff members or an independent observer. A Cohen's Kappa of ≥ .50 was considered as at least a moderate agreement (Landis & Koch, 1977). A z-score was calculated to determine the difference between registrations in which the support staff member and both the observer and second support staff member did not agree on the use of a coercive measure. A phi coefficient was calculated to determine the associations between different types of coercive measures. A phi of ≥ .50 was considered as at least a moderately strong association (Cohen, 1988).

Part two – validation and implementation study

Participants

The panel of stakeholders, which was set up to validate results of the first part of the study, consisted of nine employees of the care organization, one resident representative, and the first three authors who acted as moderators. One year and seven months after the reliability study (part one) the implementation study was performed. By that time, 5 units did not meet the criterion of at least four residents anymore, and therefore 50 units out of the 55 units in study part one, participated in part two. From the 209 residents who were still included, a random selection of 30 residents was made to test the result of the implemented registration.

Procedure

In order to form a panel of stakeholders an email with information on the study and an invitation to participate in the panel was sent

to professionals of the care organization and the committee of representatives of residents. Because the response rate of this invitation was low a reminder was sent fours week later. Nevertheless, response rate stayed low and five professionals were individually approached and asked to participate. Eventually, the panel consisted of thirteen people, including the first three authors of this article. One meeting of four hours was organized.

For the purpose of the implementation of a mandatory routine registration system senior support staff members, managers, psychologists, and physicians of fifty units were informed by email about this step of the study and invited for training in registration of coercive measures. The online system was developed to register and justify the use of coercive measures within the health care organization; it had to meet extant standards which were set by law, health care inspectorate and organizational policy. The system is part of the electronic personal file of a resident. Therefore, training focused as well as on the identification of coercive measures as on laws and regulations and policies and how the system could be used. Outcomes originating from reflections by stakeholders on results of the first part of the study contributed to the training. This meant increasing awareness and thereby the identification of coercive measures. Training was given by the first author of this paper, by a research assistant, and by several master students. At the end of the training, coercive measures were registered in the system and caregivers were able to maintain the registration. Training contained one or more visits to units to support registration of coercive measures. The number of visits depended on the number of coercive measures which had to be registered, and time needed for identification and registration of all coercive measures. Whenever a psychologist or physician was not able to come to training, the inventory of coercive measures and an explanation of the system were talked through by phone. Senior support staff members were always present at training.

When researchers and support staff, professionals, or management did not agree whether a measure was a coercive measure or not, they were registered in a different section of the electronic personal file of a resident. This section had the structure of a form

on which day to day components of care are described. Professionals were ultimately responsible for the registration of coercive measures in the system and therefore they decided if a coercive measure was registered in the registration system or not. In most cases, the researchers considered measures as a coercive measure according to the list of coercive measures, but the staff members and professionals thought it was not in that specific case.

The electronic personal file consisted of all information of a resident, including treatment plans, challenging behavior management plans, records of professionals, and forms on which information is included concisely. Conform policy of the organization, the use of coercive measures is described and supported by professionals in these plans. The first author and a research assistant checked plans of 30 residents on coercive measures which were not registered in the registration system nor in the section of electronic personal file where coercive measures could be described in case no consensus was obtained.

Instruments

In order to validate the results of the first part of the study, the panel of stakeholders discussed its results within a set structure. Results were presented and the panel was asked to generate explanations why support staff would or would not register a measure as a coercive measure. Also, they discussed consequences of results for routine registration of coercive measures by support staff and professionals. The reflections of the panel were recorded and minutes were made.

To register coercive measures, a mandatory registration system of the health care organization was used, which was developed by the health care organization in order to provide data and reduce the use of coercive measures, and was implemented after the first part of this study. The registration system included the 57 listed coercive measures used in the first part of the present study and additional coercive measures. Registration could be done at any given moment and, depending on the type of coercive measure, evaluations took place at least every three or six months, but updates could be made more frequently when necessary. The registration system was part of the

residents' electronic personal file. This file contained all information of a resident including written plans and forms. Forms are displayed as a fixed format and used to include information concisely. The form on which components of daily care were noted was used to include coercive measures on which no consensus was obtained. Support staff members were asked to use the description of coercive measures corresponding with the list of 57 coercive measures in order to obtain information in an unambiguous way. Plans of professionals or support staff members are displayed as written text, without a template.

Analysis of data

In order to validate the conclusions from the first part of the study, a panel of stakeholders discussed the psychometric outcomes. Records were made and findings were used to achieve an optimal registration of coercive measures in a mandatory routine registration system.

In order to test the success of the implementation of the new registration system, correspondence of the new routine recording of coercive measures with the coercive measures as described and approved in the residents' electronic personal file was analyzed by comparing the number of coercive measures of the different sources of the electronic personal file. In addition, type and number of coercive measure registered in the system were compared to the results of the first part of the study.

Results

Part one - Reliability study

During a period of 36 days, 43 out of 55 units registered coercive measures. Registration of coercive measures concerned 231 residents and 554 shifts. Research assistants made 28 independent observations of one shift on 28 units. Within 16 units during a total of 67 shifts, a second support staff member performed registration independent from the first support staff member.

The table in Appendix A shows the kappa and z-scores for the correspondences between the use of coercive measures during a shift as registered by the first support staff members, the independent observers, and the second support staff member. Adequate agreement (i.e. Cohen's kappa ≥ .50) was found for 25 out of 57 coercive measures concerning registration by support staff members and observers, with the next five measures achieving the highest score: orthosis used in bed, resulting the resident is not being able to move, the use of 'Swedish belt' in bed (bed belt), locks on shoes, camera/video surveillance (either within resident's private room and/or in communal part(s) of the building) and an jump suit which cannot be torn and/or prevents residents taking of their clothes. For 27 coercive measures concerning the agreement between staff members and observers or staff members and second staff members, with the next five measures achieving the highest score: limiting the use of (mobile) phones (having to hand in your phone to the staff at certain (set) times, only being allowed to call someone under supervision or at certain (set) times), closing access to the garden, camera/video surveillance (either within resident's private room and/or in communal part(s) of the building), physical coercive measure (parts of the body being held down) and limiting visitation (either receiving or visiting) of family friends and others. Adequate agreement for both staff-observer and staff-second staff correspondence was found for 15 coercive measures. An overall kappa of .64 and .70 was found for the staff-observer and staff- second staff correspondence. Both the observer and second staff member more often registered a coercive measure when the staff member did not than vice versa, respectively $z= 6.04$ and $z= 17.42$, $p \leq .01$.

Associations between different types of coercive measures were determined by calculating a phi correlation coefficients for all types of coercive measures. 13 correlations ≥ .50 were determined (see Table 1).

Table 1: Correlations of ≥ .50 between different types of coercive measures

		1	2	3	4	5	6	7	8	9
1	Jump suit which cannot be torn and/or prevents residents taking of their clothes		.56							
2	Jumpsuit which includes a lock at the back to prevent the resident taking off his clothes									
3	Locking the outer doors (to prevent the resident or other residents from leaving the care unit)				.64	.55	.58	.54		
4	Closing access to the garden					.56	.63	.61		
5	Resident is not allowed to be on the institution area without permission of staff carers						.79	.70		
6	The resident not being allowed within and outside the institutional grounds without permission							.79	.50	
7	Resident is not allowed within the institutional grounds without permission									
8	The resident not allowed outside and within the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)									.72
9	Resident is not allowed at or outside the institutional grounds without supervision (supervised by support staff or surveillance technology)									

Part two – Validation and implementation study

The panel of stakeholders discussed possible explanations of the results in part one for the differences among informants, and the implications of the findings for routine registration in day to day care. No obvious explanation was agreed upon for the variation in agreement on coercive measures between the different informants,

leaving the degree of error unexplained. Hypothetical explanations varied widely from differences in intentions of staff and targeted behavior, knowledge and awareness of support staff on the value on self- determination, visibility of coercive measure, policy of the health care organization, and the degree to which application of coercive measures were a matter of normal routine. In fact, stakeholders considered it likely that measures with a low extent of agreement would be restrictive when above explanations were not applicable. A consequence of reducing the list to measures with at least a moderate extent of agreement would be the coverage of the registration of coercive measures would drop. The discussion revealed a number of elements that determine agreement on measures, including knowledge, skills, and awareness of caregivers, that can be improved by for example training and thus could lead to stronger agreement. As an implication of these reflections for the registration of coercive measures in the second part of the study the complete list of 57 coercive measures was retained and attention was paid on training on identification and registration of coercive measures.

Data collection was completed one year and seven months after the system was released and training and registration of coercive measures started. During training coercive measures were identified using the list of 57 coercive measures and registered in the registration system. However, when there was no consensus among the multidisciplinary team and researchers on whether a measure was restrictive or not, it was noted on a form with components of day to day care, which is part of the electronic personal file. Conform process and policy of the care organization it was assumed that all coercive measures were described and substantiated by professionals in written plans as part of the electronic personal file. Therefore, electronic files of 30 residents were checked for coercive measures. Content of these plans was considered as 100% of applied coercive measures. Compared to this number 46% of the coercive measures were registered in the registration system, 38% of the coercive measures were noted at the form which contained a set of components of daily care, and 16% of the coercive measures were noted in plans as part of the electronic personal file, although they were not identified

during training. Comparing results of both parts of the study, only 4 types of coercive measures (7.0%) were measured with at least a moderate reliability and were considered and registered at least in 75% of cases as coercive measure by support staff and professionals. These were 'being confined to one's own room with the door locked', 'the resident not being allowed within and outside the institutional grounds without permission' and 'orthosis used in bed, resulting the resident is not being able to move'.

Conclusion and discussion

Findings revealed a subset of coercive measures that were recorded with reasonable reliability, and that could provide the basis for routine registration of the use of coercive measures. This registration can be used to improve care and protect the rights of persons with intellectual disabilities, at the level of individual care plans, institutional policies, as well as national policies. However, registration of coercive measures yielded reliable data for only 25 out of 57 types of coercive measures. Despite standardized definitions for each coercive measure (Matson & Boisjoli, 2009; Williams, 2010), registration that covers the broad definition of coercive measures ("any measure that is restrictive") is due to yield unreliable and variable prevalence outcomes.

The data revealed patterns of disagreement between registrations of support staff members, independent observers, and colleague support staff members. Both the observer and colleague staff member more often registered a coercive measure when the support staff member did not than the reverse. The stakeholder group, which reflected in the second part of the study on the findings concerning reliability, suggested that decisions to register particular care practices as coercive measures may be dependent on the encoding of practices performed and observed during the shift as restrictive, which would require awareness of the full set of 57 coercive measures. This awareness may have been heightened among the observers, because they were specifically trained and only had to focus on observing, rather than providing care and support. In addition to factual knowledge about practices that could be restrictive, differences in norm setting (e.g., the importance of self-determination) and being accustomed to restrictive measures may influence the encoding and interpretation of care practices, leading to differences in retrieval at the end of a shift when coercive measures were recorded (Frederiks et al., 2017). These potential explanations do not apply to the heightened prevalence according to the registrations by colleague support staff.

The need to have a broad definition of coercive measures and to have a registration that is as broad as possible was underscored by the relative independence of the use of the 57 different coercive

measures. Only nine measures were found to be associated with other coercive measures. To some extent, this incoherent pattern can be explained by the low interrater reliability, which attenuated correlations. But the number is still small relative to the 25 coercive measures that were registered with adequate agreement between support staff members and independent observers. Even for these nine coercive measures, it is possible that these correlations are the result of similarly worded items. As it clearly is impossible to make categories of coercive measures on the basis of empirical clustering or underlying factors, one could use a priori defined categories on the basis of specific characteristics of coercive measures such as physical or mechanical measures, as proposed by Matson and Boisjoli (2009). Concerning registration of coercive measures this could lead to a clear order of measures and perhaps a way to recognize coercive measures more easily.

The second part of the study raises the concern that a mandatory and structural registration system which is part of the residents' electronic personal file may yield an unreliable and incomplete picture, even after training of support staff and professionals as this was found important by the group of stakeholders. Insufficient registration risks persistent use of coercive measure against policies to reduce their use. Consensus on whether particular care measures were coercive measures or not by the team of professionals and support staff was conditional on the registration in the system. 84% coercive measures were identified and talked through during training and agreement was reached on 46% of coercive measures. In their reflections stakeholders emphasized the importance of awareness of coercive measures. However, systematic identification and training on awareness of coercive measures did not lead to consensus on coercive measures and a complete registration of all measures. Moreover, only four measures (7.0%) had a reasonable reliability in part one and were registered as coercive measure in part two of the study, underscoring that reliability may come to the expense of coverage.

Stakeholders also suggested that the meaning of the context in which a measure is applied is part of the determination of coercive measures by support staff. This could be in line with difficulties

defining coercive measures described by Matson and Boisjoli (2009). A measure can be both restrictive and non-restrictive depending on the context in which it is applied. Elements within the context which affects the interpretation of measures can be the aim and intention on which coercive measures are applied, organizational policies or culture, or the value which is assigned to self-determination by caregivers or residents. The way in which these contextual factors affect the interpretation of measures is not clear and possibly personal or determined by different interests. Results of Niemeijer et al. (2014) show that support staff members value safety more than the value of self-determination. Support staff may consider the registration of these coercive measures as less important and give it less attention than policy makers may assume, especially when registration has to lead to a reduction of coercive measures.

Limitations

Concerning the first step of the study two limitations have to be mentioned. First, the observer may not have been able to notice all coercive measures applied, especially when multiple support staff members were present during the observation and coercive measures may have been applied out of sight or hearing distance. Second, shifts registered by the second support staff members were not selected randomly but by the second staff members' themselves, which may have led to a selection bias. Regarding the second part of the study, the selection of participants of the panel of stakeholders was partly done by a broad and then direct invitation of persons who were professionally or personally related to the organization, which may have led to a selection bias. In addition, no specific methods on qualitative data processing were used in processing the reflections of the panel. Therefore, results should be interpreted with caution and seen as an indication of outcomes of a mandatory and structural registration of coercive measures.

Implications

In both parts of the study consensus on whether a measure is restrictive or not was limited across a wide range of coercive measures. A

complete, according to a list of standardized coercive measures, and reliable registration of coercive measures in day to day care appears therefore to be only partly feasible. Considering the several goals of registration on improvement and justification of the use of coercive measures, it should not be assumed that routine registrations are a reliable and valid reflection of actual care practice. Which coercive measures are included in the registration system is an outcome of the process of consideration by support staff and professionals whether a measure is restrictive in a specific context or not. Implications for policies on improvement of registration and reduction of the use of coercive measures therefore focus on this process in two ways. First, as indication and registration of coercive measures is an outcome of a group process, interventions on improvement should focus on this process. Outcomes will be improved when information obtained from the registration system is used to support caregivers (Huckshorn, 2004). A registration system should serve and challenge support staff members to provide the best care and therefore use as few as possible coercive measures. Also, independent observers can be used to test these registrations and contribute to the development of a reliable and full registration of coercive measures. Second, it should be clearer how contextual factors affect the identification of coercive measures. In the current Psychiatric Hospitals (Compulsory Admissions) Act (Wet Bopz) and also the Care and Coercion Act (Staatsblad, 2018, 36) the reason or aim of the use of coercive measures is very clear: to reduce harm for a resident. The context in which coercive measures are used, however, is not taken into account. Therefore, aims of further research should focus on addressing important context factors in using coercive measures. Also, focus has to be on how registration can serve multiple goals, such as support for staff members, professionals and management to improve quality of care. Finally, it should be clear how registration contributes to the explanation and justification of the use of coercive measures, especially in designing and adapting (new) legal frameworks about coercive measures. Preventing violation of rights of people with intellectual disabilities by the use of coercive measures should be the basis of registration of coercive measures and therefore developments in policies and legal frameworks.

Appendix A

Prevalence of coercive measures, and agreement between staff members and observers, and between staff members

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
Orthosis used in bed, resulting the resident is not being able to move	3.8	0.8	1.00	131	4	0	0	0.00	.77	322	16	7	2	1.68
Use of 'Swedish belt' in bed (bed belt)	0.1	0.0	1.00	134	1	0	0	0.00	.00	350	0	1	0	1.00
Locks on shoes	0.6	0.1	1.00	134	1	0	0	0.00	.00	341	0	0	6	-2.46*
Camera/video surveillance (either within resident's private room and/or in communal part(s) of the building)	6.0	1.3	.96	121	13	1	0	1.00	.84	272	58	14	3	2.70**
Jump suit which cannot be torn and/or prevents residents taking of their clothes	6.0	1.3	.87	126	7	1	1	0.00	.59	333	6	1	7	-2.13*
Mechanical restraint of feet and/ or legs	1.7	0.4	.85	131	3	0	1	-1.00	.61	342	4	2	3	-0.45
Types of beds where the resident is not able to get out of (bedrails, Poseybed, bedbox).	17.9	3.8	.85	103	25	1	6	-1.91	.80	271	55	13	8	1.11
Audio surveillance (either within resident's private room/ and/or in the general care unit	43.6	9.2	.78	38	84	13	0	3.70**	.79	139	172	31	5	4.45**
Belt/body harness used in wheelchair	11.4	2.4	.78	113	15	6	1	1.91	.39	282	19	40	6	5.19**
Very strict rules with regard to the use of cigarettes, alcohol or other substance use	2.5	0.5	.72	123	7	2	3	-0.45	.57	299	21	26	1	4.91**

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
A movement detector (used either within a resident's private room and/ or in the general care unit)	2.9	0.6	.72	128	4	1	2	-0.58	.53	331	6	9	1	2.55*
Jumpsuit which includes a lock at the back to prevent the resident taking off his clothes	5.3	1.1	.70	126	5	1	3	-1.01	.66	341	5	3	2	0.45
Limiting the use of internet (i.e. a fixed amount time, or only within a specific location (within sight of the carer), or limited access to certain websites)	1.7	0.4	.70	126	5	3	1	1.01	.41	325	6	9	7	0.51
Chemical restraints which modulate behavior, such as the anti-psychotics	24.6	5.2	.68	66	48	13	8	1.14	.68	216	83	32	15	2.57*
Closing access to the garden	24.7	5.3	.67	92	26	7	10	-0.75	.90	243	94	12	2	2.70**
Having to wear gloves in order to prevent a resident from scratching themselves (form of self- harm)	0.8	0.2	.66	132	1	0	1	-1.00	-	347	0	0	0	0.00
Intensive one on one care	1.7	0.4	.59	128	3	3	1	1.01	.66	339	4	4	0	2.01*
A form of surveillance technology which detects a door being opened (used either within a resident's private room and/or general care unit)	12.7	2.7	.57	90	23	12	10	0.44	.80	282	46	16	3	3.02**
Physical restraint (parts of the body being held down)	1.6	0.3	.57	123	5	0	7	-2.68**	.86	347	3	0	1	-1.00
Mechanical restraint of arms/hands	0.7	0.1	.56	130	2	0	3	-1.74	-	351	0	0	0	0.00

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
Mechanical restraint of trunk by belt/harness (other than used in wheelchair)	1.9	0.4	.55	125	4	2	4	-0.83	-.01	345	0	3	3	0.00
The resident not being allowed within and outside the institutional grounds without permission	29.1	6.2	.54	60	44	23	8	2.86**	.71	204	100	45	2	6.49**
Use of wheelchair brake which cannot be removed by the resident	4.0	0.9	.53	127	3	5	0	2.26*	.40	343	1	2	1	0.58
The resident not allowed outside and within the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)	18.5	3.9	.52	83	25	21	6	3.04**	.30	215	39	82	15	7.33**
Limited acces to rooms/area's by locked doors in the care unit.	41.6	8.8	.51	21	89	20	5	3.15**	.37	97	135	6	113	-10.76**
Locking the outer doors (to prevent the resident or other residents from leaving the care unit)	33.0	7.0	.47	73	30	18	14	0.75	.70	190	110	47	4	6.25**
Limiting the use of (mobile) phones (having to hand in your phone to the staff at certain (set) times, only being allowed to call someone under supervision or at certain (set) times.	1.2	0.2	.47	123	4	2	6	-1.44	.91	341	5	1	0	1.00
Being confined to one's own room with the door locked	4.2	0.9	.46	117	6	10	2	2.36*	.57	333	7	5	5	0.00

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
Resident is not allowed within the institutional grounds without permission	23.2	4.9	.43	67	32	22	14	1.43	.73	213	95	34	9	3.93**
Very strict rules/ agreements such as having to follow a specific day program, having fixed times and amounts with regard to eating and drink, strict rules on when to shower and sleep	16.4	3.5	.37	60	33	32	10	3.69**	.67	287	33	26	1	4.91**
Monitoring the resident by keeping a close eye on him through other means (such as the window or door)	4.5	1.0	.32	106	7	19	3	3.56**	.79	281	46	18	2	3.63**
Locking cupboards, wardrobes, kitchen cabinets, refrigerator	28.9	6.1	.31	20	76	26	13	2.25*	.32	193	52	82	20	6.65**
Very strict rules with regard to sexuality/intimacy	2.0	0.4	.28	129	1	0	5	-2.26*	.74	316	19	10	2	2.33*
Resident is not allowed at or outside the institutional grounds without supervision (supervised by support staff or surveillance technology)	16.4	3.5	.26	82	15	24	14	1.75	.47	228	50	71	2	8.53**
Administration of all forms of medication without informing the resident (e.g. crushing and mixing medication into foods)	2.5	0.5	.23	128	1	5	1	1.65	.00	350	0	1	0	1.00
The resident being confined to a room/area of the unit without the doors being locked (hallway, own bedroom)	5.0	1.1	.23	128	1	4	2	0.83	.69	264	52	31	4	4.68**

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
Resident is not allowed to be on the institution area without permission of staff carers	32.9	7.0	.22	50	32	37	16	3.22**	.79	170	144	32	5	4.56**
(Wheel) Chair with tabletop to prevent residents from getting out of the chair	2.0	0.4	.17	126	1	6	2	1.44	.50	316	11	20	0	4.54**
The resident not being allowed to enter certain communal areas (of the general care unit) without permission	13.5	2.9	.10	98	5	18	14	0.75	.38	201	55	87	8	8.72**
Chemical restraint, i.e. medication of which its (side) effects can be restrictive to resident	3.2	0.7	.05	117	1	12	5	1.75	.18	329	2	7	9	-0.51
Deep tub chair to prevent a resident from getting up Under mattress bed alarm system which can detect a resident leaving their bed	0.0	0.0	.00	134	0	1	0	1.00	-	347	0	0	0	0.00
Limiting visitation (either receiving or visiting) of family friends and others	2.6	0.6	.00	133	0	0	2	-1.42	.81	306	29	11	1	2.91**
Resigning a resident to a chair/ stool on which he or she has to remain seated without being allowed to get down	0.6	0.1	.00	134	0	1	0	1.00	.49	345	2	2	2	0.00
Under mattress bed alarm system which can detect a resident leaving their bed	1.4	0.3	.00	134	0	0	1	-1.00	.43	326	6	15	0	3.92**

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for short term forms of seclusion	0.3	0.1	.00	134	0	0	1	-1.00	.00	345	0	0	6	-2.46*
Inspection of mobile phone; checking messages and calls	0.2	0.1	.00	127	0	0	8	-2.87**	.00	338	0	9	0	3.02**
Resident had to stay in a room (other than his own) with the door locked	1.4	0.3	-.01	132	0	1	2	-0.58	.45	331	6	14	0	3.78**
All forms of medication administered under coercion	1.2	0.2	-.01	131	0	1	3	-1.01	-	351	0	0	0	0.00
Inspection of private room, cupboards, refrigerator etc.	2.1	0.5	-.03	122	0	2	11	-2.56*	.74	327	12	8	0	2.84**
Limiting the receiving and sending of letters/mail	0.9	0.2	-.04	123	0	4	8	-1.18	.40	343	1	3	0	1.74
All forms of nutrition (food and liquids) administered under coercion	1.6	0.3	-	135	0	0	0	0.00	.00	350	0	0	1	-1.00
Strip-searching	0.3	0.1	-	135	0	0	0	0.00	.00	345	0	1	1	0.00
Inspection of bags and jacket/ clothes	1.2	0.2	-	135	0	0	0	0.00	.00	345	0	1	1	0.00
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for long term forms of seclusion	0.0	0.0	-	135	0	0	0	0.00	-	351	0	0	0	0.00

	Prevalence		Staff member- observer						Staff member - second staff member					
Coercive measure	% applied	% of total	kappa	0-0	1-1	0-1	1-0	*Z*	kappa	0-0	1-1	0-1	1-0	*Z*
A tilting chair which prevents residents from getting out of the chair	0.1	0.0	-	135	0	0	0	0.00	-	347	0	0	0	0.00
A weighted down blanket preventing the person from getting up	0.3	0.1	-	135	0	0	0	0.00	-	347	0	0	0	0.00
A form of surveillance technology which can detect a resident getting out of their chair	0.3	0.1	-	135	0	0	0	0.00	-	347	0	0	0	0.00
Total	8.1	100.0	.64	6509	694	387	239	6.04**	.70	17412	1610	896	302	17.42**

Note. * = $p \leq .05$, ** = $p \leq .01$, - = Kappa could not be determined

Chapter 3

Reporting of use of coercive measures from a Dutch perspective

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Abstract

Purpose

The purpose of this paper is to advance a number of outlooks on the reporting of the use of coercive measures in the care for persons with intellectual disabilities. The following questions will be discussed: which forms of involuntary care should be externally reported and how is this external reporting influenced by environmental and other factors?

Design/methodology/approach

This paper describes an important part of the New Dutch Care and Coercion Act (in Dutch: Wet Zorg en Dwang) (Staatsblad, 2018,36) concerning reporting the use of coercive measures. The implications of reporting the use of coercive measures have been discussed at a meeting for experts in mental health law and the care of people with an intellectual disability. The issue has been presented to the participants as neutrally as possible, so as to provide the researchers a comprehensive picture of the different views on reporting the use of coercive measures. The outcome of this meeting has served as the input for a further step in the research – using the Delphi method – in order to address the issue comprehensively.

Findings

The Dutch legislation on reporting involuntary care implies that measures carried out only in the face of resistance should be externally reported. The experts that participated in this study endorse the importance of a real-time external reporting system. They believe that standardized and reliable external reporting requires involuntary care, the categories of involuntary care and the environmental and other factors that affect external reporting to be defined more concretely. They regard environmental and other factors as decisive for assessing whether a measure constitutes involuntary care. This in turn, therefore, has consequences for whether such incidents should be reported.

Research limitations/implications

Many concepts in the new Dutch Care and Coercion Act are not formally defined. Instead, the legislator has left it to those in the field to decide how they should be interpreted. This prompted many questions from those attending the expert meeting and in our own analysis. The researchers could possibly have resolved this confusion during the meeting by formulating more detailed definitions of terms such as "resistance" and "involuntary care" beforehand. The disadvantage of this, however, would have been that those attending the meeting would have had no opportunity to define the terms on the basis of their own expertise. As a result, the researchers have obtained all relevant information comprehensively to use as the input for the next step of the research, which employs the Delphi method.

Practical implications

This viewpoint emphasizes the need to take a wide range of factors into account throughout the process in order to establish whether care can be seen as involuntary. The researchers regard the care providers' expertise in dealing with these factors – client factors, and behavioral or environmental factors, for example – as being of essential importance if care is to be recognized as involuntary and reported as effectively as possible. Therefore, the researchers discuss whether the legal position of clients is protected if care providers register only those forms of involuntary care where there is obvious resistance. In this case, many forms of resistance are overlooked, which may be to the detriment of the legal protection of clients with intellectual disabilities. However, the system in the UK shows that it can be quite complicated to develop a clear definition of involuntary care that is usable in practice, without giving rise to an enormous amount of bureaucracy and thus distracting from the real issue: protecting the legal position of clients with an intellectual disability.

Originality/value

Academic papers clearly demonstrate that external reporting of involuntary care has not yet become properly established, either in the Netherlands or elsewhere, such as in the UK. This paper seeks to provide insights into new Dutch legislation about external reporting of involuntary care. By organizing a meeting with experts, the factors that have so far acted as obstacles in the reporting of involuntary care are problematized. The findings of this paper will help to further the process of developing an effective system for reporting involuntary care.

Legal framework involuntary care

Since 1994, the Psychiatric Hospitals (Compulsory Admissions) Act (Wet Bopz) has served as the legal framework for compulsory admissions and restrictive measures applied to people with an intellectual disability in the Netherlands. The transition from this legislation to the Care and Coercion Act (Staatsblad, 2018, 36; in Dutch: Wet Zorg en Dwang) has far-reaching implications for the way in which people with an intellectual disability are cared for. The aim of this Act is to protect the rights of persons with an intellectual disability in an effective and fitting way, also taking into account the Convention on the Rights of Persons with Disabilities (CRPD, United Nations, 2006) which the Dutch Government ratified on the 14th of July 2016. An important premise of the CRPD is that the essential elements that together form the legal position of clients, regardless of their impairments, are guaranteed in the same way. Psychiatric patients, however, will fall under another new Act, the Compulsory Mental Healthcare Act (in Dutch: Wet verplichte GGZ) (Staatsblad, 2018, 37), creating in the Netherlands a situation, similar to the UK, with two different Acts for compulsory care (Dörenberg and Frederiks, 2012). The question is whether this is in line with the principles of the CRPD.

The term "involuntary care" plays a major role in the Care and Coercion Act, which was adopted by the House of Representatives in September 2013, but has not yet been adopted by the Senate. The Dutch legislator takes the term "involuntary care" to mean "all forms of care resisted by the client or his representative". This new legislation also includes an extensive requirement for external reporting, with the aim being for the Health Care Inspectorate, as an external party, to be able to supervise involuntary care provided internally. Care providers have to ensure real-time reporting of all involuntary care provided; in other words, to maintain up-to-date records of all involuntary care provided within their institution. The Health Care Inspectorate can examine these records at any time. According to the legislator, the purpose of this reporting system is to ensure that clients receive proper legal protection. Every six months, care providers also have to send an overview to the Inspectorate, together with an analysis, of all involuntary care provided.

Defining involuntary care

The currently applicable Psychiatric Hospitals (Compulsory Admissions) Act does not define freedom-restricting measures, but instead distinguishes various ways in which freedom can be restricted. This includes coercive treatment measures, such as the forced administration of fluid, food or medication; or seclusion, separation and restraint for periods of up to seven days depending on whether the measure is written down in the care or support plan.

The lack of a definition in the current legislation is one of the reasons why care providers, the government and the academic world in the Netherlands define restrictions on freedom in very different ways (Schippers &Janssen, 2016; Schippers, Frederiks, Van Nieuwenhuijzen, & Schuengel, 2018: Chapter 2 of this dissertation). This, in turn, has considerable consequences in practice, including both under-reporting and over-reporting of involuntary care. For years, many restrictions on freedom have not been recognised as such and have not, therefore, been reported. This was one of the main conclusions reached in 2002 at the time of the second evaluation of the Psychiatric Hospitals (Compulsory Admissions) Act (Arends, Blankman, & Frederiks, 2002).

Similarly, the issues of defining coercive measures are found in other countries (Romijn &Frederiks, 2012). In the UK, many questions have arisen about the interpretation of deprivation of liberty. The Deprivation of Liberty Safeguards (DOLS) were introduced in April 2009 to amend the Mental Capacity Act 2005. DOLS govern the process by which people who lack capacity to consent to accommodation in a care home of hospital can be deprived of liberty (Bartlett, 2014). Capacity is an element which is of less importance in the Care and Coercion Act, in which serious disadvantage is the main criterion for deciding whether coercive measures are allowed. The Mental Capacity Act allows certain restrictions and restraints, but when the measures cross the line and lead to the deprivation of a person's liberty, an "external" authorisation is required (Department of Health, 2008). The DOLS Code of Practice seems to leave a lot of room for interpretation, for example, page 10: "a decision as to whether or not deprivation of liberty arises will depend on all the circumstances of

the case", and page 14: "there is no simple definition of deprivation of liberty". The content of the DOLS Code of Practice is mainly based on the Bournewood case (HL v. the United Kingdom, 2005) in which the European Court of Human Rights said that "to determine whether there has been a deprivation of liberty, the starting-point must be the specific situation of the individual concerned and account must be taken of a whole range of factors arising in a particular case such as the type, the duration, effects and manner of implementation of the measure in question. The distinction between a deprivation of, and restriction upon, liberty is merely one of degree or intensity and not one of nature or substance".

Since 2008, the Dutch Health Care Inspectorate has applied a very broad definition of restrictions on freedom, being "all physical and verbal measures that restrict the freedom of clients". This definition was designed to promote greater awareness in practice of all the possible ways in which freedom can be restricted; in other words, not only the forms of restraint and seclusion as referred to in the Psychiatric Hospitals (Compulsory Admissions) Act, but also lesser forms of restriction (i.e. those not specified in this Act), such as not being allowed to drink coffee, having to hand in cigarettes, or not being allowed to go outside. The Care and Coercion Act, by contrast, refers to "involuntary care", which, according to the legislation, should be taken to mean "care resisted by the client or his representative". Involuntary care is thus used as an umbrella term for all major and minor restrictions on freedom, both those currently covered by the Psychiatric Hospitals (Compulsory Admissions) Act and those that now, strictly speaking, fall outside the scope of the legislation. Involuntary care is subdivided in the Care and Coercion Act into nine categories (see "Nine forms of involuntary care, as referred to in the Care and Coercion Act"). These nine categories can be interpreted very broadly. In the explanatory notes the legislator states the difference between "locking a person in" and "restricting a person's freedom of movement" to be that the former involves the person being secluded or separated in an appropriate space. It was consciously decided not to specify the other categories of involuntary care in any further detail and to leave this to the sector to interpret (Parliamentary Papers,

2015/ 16, 32399, No. 25). According to Steen, de Schipper, and Frederiks (2016), the legislator consciously opted for a broad definition of involuntary care, thus seeking to end the discussion of what does and does not constitute a restriction on freedom. The question remains, however, as to whether the current definition actually achieves its aim. According to the definition, care is involuntary only if resisted by the client or his representative, whereas the legislator acknowledges that resistance by people with an intellectual disability is not always evident. Research (De Boer et al., 2018) has also shown that even carers who know their clients well can find it difficult to recognise and interpret behavioural and other signals of possible resistance. As well as obvious externalised behaviour, such as saying something (verbal resistance) or demonstrating aggression (active resistance), it is also possible for internalised behaviour, such as avoidance or fear, to constitute passive expressions of resistance.

Due to a recent case in the UK (the case P v Cheshire West and Chester Council) the scope of deprivation of liberty is interpreted much more broadly. In this case the Supreme Court identified three new elements or factors which are not relevant to the definition of deprivation of liberty: whether the client agrees or disagrees with the detention, the purpose of the detention, and the extent to which it enables the client to live what might be considered a relatively normal life (The Law Society, 2015). Consequently, many elderly and people with a mental disorder or intellectual disability in the UK seem to need the protection of the DOLS.

The Dutch legislator has opened the door a little bit, in terms of broadening the definition of coercive measures. He stipulates various forms of care that have to meet the standards applying to involuntary care even if there is no resistance, but where the client is legally incapacitated and the representative gives consent. These forms of care comprise the administering of medication that influences the client's behaviour or freedom of movement and is not administered in accordance with the applicable professional guidelines, measures that result in the client's freedom being restricted for any period of time, and situations where a person may be locked in a room. Although these measures do not need to be reported, their provision

to a person who is legally incapacitated must be in accordance with a predefined and phased plan, and the person's representative must also give consent.

Nine forms of involuntary care, as referred to in the Care and Coercion Act are as follows:

1. administering fluid, food or medication; performing medical checks or other medical interventions, or applying other therapeutic measures in order to treat a psychogeriatric condition, a mental disability or related psychological disorder, or a combination of such, or treatment of a somatic condition relating to a condition, disability or disorder;
2. restricting a person's freedom of movement;
3. locking a person in;
4. exercising supervision over a person;
5. searching a person's clothing or body;
6. searching a person's residence or accommodation for behaviour-affecting substances or dangerous objects;
7. monitoring for the presence of behaviour-affecting substances;
8. restricting a person's freedom to determine his own life, including restrictions on use of means of communication, with the result that the person has to do or is unable to do something; and
9. restricting the freedom to receive visitors.

National reporting system of involuntary care

The real-time external reporting system that care providers are required to maintain under the planned Care and Coercion Act creates the opportunity for the Netherlands to introduce a national reporting system for involuntary care. Various sources have expressed a need for this (Schippers et al., 2018; Chapter 2 of this dissertation; Romijn &Frederiks, 2012; Dutch Health Care Inspectorate, 2012). At present, however, too many aspects remain unclear (as a result, e.g. of the use of varying definitions) for a targeted reporting system for external use to be devised. Research (Romijn & Frederiks, 2012) shows that other countries (including the UK, USA, and Australia) recognise the importance of a national database for establishing the prevalence of involuntary care. However, these countries too currently have insufficient insights into the frequency of involuntary care and how it is reported. The Dutch Health Care Inspectorate has emphasised that standardised reporting is important if we are to understand the extent to which such care is provided and to reduce its frequency. Although involuntary care is believed to be decreased, no concrete figures are available (Dutch Health Care Inspectorate, 2015).

According to Huckshorn (2004), maintaining comprehensive records will not only identify any possible decrease in involuntary care, but also actively contribute to reducing its frequency. Although it is important, in accordance with the wishes of the Dutch Health Care Inspectorate, for all forms of involuntary care to be reported, the Association for the Care of the Disabled (VGN), the sector organisation for care of the disabled in the Netherlands, has asked for those working in the field to be allowed to compile more limited and less detailed reporting. In this way, the VGN is seeking to limit the administrative burden on day-to-day practice (Parliamentary Papers II, 2016/17, 32399, No. 35). This is also seen in the UK with the use of the DOLS. Professionals worry about the bureaucracy and complexity of the procedure (Blamires, Forrester-Jones, & Murphy, 2016), which could be an explanation for the low number of applications for DOLS by managing authorities of care homes or hospitals. Bartlett (2014) also stresses the importance of a simple procedure to avoid averseness

and errors. Furthermore, it is noticed that it is important to maintain a clear definition and that care takers know the benefits of the procedure before they initiate applications (Blamires et al., 2016; Bartlett, 2014).

Research has shown that applying a single definition of involuntary care, as provided for in the legislation, is not sufficient to ensure reliable reporting of involuntary care. Schippers et al. (2018; Chapter 2 of this dissertation) demonstrate that it is nevertheless possible for a great deal of involuntary care to be reliably reported. As possible explanations for the current discrepancy they suggest that there is currently too little understanding or appreciation of the right to self-determination in day-to-day practice, and that actions can often unconsciously be performed as a matter of routine, with the result that providers fail to report a significant amount of care that is provided involuntarily. It was also found that synonyms used in day-to-day practice, including "rest moments" or "room time", could trivialise the invasiveness of measures, while what was actually happening was in fact seclusion. By using language in this way, care providers may be unaware that the care they are providing is involuntary. Furthermore, around half of the measures that care providers recognise as constituting involuntary care are actually internally reported. That means that others are not being reported, albeit that some measures in this second category may be recorded in the care plan as agreements with clients. Research by Dörenberg et al. (2018) found that care providers agreed almost unanimously that physical restrictions (restraint and seclusion) should be seen as the most drastic forms of involuntary care. Providers would seem to be aware that these measures should be avoided wherever possible, and that if they are applied, this should be in accordance with agreed procedures. In the case of other measures, however, the question of whether care should be regarded as involuntary is subject to more discussion. According to Matson and Boisjoli (2009), involuntary care is not a binary construct, and environmental factors always play a role in assessing it. The way in which environmental factors affect the interpretation remains unclear (Schippers et al., 2018; Chapter 2 of this dissertation). What is clear, however, is that these factors have direct consequences for the way in which information is internally

and externally reported. As well, therefore, as using a single definition, it is vital to establish a framework that specifies which environmental factors are important, and how these influence the interpretation of involuntary care (Romijn & Frederiks, 2012; Schippers & Janssen, 2016), if a clear reporting policy that can be accessed by the Health Care Inspectorate is to be established.

Methodology

In order to gain greater insights into the relevant factors and to understand how these influence the external reporting of involuntary care, the Dutch Ministry of Health, Welfare and Sport commissioned a project to examine the targeted reporting of involuntary care. This project involves experts from the academic world and practice investigating how important elements can be translated into the external reporting system that will be required when the Care and Coercion Act comes into force. The first phase of the project entailed organising an expert meeting, during which an inventory of the major obstacles was prepared. Efforts were made to ensure that those invited to the expert meeting included experts from different backgrounds. Experts ranged from lawyers with expertise in mental health law, ethicists, academics, and behavioural scientists to nursing specialists, doctors, and experts from the client's perspective as well as and experts working with a variety of target groups (including people with multiple serious disabilities or mild intellectual disabilities, young people, and people with psychiatric problems). This meant that practice, academia and policymaking were all represented, while various target groups in the field of care for people with an intellectual disability were also taken into account. The expert meeting focussed on the following question: Which forms of involuntary care should be externally reported and how is this external reporting influenced by environmental and other factors?

Expert opinion

Opinions about definition of involuntary care

The experts believed that the definition of involuntary care used in the Care and Coercion Act – all forms of care resisted by the client or his representative – is inadequate. The inclusion of resistance in the definition of involuntary care (or, indeed, limiting the definition to situations involving resistance) provoked critical comments. Indeed, as the legislator states, resistance is by no means always easy for care providers to recognise (Parliamentary Papers II, 2015/16, 32299, No. 25). The experts endorsed this and expressed their concern that this definition has been worded "too narrowly" and would not help, therefore, to ensure reliable and uniform reporting of involuntary care. Adding the word "resistance" to the definition of involuntary care would result in a lack of clarity, given that care providers do not always notice resistance, while it is also possible that clients might not resist. Resistance can also weaken, or disappear, if it fails to produce the result the client wants within a certain period. As the research by De Boer et al. (2018) and Dörenberg et al. (2018) shows, there is a discrepancy between how care providers assess situations and the way in which clients' resistance to involuntary care is actually experienced or recognised. If care providers lack the expertise needed to recognise resistance, involuntary care will be externally under-reported. Paying more attention to recognising signs of resistance would, therefore, seem vital if the legislator wishes to maintain this limited definition of involuntary care. Another potential conflict can arise if a client and his legal representative are not in agreement. In the experts' view, the description of the nine forms of involuntary care is insufficiently concrete and so will not end the discussion of what involuntary care does and does not constitute. This, however, is precisely what the legislator is seeking to achieve by introducing the new definition and subdividing such care into categories (Steen et al., 2016). According to the experts, the categories set in the legislation do not provide a sufficiently clear basis for achieving a uniform external reporting system, and more concrete specification is, in the opinion of the experts, needed to achieve change in practice. The problems include

an overlap between various categories, with the experts regarding the category of "Restricting a person's freedom to determine his own life" as a bucket category. As they see it, this category includes situations where patients are not allowed to choose what they eat or drink, or to choose who they live with. The experts recognise that more attention needs to be paid to rights of self-determination, but doubt whether the current wording of the definition and categories allow this, given, for example, the lack of clarity caused by the use of differing terminology for involuntary care(and various forms of this).

The legislator believes, however, that further specification will obstruct current developments in the field (Parliamentary Papers II, 2015/16, 32399, No. 25). A similar discussion is on-going in the UK, where the definition of deprivation of liberty remains unclear. Results from studies concerning the DOLS illustrate that a clear definition is important for implementation. In a study on the use of vignettes, Cairns et al. (2011) find only minor agreement between professionals on what constitutes deprivation of liberty. Despite the impact of the recent Cheshire West decision in the UK, Blamires et al. (2016) still question the current legal system in the UK concerning DOLS. They think that a major revision is needed. At this moment, opportunities to identify the best form of support and the least restrictive options are (still) missing.

The experts also referred to certain forms of care that, in view of their invasiveness, should always be regarded as involuntary, regardless of whether the client resists. Examples of such forms of care include the administration of fluids, food or medication, and the imposition of restraint, seclusion or separation. These forms of care are covered by some of the nine categories for which the legislator has set standards that are to be applied in the event of resistance by a client or his representative. The experts did not mention forms of involuntary care that, at first sight, may appear less significant, such as situations involving use of surveillance technologies, and restrictions on clients' freedom of choice, but which the Care and Coercion Act also requires to be included in the new reporting system in the event of resistance.

Relevant factors reporting involuntary care

Resistance is not the only crucial concept influencing the reporting of involuntary care. According to the experts, there are far more factors that affect how care providers interpret involuntary care. Differing interpretations of involuntary care can result in these forms of care being under-reported or not being reported at all. The factors mentioned by the experts can be divided into three subcategories: organizational, contextual, and client-related. Organizational factors include staff shortages, poorly educated staff, and working on the basis of fixed routines. From an organizational perspective, it is of particular importance that external reporting is not made too burdensome, that the purpose of the reporting is clear, and that external reporting is not used as a means of or tool for reprimanding staff. It may also be important for an external reporting system to include certain client characteristics – such as age, developmental level, the existence of a psychopathology, details of physical illnesses/medical conditions, and whether a client has been admitted voluntarily or involuntarily. The experts also believe that all forms of involuntary care provided to children should be reported, regardless of whether the client resists. In addition, they believe that more details need to be recorded of clients who are legally incapacitated than of clients who are not legally incapacitated. Mention was also made of the term "pedagogical measures" with regard to the provision of care in a developmental context, with specific attention being paid to the acquisition of certain skills, where, for example, boundaries may need to be set. The experts' views on whether such care should be regarded as involuntary varied. Certain environmental factors also play a role: living in group accommodation, for example, involves certain rules that clients may regard as restricting their freedom. So, too, may measures that are applied in response to behavior by fellow residents, or the sharing of accommodation without having any say about the other people living there. In the experts' view, the external reporting system should also take account of the risks for the client or his surroundings, or both, when a measure is not applied.

Finally, the experts believe that how measure is applied has consequences for the reporting, as does the duration of the measure.

There are certain forms of care for which periodic reporting would be sufficient, such as situations involving surveillance technologies, or where visits or use of a telephone are restricted. In the case of restraint and separation measures, meanwhile, both the frequency and duration should be reported. It was also stated that the measure itself should be described, together with any risks that could possibly arise, such as the risk that the client may suffer physical or psychological damage. If external reporting is to be effective, it is also seen as essential for care providers to have an awareness of what involuntary care means and an understanding of the client's perspective.

Improving awareness

In the experts' view, careful and comprehensive reporting will require clearer definitions of the nine described forms of involuntary care and an increased understanding of the concept of resistance. This in turn will help to ensure proper legal protection for clients. The experts believe that providing clear guidelines on what care providers have to report on a real-time basis and explaining the purpose of the reporting can have a significant impact on increasing the awareness process in the field. And this awareness, in turn, may also have a positive effect on the quality of externally reporting of involuntary care. Many lessons can be learned from the UK. According to Bartlett (2014), figures confirm that the DOLS have made little impact in practice. Bartlett suggests that the government must be more clear as to what is intended to be achieved. Only then the system can be effective. Blamires et al. (2016) emphasize that training and raising awareness about the DOLS are crucial. They believe that perceptions arising from the wording "deprivation of liberty" may have made care home managers less able to see the potential benefits and importance of using the safeguards. Other important factors are assessors who have a good knowledge of persons with intellectual disabilities and access to good quality advocacy and representation.

Conclusion

Our review of the literature demonstrates that external reporting of involuntary care has not yet become properly established, either in the Netherlands or elsewhere such as in the UK. The experts in this study fully endorse the importance of standardized, real-time external reporting. However, they do not believe that this objective will be achieved if the Dutch legislator continues to adhere to the wording as currently used in the text of the Care and Coercion Act. The meeting with experts also illustrates that a lot of factors remain unclear, which is in line with the on-going discussion about the system of DOLS in the UK. The primary question posed to a group of experts in the care of people with an intellectual disability was: Which forms of involuntary care should be externally reported and how is this external reporting influenced by environmental and other factors? For the purposes of this study, reporting was taken to mean an external reporting system that can be accessed at any time by the Health Care Inspectorate. Although the experts' answers to this question were not unequivocal, they indicated that a client's resistance to involuntary care must in any event be reported, while the administration of fluids, food or medication, as well as the imposition of restraint, separation or seclusion, should also always be reported, regardless of whether the measure is resisted. These findings reiterate the need for more concrete definitions of involuntary care and the legislator's nine categories, if uniform and reliable reporting of involuntary care is to be achieved in a manner that will help protect clients' legal position. The challenge is to ensure that the beneficial effects of the protective function of reporting involuntary care are not diminished by the inevitable bureaucratic elements of the reporting system.

Chapter 4

In search of factors associated with coercive care for people with intellectual disability: A multilevel analysis

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Abstract

Background

Little systematic insight exists in the extent to which coercive measures are applied in residential care and how this depends on characteristics of the person with the disability and the situation.

Specific aims

To integrate previously reported disparate factors, this study examined links between resident-related and staff-related factors and coercive measures. The study also explored whether measures used to prevent from direct and unplanned danger, and measures restricting participation in daily life activities to protect from indirect danger or disadvantage had different associated factors.

Methods

Participants were 209 residents with intellectual disabilities who lived in 41 units where 24/7 care was provided. A list of 76 coercive measures was recorded by support staff and professionals in a mandatory registration system. Resident-related factors included challenging behavior, attachment behavior, and level of communication and socialization. Staff related factors included causal attributions on challenging behavior and staff self-efficacy in handling challenging behavior. In multilevel analyses, estimates of independent effects accounted for group home effects.

Results

Lower communication and socialization functioning was associated with more coercive measures. Challenging behavior was associated with coercive measures applied at direct and unforeseen danger. Also, staff attribution with regard to the stability of challenging behaviour was associated with the total of coercive measures applied. Found associations concerning Lower communication and socialization functioning and challenging behavior remained significant in a multivariate model with all resident related variables, the association concerning staffs attribution on the stability of challenging behavior did not remain. Only the association with challenging behavior remained significant if staff factors were included as well.

Discussion

To improve our understanding of the use of coercive measures, research may need to move beyond static resident- and staff-related factors.

Introduction

Coercive measures are common in care for people with intellectual disabilities (ID) (Fitton & Jones, 2018). Health care organizations are expected to resort to coercive measures only temporarily and only when risk is unacceptable and other means to avert this risk are exhausted (Deveau & Leitch, 2015; Romijn & Frederiks, 2012). Disproportionate and routine usage, when encountered, should therefore be actively reduced. Insight into the use of coercive measures is needed to make structural adjustments to the operation of health care providers and to formulate policies, laws, and regulations that prevent and reduce coercive measures (Romijn & Frederiks, 2012; Frederiks, Schippers, Huijs, & Steen, 2017; Chapter 3 of this dissertation). Such insight may include knowing the characteristics of persons with a disability who are confronted with coercive measures and characteristics of the situations in which these are applied (Emerson et al., 2000; Merineua-Côté & Morin, 2014; Sturmey, Lott, Laud, & Matson, 2005).

Currently, no comprehensive and integrated overview of the use of coercive measures and factors in long term care organizations exists (Lundström, Antonsson, Karlsson, & Graneheim, 2011; Merineua-Côté & Morin, 2014; Scheirs, Blok, Tolhoek, Aouat, & Glimmerveen, 2012; Sturmey, 2009; Webber, McVilly, & Chan, 2011). Information is limited because studies each focused on different subsets of coercive measures and factors (Matson & Boisjoli, 2009; Merineua-Côté & Morin, 2014; Webber, Richardson, & Lambrick, 2014). Also, definitions of coercive measures, and consequently recording of care practices as restrictive, may vary by setting and even by informant. Schippers, Frederiks, Van Nieuwenhuijzen, and Schuengel (2018; Chapter 2 of this dissertation) reported that only a subset of coercive measures could be recorded in routine care with sufficient reliability. Factors that have been found associated with coercive measures in single studies have seldom been replicated across studies. Moreover, their unique effects relative to factors found in other studies have not been tested, impeding the development of an integrative approach to coercive measures that takes into account factors at the level of individual residents and context.

The present study explored a set of resident and staff factors that have been suggested to explain the use of coercive measures and subsets of coercive measures in a large, diverse residential care organization. Coercive measures are broadly defined as every measure that is restrictive in a specific situation and includes a wide range of measures (Frederiks et al., 2017). Because factors may be specific to different care practices, two subsets of coercive measures were tested. The first subset referred to measures applied during acute, directly dangerous incidents. Examples of measures included in the first subset are locked seclusion and physical and mechanical restraint. The second subset referred to measures applied to prevent a resident from indirect danger or serious disadvantage. Most of these measures concerned limitations of participation in daily life activities.

Broadly speaking, studies of the use of coercive measures usually examined resident characteristics and sometimes characteristics of the care that is provided (Fitton & Jones, 2018). Concerning factors related to residents, their challenging behavior (CB) has been found associated with the use of coercive measures (Allen, Lowe, Brophy, & Moore, 2009; Didden, Duker, & Korzilius, 1997; Heyvaert, Saenen, Maes, & Onghena, 2014; Matson & Boisjoli 2009; Sturmey, 2009). Challenging behavior refers to "behavior of such an intensity, frequency or duration that the physical safety of the person is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to and use of ordinary facilities" (Emerson, 2001, p 3.). Using coercive measures as a response to CB may occur within the bounds of law and regulations, which state that coercive measures may be used as a last resort to prevent people with ID from harm. Physical and mechanical restraints and environmental restraints, for example locked doors, are often used to guarantee safety (Heyvaert et al., 2014). However, not all studies have found an association between CB and coercive measures (Lundström et al., 2011). This variation in outcome may be due to variations in definition and measurement of CB, coercive measures, as well as having alternative methods available to reduce the risk of harm (McGill, Murphy, & Kelly-Pike, 2009; Scheirs et al., 2012), but these explanations await empirical testing.

Another resident-related factor is the level of communicative and social functioning, which are almost by definition impaired in people with lower adaptive functioning (Emerson 2000; Lundström et al., 2011; Scheirs et al., 2012). Several studies (Knotter, Wissink, Moonen, Stams, & Jansen, 2013; Lundström et al., 2011) suggest that misunderstanding of residents' behaviors by staff might lead to responses that thwart residents' intentions and wishes. Given the power differential between residents and staff, such misunderstandings may lead to practices that are coercive from the perspective of the resident. A study by Scheirs et al. (2012) confirms this suggestion by showing a significant association between the use of coercive measures and the combination of social withdrawal and maladaptive behavior. In addition, other studies (Chan, Webber, & Hayward, 2013; McGill et al., 2009; Rosenberg et al., 2010) showed that persons with ID and autistic spectrum disorder (ASD) were more likely to be exposed to coercive measures than other persons with ID. For example, challenging behavior may be more often responded to with communication rather than coercion. Studying the highly interrelated CB and social and communicative adaptive functioning alongside each other may offer insight in the potential for compensatory effects.

Underlying both challenging behaviors and social and communicative functioning may be the regulation of stress that is afforded by the relationships between residents and caregivers. The attachment system, in which seeking security or help in another person is understood as a way of handling stress, may not be adapted to an unstable context with many professional caregivers and high turnover (Janssen, Schuengel, & Stolk, 2002). De Schipper and Schuengel (2010) found that young persons who presented more attachment behavior towards support staff showed less irritable, lethargic, and stereotyped behavior than persons who presented less attachment behavior. The association between attachment and the use of coercive measures emerged in a study on a two-phased therapy. A reduction of the use of arm restraints was found during the attachment based phase of a therapy on a person with a severe ID, visual impairment and CB (Sterkenburg, Janssen, & Schuengel 2008). Attachment behavior facilitates the social regulation of stress

and thereby may prevent or adequately address CB. Consequently, it may be hypothesized that with residents showing more attachment behavior, there is less need for coercive measures.

Because support staff are tasked with the safety of their clients and themselves and therefore also with the application of coercive measures, studying their characteristics may shed additional light on variations in the use of coercive measures. Staff members are guided by their beliefs, thoughts, and emotions regarding CB (Hastings & Brown, 2002; Meehan, Vermeer, & Windsor, 2000; Mérineau-Côté & Morin, 2014). Within the framework of attribution theory, Weiner (1985) distinguished between two categories of attributions. The first category of controllability regards the location of causes for behavior within or outside persons. The second category of stability regards whether the cause of the behavior is stable or temporary. Attributions affect cognitive and emotional reactions to other people's behaviors, guide our expectations of the changeability of these behaviors, and thereby influence social interactions (Weiner, 1985; Willner & Smith, 2008). Applied to professional care, support staff may experience anger and aversion when they attribute challenging behavior to causes within the residents' control. Staff may act in resignation when they attribute challenging to stable characteristics, whether these may be perceived as inside or outside the control of residents. Anger, aversion, and resignation may undermine supportive care giving and efforts to change suboptimal practices such as the use of coercive measures. In support of this hypothesis, Leggett and Silvester (2003) found associations between attributions of nurses and seclusion of patients in a psychiatric hospital. They found seclusion was used more often if nurses attributed challenging behavior as in control of patients. However, Willner and Smith (2008) concluded on the basis of their review of studies on attributions, emotions, and behavior of support staff in care for people with ID that support for the role of attributions was equivocal. Not all studies confirmed an association between type of attribution and staff behavior.

Independent from staff attributions of CB, staff self-efficacy with respect to intervening in CB may be related to reliance on coercive measures. Self-efficacy may either refer to expected ability to perform

appropriate interventions or to expected success resulting from performing an intervention (Bailey, Hare, Hatton, & Limb, 2006). In either form, following Bandura (1993), low self-efficacy reflects a history of failed attempts, poor modelling or negative vicarious experiences, and negative affective responses to dealing with CB through intervening. Low staff self-efficacy is therefore a likely predictor of unsuccessful interventions (Cudré-Mauroux, 2011; Hastings & Brown, 2002), leading to more reliance on coercive measures. Thus far little evidence exists on the possible linkage between staff self-efficacy and the incidence of coercive measures.

To further integrate disparate findings, this study sought to test the hypothesis that resident challenging behavior, social and communicative adaptive functioning, attachment behavior, staff attributions, and staff self-efficacy were uniquely associated with residents' exposure to coercive measures in a large residential care organization. A secondary goal was to explore the extent to which associated factors varied according to the type of measures that were considered, hypothesizing that resident and staff characteristics may be especially associated with coercive measures that serve a protective function rather than organizational functions. Coercive measures that serve a protective function can be divided in two subsets: a subset of measures applied to protect from direct and mostly unforeseen danger and a subset of measures preventing from indirect, not acute danger or disadvantage. The resident characteristics CB, communication and attachment behavior were hypothesized to be associated with both subsets. Staff characteristics focus on challenging behavior that directly leads to danger and therefore, and therefore were hypothesized only to relate to the first subset of coercive measures.

Method

Study setting

The study was performed within a health care organization for people with ID in the Netherlands, providing care for approximately 9,500 residents. Type of care included residential care located at parks owned by the institution, community settings located within districts of villages and cities, day-care centers, and outpatients clinics. Type of care is rather diverse; it focuses on intellectual and physical disabilities and additional psychiatric problems, challenging behavior, and medical care.

Participants

In total 209 residents participated in the study. Of these, 123 (58.8%) were male and 86 (41.2%) female. The average age was 47 years, varying between 13 and 86 years with a standard deviation of 18.8 years. There were 242 support staff members participating in the study. Staff had a level of education varying from 3 (upper secondary) to 6 second stage tertiary; ISCED, 2011), and had an average of 13 years of professional experience in caring for people with a mental disability.

Procedure

Present study was approved by the Ethical Review Board of [institution blinded]. Fifty five care units were randomly selected from a total of 566 24-hour care units. Units could be included if they provided care for at least four residents with an average of six residents, as they consecutively participated in an effect study in which results are obtained at the level of units. Data collection covered a period of three years (2014 – 2017). Due to turnover as a result of movement and death of residents the number of participants in a unit varied. Therefore, every three months units and the organization administration section gave an update on persons residing within the unit. New residents or their representatives were approached in writing with information on the study and a form to indicate informed consent and permission to participate in the study. Capacity of a resident to decide to participate in the study or not was set by consultation of

caregivers, legal representatives, and sometimes by the residents themselves. When no form was received within three weeks the first author or a research assistant contacted them by phone to provide further explanation. Data collection regarding the current study covered one year. The sample consisted of 50 units during this period. There was an average turnover of 2.3 residents per month. At the start of the study, the response rate was 60.5% (265 residents) and at the end of the study 54.2% (238 residents).

Support staff members were asked to participate by sending an email to one support staff member per unit, requesting them to discuss the study and participation with all staff members in the care unit. Afterwards the staff member were asked to confirm that the invitation was well understood by the full team of support staff, or to request additional email or phone consultation until full comprehension was reached. Whenever there was no response or support staff expressed questions, further explanation was given by phone. When staff members did not confirm participation or expressed questions, further explanation was given by researchers by phone or site visit. No support staff refused to participate.

Coercive measures were registered in a newly implemented mandatory registration system of the health care organization. Therefore, registration was already supported by researchers, and completed and maintained by support staff and professionals.

Information on factors in residents and support staff was collected by electronic questionnaires, an interview, and an observation list. First, all questionnaires were sent to support staff to fill out. Next, the observation list was sent on paper to all support staff members. They had to choose one resident which they observed before filling in the digitalized version of the list. Finally, support staff members were interviewed by psychologists who were part of the team of professionals working with the specific units under study.

Instruments

Social and Communicative Adaptive behavior

The Dutch version of Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984; van Berckelaer-Onnes, Buysse, Dijkxhoorn,

Gooyen, & Van der Ploeg, 1995) was used to assess two domains, Communication and Socialization, of adaptive functioning. Communication refers to receptive, expressive and written language skills (133 items), and Socialization refers to skills needed to get along with others (134 items). The VABS was found moderately associated with IQ measures in young adults and is regularly used in studies with people with ID (Dacey, Nelson, & Stroeckel, 1999). The Dutch version of the VABS has been proven valid and reliable (De Bildt, Kraijer, Sytema, & Minderaa, 2005). The items of the questionnaire assess performance of discrete skills. Items were rated from 2 (yes, usually), 1 (sometimes, partially), and 0 (no, never). One is also scored whenever an answer is unknown or performance of the skill was not possible. A higher score refers to a higher developmental age. A strong Pearson correlation of .90 was found between both scales. Therefore these were combined into the scale 'Social adaptive behavior' by calculating the mean score of both scales. Cronbach's alpha for this scale was .95.

Challenging behavior

Challenging behavior was assessed by the Dutch translation of the Behavior Problem Inventory BPI-01 (Lambrechts, Kuppens, & Maes, 2009; Rojahn, Matson, Lott, Esbensen, & Yemonja Smalls, 2001). The BPI-01 measures three domains of problem behavior, using 24 items for Stereotyped Behavior (SB), 14 items for Self-Injurious behavior (SIB), and 11 items for Aggressive/destructive behavior (AB). The BPI-01 defines SB as 'repeated uniform body movements or postures that are obviously not part of some goal-directed act and includes rocking; twirling or twisting objects, smelling objects and screaming and yelling. SIB is defined as 'behavior that can cause damage to the person's own body and that occurs repeatedly and in an essentially unvarying manner'. SIB includes for example: hitting the head with the hand or other body parts, biting oneself, hair-pulling, regurgitating, and hitting the head with or against objects. AB is defined as 'an offensive action or a deliberate overt attack directed towards people or objects' and includes grabbing, pulling or hitting others (Rojahn et al., 2001). After the corresponding definition was mentioned in the list, descriptions of specific behaviors were provided. Then, respondents

had to indicate which behaviors they had observed during the last two months. For each item one could indicate how frequently the specific behavior occurred (1 = monthly, 2 = weekly, 3 = daily and 4 = hourly), and how severe the behavior was (1 = slight, 2 = moderate and 3 = severe). The clinical criterion validity of the BPI-01 was good according to Rojahn et al. (2001). Lambrechts et al (2009) studied the psychometric properties of the Dutch translation for people with a profound ID and found a good to excellent internal consistency. Also, the test-retest reliability of the frequency scale was good to excellent. Pearson's correlation coefficient was computed between all frequency and severity scales and subscales. Correlations ≥.50 suggested that scales overlapped. In the current study this was found between all frequency and severity subscales, consistent with findings of Rojahn et al. (2001). Following their recommendation, the frequency scales were excluded. Pearson correlations were .43 between SIB and AB, .45 between AB and SB, and .53 between SIB and SB. Therefore these scales were averaged into a 'Challenging behavior' scale showing marginal internal consistency as Cronbach's alpha was .59.

Attachment behavior

Residents attachment behavior towards support staff members was assessed by the Secure Base Safe Haven Observation List (SBSH-OL; De Schipper & Schuengel, 2006). The SBSH-OL was developed to assess relation specific attachment behavior of young people with ID and contains 20 items using a 7 points Likert-scale. Every item describes attachment behavior in a specific situation. Support staff had to indicate to what extent the behavior is applicable towards other support staff members and themselves. Before filling in the questionnaire, support staff members were asked to observe residents' behavior for at least one day. Examples of items are: 'When this person is ill of hurt, he/she stays closer to me than on other days' or 'when this persons finishes with an activity or toy, he/she returns to me for play, for a hug, for a touch, or for help finding something else to do'. A high score reflects frequent attachment behavior. Only the scale assessing attachment behavior towards the caregiver filling out the list was used. Cronbach's alpha was .92 indicating good internal consistency.

Causal attributions

Support staff causal attributions on challenging behavior were measured with the Dutch version of the Challenging Behavior Attribution Scale (CHABA, Hastings, 1997; Zijlmans, Embregts, Bosman, & Willems, 2012). The questionnaire contains 33 items on a 5 point Likert scale (-2 very unlikely and 2 very likely). The questionnaire distinguishes five causal attributions: learned behavior (six items, three items for learned positive and three for learned negative behavior), medical/biological factors (six items), emotional factors (seven items), aspects of the physical environment (eight items) and self-stimulation (six items). Examples of items are 'because he/she cannot cope with stress' (emotional cause), 'because he/she lives in a noisy place' (physical environment cause), and 'because he/she wants attention of people' (learned behavior). Subscale scores were determined by summing all scores of the five causal models and dividing them into the amount of items belonging to a model. A low score, below zero, indicated that the respondent considered this cause unlikely as an explanation for challenging behavior and a high score the reverse. Hastings (1997) showed acceptable to good internal consistency values for all of the CHABA subscales, Cronbach's alpha varied from .65 to .87. The present study aimed at testing hypotheses based on the theory of Weiner (1985, 1986). Therefore, the items of the CHABA were transformed into the subscales stability and controllability using computations of the studies of Bailey et al. (2006), Lambrechts et al. (2009), and Zijlmans et al. (2012). Cronbach's alpha for the scales controllability and stability was respectively .80 and .85. Scores of support staff within a care unit were aggregated to a mean score. A moderate Pearson correlation of .74 was found. Because the two scales measure two mutually exclusive sub-aspects of attribution, the two scales were retained separately.

Difficult Behavior Self-Efficacy Scale

Self-efficacy of support staff was assessed by the Dutch version of the Difficult Behavior Self Efficacy Scale (DBSES) (Hastings & Brown, 2002; Willems, Embregts, Hendriks, & Bosman, 2016). The five items were presented digitally and rated on a 7-point Likert scale. Items

concerned support staff's trust, controllability, and satisfaction in handling challenging behavior. An example is 'how confident are you in handling challenging behavior'. A score was calculated by summing all items and divide them by the number of all items. Scores of support staff within a care unit were aggregated to a mean score. A high score implies a high extent of self-efficacy. Hasting and Brown (2002) found a Cronbach's alpha of .94 which indicates a high internal consistency. In the present study internal consistency was good as well, indicated by a Cronbach's alpha of .88.

Coercive measures

Coercive measures were registered in a mandatory registration system of the organization. The registration system is part of the residents' electronic care records and describes coercive measures in a broad way, irrespective of whether residents resisted the measure or not. Coercive measures were identified by researchers together with professionals responsible for daily care and treatment, using a list of 57 clearly described coercive measures. A recent study by Schippers, Frederiks, Van Nieuwenhuijzen, and Schuengel (2018; Chapter 2 this dissertation) on reliability of the list and registration system showed at least 25 coercive measures to be adequately consistent across informants, either a staff member colleague or a trained observer. In addition, they found 46% of the identified measures to be registered in the system, and 38% in the personal file. Another 16% were described in personal care plans. Therefore, the current study used both sources. Coercive measures regarding medication used to regulate behavior or medication which (side) effects can restrict residents were not recorded in the registration system by physicians and therefore excluded. However, administration of medication under coercion or without informing the resident was included. Additionally, file studies revealed 21 additional coercive measures which were added to the list. This yielded a total available set of 76 coercive measures.

Coercive measures differ in form and function (Dörenberg et al., 2018; Matson & Boisjoli, 2009; Williams, 2010). Four subsets were created. The first subset contained 14 measures applied to protect from direct and mostly unforeseen danger. The second subset contained 46

measures aimed to prevent from indirect danger or disadvantage. The third subset contained 6 coercive measures resulting from the use of surveillance technology. The fourth subset contained 10 coercive measures resulting from the of use of material to physically support the resident. Hypotheses concerned the sum of all applied coercive measures, the sum of coercive measures applied at direct danger, and the sum of coercive measures preventing from indirect danger or disadvantage. Per resident it was calculated how many measures of each type of measure were registered at that moment. Appendix A contains the full list of coercive measures by subset and their frequency.

Statistical analysis

Associations between characteristics of residents and support staff and the use of coercive measures were tested by using generalized linear mixed modelling in SPSS version 24. This modelling technique accounts for the dependency of observations due to the multilevel structure of the data (residents nested within units) (Hox, Moerbeek, & van der Schoot, 2017). Dependency among the factors related to unit staff was addressed by averaging scores from staff belonging to the unit of each resident. Because the dependent variable was a count variable, a negative binomial regression analysis was conducted, which uses a log function to link the dependent count variable to the independent variables in the model. This model was deemed more adequate than the Poisson regression model that can also be applied to count data, because the variance of the count variable 'total number of coercive measures' was larger than its mean (overdispersion). The analysis were conducted in several steps. First, a so-called 'empty' model was run in which the nested data structure was specified but no predictors were included. This model allows to estimate the intraclass correlation (ICC), which is the proportion of variance in the count variable that can be attributed to the level of the unit. This correlation indicates to what extent residents within the same units resemble one another on 'total number of coercive measures'. A rule of thumb is that if the ICC is larger than .05 the multilevel data structure cannot be ignored and mixed modelling is indicated (Hox

et al., 2017). In the second step, each predictor was entered separately into the model. Continuous predictors were centered prior to analysis. For the two variables number of coercive measures per subset, the same procedure was repeated. However, because the occurrence of 2 or more applied measures in the subset 'applied at direct danger' was rare (only 9 persons out of 209 persons), it was decided to dichotomize this count variable (0 = no coercive measures applied at direct danger; 1 = one or more coercive measures applied at direct danger) and analyze this variable with a binary logistic regression model as the type of generalized linear mixed model. In a third step, to determine the extent to which the disparate independent variables are mutually related to coercive measures, the factors have been jointly added to the analysis model. Within this third step the multivariate analysis was carried out in phases by first separate adding the resident related and then separate adding the staff related variables.

Results

Descriptive results

For 209 residents, residing in 41 units, 61 different types of coercive measures were recorded. Most frequent were audio surveillance (on 48.8% of residents), limited access to areas in the unit (on 27.8% of residents), and locking cupboards/wardrobes/kitchen cabinets/ refrigerator (on 21.5% of residents). The most frequent 17 coercive measures represented 80% of all occurrences. Distribution among subsets was as follows: 12 times measures were applied to prevent from direct danger, 36 times measures were applied to prevent from indirect danger or disadvantage, 5 times coercive measures arose from the use of surveillance technology, and 8 times from the use support material. Descriptive data of all predictors are presented in Table 1. An overview of the correlations between the predictors is given in Table 2.

Table 1: Descriptives resident and staff related variables

Instrument	*N*	Range	*M*	*SD*
Social adaptive behavior	173	0.0 - 185.5	29.9	30.1
Attachment behavior	127	22.0 - 130.0	68.7	27.2
Challenging behavior	133	0.0 - 54.0	11.6	13.0
Staff self efficacy	183	4.5 - 6.3	5.2	0.4
Attribution stability	183	26.7 - 40.6	33.6	3.4
Attribution controllability	183	23.3 - 33.6	29.4	2.8

Table 2: Correlations resident and staff related variables

Observed variables	1	2	3	4	5	6
1. Social adaptive behavior		.07	-.37**	.13	-.01	.10
2. Attachment behavior			.16	-.02	.17	.09
3. Challenging behavior				-.06	.15	.05
4. Staff self efficacy					-.30**	-.08
5. Attribution stability						.74**
6. Attribution controllability						

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Multilevel analyses

The first step of the analyses showed an ICC correlation of .08 at the care unit level. The variance in total number of coercive measures across units was significant (.27; z = 2.80, p = .005). This shows that the hierarchical data structure should not be ignored and multilevel analysis is indicated.

In the second step each predictor of either the level of resident or the level of unit was added separately to the model. A negative association was found between level of social adaptive behavior skills and total coercive measures (b = -0.01, t = -3.0, p = .003). In addition, a positive association was found between attribution of stability and the total of coercive measures (b = 0.063, t = 0.03, p = .032). Also, a positive association was found between challenging behavior and coercive measures applied to prevent from direct unforeseen danger (b = 0.06, t = 3.04, p = .003) (Table 3).

The third step to include all factors simultaneously was carried out in two phases. First the resident related variables were entered in the model and second the staff related variables were entered. Findings showed a negative association between social adaptive behavior and coercive measures (b = -0.01, t = -2.25, p = .027) and a positive association between challenging behavior and coercive measures applied to prevent from direct unforeseen danger (b = 0.04, t = 2.14, p = .035) (Table 4).

Table 3 Univariate analyses resident and staff related variables

	Coercive measures total			Coercive measures direct danger			Coercive measures indirect danger		
Predictor	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*
Level of resident									
Social Adaptive behavior	-0.01 (0.00)	-3.0	.003	-0.01 (0.01)	-1.1	.277	-0.01 (0.00)	-1.22	.224
Challenging Behavior	0.01 (0.01)	1.3	.21	0.06 (0.02)	3.04	.003	0.01 (0.01)	1.53	.128
Attachment Behavior	0.00 (0.00)	0.42	.675	0.01 (0.01)	1.60	.111	0.003 (0.00)	0.69	.490
Level of staff/unit									
Attribution 'controllability'	0.05 (0.03)	1.51	.142	0.09 (0.09)	0.90	.371	0.04 (0.06)	0.63	.533
Attribution 'stability'	0.06 (0.03)	2.24	.032	0.01 (0.08)	0.08	.939	0.06 (0.05)	1.23	.234
Staff self efficacy	-0.13 (0.27)	-0.47	.643	0.12 (0.76)	0.16	.877	-0.018 (0.37)	-0.05	.961

Table 4 Multivariate analyses resident and staff related variables

	Coercive measures total			Coercive measures direct danger			Coercive measures indirect danger		
Predictor	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*
Level of resident									
Social Adaptive behavior	-0.01 (0.00)	-2.25	.027	-0.00 (0.01)	-0.29	.774	-0.00 (0.01)	-0.37	.710
Challenging Behavior	0.00 (0.01)	0.74	.459	0.04 (0.02)	2.14	.035	0.01 (0.01)	1.30	.196
Attachment Behavior	0.00 (0.00)	0.66	.508	0.01 (0.01)	0.87	.387	0.04 (0.04)	0.88	.382
	Coercive measures total			Coercive measures direct danger			Coercive measures indirect danger		
Predictor	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*	*b (se)*	*t*	*p*
Level of staff/unit									
Attribution 'controllability'	-0.04 (0.05)	0.08	.941	0.16 (0.14)	1.17	.25	-0.03 (0.09)	-0.34	.74
Attribution 'stability'	0.06 (0.04)	1.53	.134	-0.09 (0.12)	-0.75	.46	0.09 (0.08)	1.06	.300
Staff self efficacy	0.02 (0.28)	0.09	.932	-0.01 (0.79)	-0.13	.990	0.22 (0.50)	0.43	.674

Conclusion and discussion

Overall, previously identified predictors at resident and staff level offered scant explanation of coercive measures applied in residential care. Only challenging behavior was found associated with coercive measures to prevent from direct danger and social adaptive functioning and staff attribution with regard to the stability of challenging behaviour was associated with the total of coercive measures applied. The resident factors remained uniquely predictive when accounting for other resident factors. In addition, staff's attribution regarding stability of challenging behavior was not predictive when accounting for other staff factors. Overall, 61 different types of coercive measures were recorded among the 209 residents, with residents on average experiencing 3.23 coercive measures at any given point. The findings underline expectations in the field that coercive measures are widely used (e.g., Romijn & Frederiks, 2012).

While findings for challenging behavior and social adaptive functioning were in line with previous reports (Fitton & Jones, 2018; Knotter et al., 2013, Lundström et al., 2012), the results for the other factors stand in contrast. Variation of the use of coercive measures across units was only partly explained by characteristics such as attributions by staff on the causes of CB and self-efficacy in handling CB of support staff, in contrast to earlier findings (Hastings & Brown, 2002; Knotter et al 2013; Meehan et al., 2000; Mérineau-Côté & Morin, 2014). Zijlmans et al. (2012) suggested that support staff behavior is best seen as a response to a complicated and constantly changing context. The effect for attribution with regard to the stability of the cause of challenging behavior, uncorrected for other factors, is therefore unlikely to reflect the full extent of staff factors in coercive care. Therefore, longitudinal and intervention studies may be needed to uncover the circumstances under which staff characteristics do and do not play a role. Also, Willner and Smith (2008) in their review showed inconsistent results of studies on Weiner's attribution theory and helping behavior of support staff. Given the weak associations between challenging behavior and coercive measures, perhaps more complex models are needed to describe the role that attributions and

other cognitions such as caregivers' self-efficacy play in determining responses to challenging behavior.

Limitations and implications

All data reflected, in one way or another, the perspective of care staff, including decisions to record coercive measures. Schippers et al. (2018; Chapter 2 this dissertation) found reasonable reliability for some but not all coercive measures and also reported that implementation of the registration system did not result in complete recording of coercive measures. For the purpose of the current study, registration of support staff and professionals was checked and updated. This led to the inclusion of an additional 22 coercive measures to the study. However, because reliability of reports was not tested, results of present study must be interpreted with caution. Furthermore, the subsets of coercive measures are yet to be validated, and different subdivisions may be considered (Dörenberg et al., 2018; Matson & Boisjoli, 2009; Williams, 2010). Another limitation is that some of the factors at the level of residents and staff reflect these factors at one point in time whereas coercive measures were counted over a one year period, attenuating predictive associations. Although overall sample size was adequate, missing values on several factors studied limited statistical power in the multivariate analyses, preventing the detection of possibly weak effects. Furthermore, staff factors were studied at the team level rather than at the level of individual caregivers. While this was done because coercive measures are decided upon at team level, group dynamics may play a role that are not captured by averaging individual caregiver cognitions. Finally, the cross-sectional design of the study limits any causal conclusions to be drawn.

Implications

The association between challenging behavior and coercive measures against direct risk of harm underlines the importance of ongoing efforts to test and implement alternative interventions to prevent and control challenging behavior. The association between social adaptive functioning and coercive measures irrespective of type underlines the important role of communication. Learning how best

to communicate with persons with intellectual disability presents some of the biggest challenges for care staff. Supporting staff in this task may have the desired side effect of reducing coercive measures, although this awaits empirical testing. The current findings suggest that more complex and dynamic models may be needed to fully understand the situations in which coercive measures are applied in residential care.

Appendix A: Overview of coercive measures and subsets

Restraint	Total	% of total	% of residents applied to	Subset
Audio surveillance (either within resident's private room/ and/or in the general care unit)	102	15.1	48.8	ST
Locking cupboards, wardrobes, kitchen cabinets, refrigerator	58	8.6	27.8	ID
Limited acces to rooms/area's by locked doors in the care unit	45	6.7	21.5	ID
Locking the outer doors (to prevent the resident or other residents from leaving the care unit)	41	6.1	19.6	ID
Resident is not allowed at or outside the institutional grounds without supervision (supervised by support staff or surveillance technology)	40	5.9	19.1	ID
Types of beds where the resident is not able to get out of (bedrails, Poseybed, bedbox)	39	5.8	18.7	SU
A form of surveillance technology which detects a door being opened (used either within a resident's private room and/or general care unit)	36	5.3	17.2	ST
Belt/posey vests (weel)chair	35	5.2	16.7	SU
Jump suit which cannot be torn and/or prevents residents taking of their clothes	25	3.7	12.0	ID
Locking the bedroom door	23	3.4	11.0	ID
The resident not being allowed beyond the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)	22	3.3	10.5	ID
Physical restraint (parts of the body being held down)	16	2.4	7.7	DD
Limiting the use of media (radio; tv; magazines), either in choice or in set times	15	2.2	7.2	ID
Being confined to one's own room with the door locked	13	1.9	6.2	DD
Very strict rules/ agreements such as having to follow a specific day program, having fixed times and amounts with regard to eating and drink, strict rules on when to shower and sleep	11	1.6	5.3	ID
Locked windows	11	1.6	5.3	ID
Closing access to the garden	10	1.5	4.8	ID
Limiting the use of internet (i.e. a fixed amount time, or only within a specific location (within sight of the carer), or limited access to certain websites)	10	1.5	4.8	ID
Mechanical restraint of feet and/or legs	8	1.2	3.8	SU

Restraint	Total	% of total	% of residents applied to	Subset
The resident being confined to a room/area of the unit without the doors being locked (hallway, own bedroom)	7	1.0	3.3	DD
Camera/video surveillance (either within resident's private room and/or in communal part(s) of the building)	7	1.0	3.3	ST
Very strict rules with regard to the use of cigarettes, alcohol or other substance use	7	1.0	3.3	ID
No interactions with other clients without supervision	6	0.9	2.9	DD
Stretcher with bed rails or shower stool for in the shower	6	0.9	2.9	SU
closing off the water supply	5	0.7	2.4	ID
Adjusted lights, so that the resident cannot turn off the light themselves	5	0.7	2.4	ID
Mechanical restraint of arms/hands	4	0.6	1.9	DD
A movement detector (used either within a resident's private room and/ or in the general care unit)	4	0.6	1.9	ST
Under mattress bed alarm system which can detect a resident leaving their bed	4	0.6	1.9	ST
Limiting visitation (either receiving or visiting) of family friends and others	4	0.6	1.9	ID
Set times for resting	4	0.6	1.9	ID
Locking all the doors	4	0.6	1.9	ID
Resident had to stay in a room (other than his own) with the door locked	3	0.4	1.4	DD
Mechanical restraint of trunk by belt/harness (other than used in wheelchair)	3	0.4	1.4	SU
Orthosis used in bed, resulting the resident is not being able to move	3	0.4	1.4	SU
Monitoring the resident by keeping a close eye on him through other means (such as the window or door)	3	0.4	1.4	ID
Very strict rules with regard to sexuality/ intimacy	3	0.4	1.4	ID
Restricting participation in traffic	3	0.4	1.4	ID
The resident not being allowed within and outside the institutional grounds without permission	2	0.3	1.0	ID
Inspection of private room, cupboards, refrigerator etc.	2	0.3	1.0	ID
Locks on shoes	2	0.3	1.0	ID

Restraint	Total	% of total	% of residents applied to	Subset
Intensive one on one care	2	0.3	1.0	DD
Matrass attached to the bed	2	0.3	1.0	ID
Permanent supervision in communal area's	2	0.3	1.0	ID
Blanket which can't be torn	2	0.3	1.0	ID
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for short term forms of seclusion	1	0.1	0.5	DD
Use of 'Swedish belt' in bed (bed belt)	1	0.1	0.5	ID
All forms of medication administered under coercion	1	0.1	0.5	DD
Resident is not allowed to be on the institution area without permission of staff carers	1	0.1	0.5	ID
Resigning a client to a chair/stool on which he or she has to remain seated without being allowed to get down	1	0.1	0.5	DD
Limiting the receiving and sending of letters/ mail	1	0.1	0.5	ID
Limiting the use of (mobile) phones (having to hand in your phone to the staff at certain (set) times, only being allowed to call someone under supervision or at certain (set) times	1	0.1	0.5	ID
Inspection of mobile phone; checking messages and calls	1	0.1	0.5	ID
Strip-searching	1	0.1	0.5	DD
Having to wear gloves in order to prevent a resident from scratching themselves (form of self- harm)	1	0.1	0.5	DD
hands under the table during mealtimes	1	0.1	0.5	ID
Not being allowed to cycle unsupervised	1	0.1	0.5	ID
Limiting the amount of things that can be collected	1	0.1	0.5	ID
Wearing pyjamas with socks sewn on tot hem	1	0.1	0.5	ID
Having to wear a (fall) helmet	1	0.1	0.5	SU
Putting the weelchair on the brakes so that the resident is not able to ride off	1	0.1	0.5	SU
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for long term forms of seclusion	0	0.0	0.0	DD
Jumpsuit which includes a lock at the back to prevent the resident taking off his clothes	0	0.0	0.0	ID

Restraint	Total	% of total	% of residents applied to	Subset
Administration of all forms of medication without informing the resident (e.g. crushing and mixing medication into foods)	0	0.0	0.0	ME
All forms of nutrition (food and liquids) administered under coercion	0	0.0	0.0	DD
Resident is not allowed within the institutional grounds without permission	0	0.0	0.0	ID
The resident not being allowed to enter certain communal areas (of the general care unit) without permission	0	0.0	0.0	ID
The resident not allowed outside and within the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)	0	0.0	0.0	ID
Belt/body harness used in wheelchair	0	0.0	0.0	SU
(Wheel) Chair with tabletop to prevent residents from getting out of the chair	0	0.0	0.0	SU
Deep tub chair to prevent a resident from getting up	0	0.0	0.0	ID
Use of wheelchair brake which cannot be removed by the resident	0	0.0	0.0	ID
A tilting chair which prevents residents from getting out of the chair	0	0.0	0.0	ID
A weighted down blanket preventing the person from getting up	0	0.0	0.0	ID
A form of surveillance technology which can detect a resident getting out of their chair	0	0.0	0.0	ST
Inspection of bags and jacket/clothes	0	0.0	0.0	ID
The resident always being under supervision of the support staff	0	0.0	0.0	ID
Total	675	100.0		

Chapter 5

Multidisciplinary reduction of coercive measures for people with intellectual disabilities: A randomized trial

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Abstract

Background

There is little information on the effects of action that care organizations take to reduce the use of coercive measures.

Specific aims

To test the efficacy of a multi-component program on the reduction of coercive measures. The program focused on increasing awareness and registration at the organizational level, multidisciplinary consulting at the residential care unit level, and multidisciplinary intervention at the resident level.

Method

30 Residential units participated in a clustered randomized trial. Reduction was tested on N = 428 coercive measures applied to 107 residents, using the organization-wide registration system.

Findings

Units assigned to the experimental group reported a stronger reduction of coercive measures than units in the control group (40% versus 20%, p = .009). No differential effects were found for type of coercive measure.

Discussion

Multidisciplinary consulting at care unit level appears a promising strategy to test in a wider array of settings.

Introduction

Coercive measures in long-term care for people with intellectual disabilities (ID) are widely seen as undesirable (United Nations, 2006). The systematic elimination and reduction of coercive measures are accepted as a standard for good care in many countries (Deveau & McDonell, 2009; Frederiks, Schippers, Huijs, & Steen, 2017; Chapter 3 of this dissertation, Schreiner, Crafton, & Sevin 2014; Singh et al., 2009). Little is known about the effects of actions that care organizations may take to reduce coercive measures towards their residents (Williams, 2010; Williams & Grosset, 2011). Given the multi-determined nature of coercive care, a multidisciplinary approach would be most likely to succeed. This study tested the effect of a multidisciplinary expert team for supporting staff in residential care units to reduce coercive measures for people with ID.

Definitions of coercive measures vary with context and historical period. In the Netherlands, restraints are currently broadly defined as every measure in a specific situation that is restrictive, which is reflected within regulations set by the Dutch Health Care Inspectorate and the upcoming Care and Coercive Act within the Netherlands (Frederiks et al., 2017). Definitional differences therefore need to be held in mind when comparing and evaluating methods to reduce coercive measures and their effects. The knowledge base on methods to reduce coercive measures has coalesced around three approaches.

The first approach strives to replace coercive measures using Applied Behavior Analysis (ABA) (Williams, 2010). ABA is based on the assumption that behavior serves specific functions bound to individuals and their contexts. ABA reveals antecedent and consequent conditions that cause and maintain particular behavior, such as harmful risk behavior. Studies using ABA have revealed that coercive measures may in themselves reinforce the target behavior, leading to chronic and recurrent risk behavior and coercion (Matson & Boisjoli, 2009). Behavior modification trains low risk alternatives for high risk behavior while removing reinforcement of high risk behavior by coercive measures. While a review of research showed positive results (Williams, 2010), sample sizes have been small and results

from single case experiments have unknown generalizability. It is difficult to know how often interventions fail to deliver the predicted results (as these may not have been published; Kilgus, Riley-Tillman, & Kratochwill, 2016), which factors may be important for success, and how stable intervention results are (Luiselli, 2009).

The second approach involves training support staff (Williams, 2010). Sanders (2009) combined staff training in alternative methods to prevent danger and injuries with direct support of team management. He reported a reduction of 99% in the use of physical restraints. Deveau and Leitch (2015) reported a reduction of 32% in restrictive physical interventions after holding restraint reduction meetings on physical restraint use in children residential services. While promising, the lack of experimental control means that it is uncertain whether the training changed the rate of reduction beyond attention to the subject or external factors (Williams, 2010).

The third approach involves multicomponent interventions aimed at residents, staff, and management. Schreiner et al. (2004) studied this approach in an inpatient unit treating adolescents with developmental delays and severe psychiatric disturbances. The intervention included thorough assessment of coercive measures used and comprehensive assessment of initiating and maintaining factors. Informed by these assessments, interventions focused on staff education, treatment interventions, and instigating collaboration between a multidisciplinary advisory committee and an interdisciplinary treatment team. During the intervention phase the use of seclusion declined with 35% and the use of mechanical restraints with 43%. Williams and Grosset (2011) studied implementation of a behavior management-based plan for organization wide reduction of mechanical restraint in a residential setting for people with ID. Direct instruction was used to implement obligatory deployment of behavior interventions plans and positive or corrective feedback to psychologist and support staff was given by the management coordination team. After 17 months a reduction of 80% and a doubling of behavior interventions plans were found. Neither study compared a behavior intervention group aimed at reduction to a control group in a randomized study, however.

To change care practices where coercive measures are employed routinely to address risk behavior, authors have recommended to intervene at multiple interlocking system levels (Huckshorn 2004; Luiselli, 2009; Schreiner et al., 2004; Williams & Grosset, 2011). Stelk (2006) also indicates that the implementation of healthcare innovations is complex and extensive. Behavior and beliefs of employees and standard operating procedures of organizations are likely to persist even after new practices are put in place, because staff and client behavior and expectations will be strongly intertwined. In principle, a multi-component approach needs to affect these interlocking levels to perturb the steady state and cause sustained change.

This study

To test the extent to which a multi-component approach can cause a meaningful change in the number of coercive measures employed, a program was developed and tested aimed at awareness and registration at the organizational level, multidisciplinary consulting at the residential care team level, and multidisciplinary intervention at the resident level. The overall study aim was to test the effect of this program on reducing existing coercive measures. Within the broad definition of coercive measures as 'every measure that is restrictive in a specific situation', distinctions were made between physical and mechanical restraint, seclusion, but also restrictions as a consequence of the use of surveillance techniques, and strict rules concerning the use of mobile phones or limitations about when to go leave the unit. Because reasons for specific coercive measures may be time- and context-dependent, we specifically hypothesized program effects on coercive measures aimed at protection of harm and danger as a consequence of challenging behavior or other risks arising from intellectual impairments and related issues. In addition, it was not expected that the application of coercive measures following from organizational policies, for example surveillance techniques, or coercive measures applied to physically support a resident, such as wheelchair tables, would decline.

Method

Study setting

The care organization in this study served around 9,500 people with ID across all levels of severity and all ages. Spread throughout the Netherlands, residential care was provided in areas designed as parks owned by the institution or in districts of villages and cities, including day-care centers and outpatient clinics. A broad spectrum of care was provided, including support for living with intellectual and physical disabilities as well as treatment for additional psychiatric problems, challenging behavior, and health problems. For the trial, care units (N = 50) were randomly selected from a total of 566 24-hour care units. Units were included if they provided care for at least four residents, in order to allow estimation of unit-level effects. There were no other inclusion criteria in addition to 24/7 care.

Procedure

Recruitment and data collection followed a study protocol approved by the Ethics Committee of the Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam. Over a period of two years, data were collected on the starting dates and end dates of coercive measures recorded for each of the units participating in the trial. Staff and residents of these units were informed about the study and asked for their consent for participation in the trial. Residents or their representatives were approached by letter, which contained information on the study and a form to indicate informed consent a with study participation. Capacity of residents to make informed decisions was determined in consultation with care staff, legal representatives, and residents themselves. The letter was followed up by a phone call by an employee of the care organization.

At the start of the study 169 residents or representatives indicated written consent. Support staff was invited for participation by e-mail. Additional explanation was provided by e-mail or phone. No members of staff refused participation.

Design

The target variable of this effectiveness trial was the ending of individual coercive measures that already existed before the trial started or were implemented during the trial period for the participating residents. The sample consisted of 50 randomly selected units. In order to determine the sample size, attention was paid to the clustering of cm, which required the intra-class correlation, and to the variation of cm at the level of residents. Since the intra-class correlation is unknown, the power calculated conservatively with an ICC = .30. The variance is based on a rather high percentage of cm found in prevalence studies, namely 25%. Based on this data and an alpha of .05, the study has a power of .80 for testing a intervention effect of 4.5% on the prevalence of cm. Due to the high turnover of residents, 10 extra units were selected. The 50 recruited care units were randomized into the experimental and care as usual condition, making this a cluster randomized trial of coercive measures nested within residents who were nested within units. Cluster randomization was conducted by an independent researcher using a random number list. Coercive measures were recorded as mandated by the care organization in a register as part of the electronic resident file of the care organization. The register was developed and implemented as part of a wider project in which the trial was included (Schippers, Frederiks, Van Nieuwenhuijzen, & Schuengel, 2018; Chapter 2 this dissertation). Support staff and professionals were supported by researchers to complete and maintain a comprehensive and accurate record of coercive measures. To test whether randomization to the experimental condition in which units participated in the program was effective in reducing coercive measures, dates of onset and dates of termination were recorded for coercive measures from three months preceding the start of the intervention to 18 months after.

Intervention

Multidisciplinary expert team

For the coercive measures subjected to the experimental condition, a multidisciplinary expert team was deployed. The multidisciplinary expert team consisted of Special Education specialists (7), psychologist

(2), behavioral therapist (2), physicians (2), physical therapists (2), occupational therapists (1), video feedback trainers (4), manager (1), resident representative (1) and a coordinator (1). Type and number of experts were determined on the basis of the research literature on reduction of coercive measures (see Introduction) and interviews with candidate members. All experts were employed at the organization in which the study was conducted.

Consultation plan

The work plan of the multidisciplinary expert team included making an inventory of the coercive measures and their possible causes, and developing a treatment plan for reduction. Both the inventory of coercive measures and the treatment plan were included in the consultation plan.

The inventory of coercive measures was based on the information from the registration system for coercive measures, the residents' digital personal file, and in several cases additional information from support staff or professionals. The overview of coercive measures was set up by a member of the multidisciplinary expert team. For each coercive measure, hypothesized causes (such as antecedent and consequent conditions) were listed. The treatment plans were based on these hypotheses, following principles of evidence based practice where plans were informed by research evidence on effective practices, experts' experiences and insights, and preferences of residents, family member, and care staff. For example, a treatment plan could be developed based on the evidence based method of Applied Behaviour Analysis. Its goals would be to assess and modify risky or harmful behavior of the resident within the care context. Another example relates to attachment-based interventions. The stress-attachment model of challenging behavior (Schuengel & Janssen, 2006) points towards the important role of the attachment behavioral system to regulate stress, and therefore points towards relationship-focused interventions, such as video-feedback to promote adaptive regulation of perceived stressors (Schuengel, De Schipper, Sterkenburg, & Kef, 2013). Other elements of consultation plans derived from best practice experience gained by members

of the expert team themselves and from professionals working in the organization. These elements often focused on the reduction of coercive measures applied as physical support for a resident, reorganizing spaces within the unit and reorganizing daily routines. Also, expertise on the operation and developments and best practice experiences on surveillance technology was employed.

Prioritization of treatment plans was done by weighing the severity of the coercive measure and the preferences of care staff. Risk analyses informed the prioritization of treatment plans as well as the implementation of preemptive measures to prevent or management adverse responses to the reduction of coercive measures.

The multidisciplinary expert team coordinator and the first author were regularly briefed by the members of the team in order to maintain adherence to the design of the intervention. The intervention stopped when the consultation plan had been implemented.

Care as usual

Care as usual consists of a team of support staff members who provide daily care to residents. Treatment professionals such as physicians and psychologists are responsible for supporting the support staff and carrying out the treatment. They work together with management who can set up the organisation in such a way that treatment and supervision can be carried out. Management, professionals and support team together form the regular team that is involved in the unit. Part of the work of this team is to reduce the use of coercive measures. If they fail to make progress in this respect, they can request advice from the coercive measure committee of the organisation which, among other things, supervises the careful use of coercive measures and supports their phasing out. Additional expertise may also be requested, for example specialists working within the same organisation or with another organisation. Care as usual is also subjected to organisation-wide efforts to raise employee awareness of the use of coercive measures and the need to reduce these. The implementation of a mandatory registration system was part of this organisation-wide program.

Coercive measures

Recorded coercive measures in the mandatory registration system of the care organization were used to test program effects. The system is part of the residents' electronic personal file. The registration includes a broad range of coercive measures, which are recorded irrespective of whether residents resist the coercive measure or not. The registration system included a list of 57 coercive measures which was developed for a reliability study (Schippers et al., 2018) prior to the current study. The list was compiled on the basis of three types of sources. The first source were studies on coercive measures (Dörenberg et al., 2018; Matson & Boisjoli, 2009; Williams, 2010), the source were informational resources of the Dutch Health Care and Youth Inspectorate (2007, 2008, and 2012) and, the third source were coercive measure committees of the care organization. These coercive measure committees supervise and support the implementation and enforcement of the organisational policy concerning the use of coercive measures. Reliability was tested (Schippers et al., 2018; Chapter 2 this dissertation) and at least 25 coercive measures were found to be adequately consistent across informants, either colleague caregiver or trained observer. Further resident file studies revealed 21 additional coercive measures which were added to the list. Medication used to regulate behavior or medication which restricts residents in their functioning are not recorded in the registration system by physicians. Given the lack of consensus on which medication belongs to these categories, these two measures were not included in the registration. However, administering medication under coercion or without informing the client was included. This yielded a total available set of 76 coercive measures.

Four a priori defined subsets of coercive measures were distinguished. The first subset consists of 14 measures applied to protect from direct and mostly unforeseen danger. This can be a danger that arises from physical aggression by a resident. The danger is then averted, for example, by the application of physical restraint or seclusion. The second subset contains 46 measures preventing from indirect danger or disadvantage. These are measures such as having to follow a very strict daily program, being obliged to follow a diet,

restrictive rules on the use of a mobile phone or the Internet or limited opportunities to receive visits. These measures are applied to prevent a resident from ending up in a dangerous situation or suffering serious harm in the (near) future, for example as a result of health risks, or social decline. The third subset contains 6 coercive measures resulting from the use of surveillance technology. The fourth and final subset includes 10 coercive measures resulting from the of use of ergonomic material to physically support the resident. An overview of coercive measures and what subset they belong to is displayed in Appendix A. Registrations were updated regularly by direct care staff and permanent unit consultants. Researchers sent regular prompts for updates to take place. Registrations were double checked by the researchers against case files and treatment plans and corrected if necessary.

Statistical analysis

The dataset was structured to contain for each coercive measure per resident, per unit, a variable that indicated whether or not the coercive measure terminated during the intervention period (1 = stopped; 0 = not stopped). Hence, the dataset had a hierarchical structure, with coercive measures (level 1) nested within residents (level 2) who were nested within residential units (level 3). This strategy was chosen to accommodate turnover of clients within care units, but also aligned with the goal of the multidisciplinary expert team to reduce coercive measures, irrespective of which clients were affected. The effect of the program on reduction of restraint use was tested using generalized linear mixed modeling in SPSS version 23. Mixed modeling is a suitable technique for data with a multilevel structure, and correctly takes into account the dependencies of observations coming from the same clusters (in this case, coercive measures applied to the same resident, and residents residing in the same unit) (Hox, Moerbeek, & Van der Schoot, 2017). Given the dichotomous outcome variable, the binary logistic regression model (with logit link function) was used as the specific type of generalized linear mixed model to test the effect of the program on reduction of coercive measures. The multilevel analyses were conducted in four steps. First, an 'empty' model specified

the hierarchical data structure without any predictor variables. In this model, the intraclass correlation was computed for the level of coercive measures and for the level of residents by computing the proportion of 'variance' in the outcome variable attributed to each level (Davis & Scott, 1995). Second, the predictor Group (1 = program; 0 = control) was entered into the model to test the main hypothesis. Third, three dummy variables, together representing the four types of coercive measures, were entered as additional predictors in the model, in order to test whether, independent of the program effect, there was a difference between the types of coercive measures in the reduction of restraint use. Fourth, interaction terms between each dummy variable for type of coercive measure and the experimental group variable were added to the model to test whether the program effect was stronger for some types of coercive measures (protection from harm and danger as a result of challenging behavior) than others (reasons of surveillance techniques or physical support).

In a final step, analyses were added in which only the coercive measures registered prior to the intervention period were included. This was done to address the possibility that the intervention led to more awareness of coercive measures, and thus more registration and as a necessary consequence also more reduction of coercive measures. Additional analyses were carried out to address the alternative explanation for increases in reductions of coercive measures by heightened attention towards registration in the experimental condition.

Results

Descriptive analyses

At the time of the start of the study, 202 residents participated in the study, spread over 40 units. Coercive measures were applied to 169 residents, who were spread over 39 units. Analyses were carried out on coercive measures applied to 107 residents, spread over 30 units, as these residents were part of the sample for the entire duration of the study, i.e. these residents were resident in the unit in question until the end of the study.

Before the start and during the intervention period, N = 428 coercive measures were recorded distributed across 41 types. The most commonly recorded types were audio surveillance (on 40.2% of residents), a form of surveillance technology which detects a door being opened (on 25.2% of residents) and locking the outer doors (on 24.3% of residents). Sixteen types accounted for 80% of all coercive measures. Applied coercive measures were distributed over four subsets as follows: seven measures applied to prevent from direct danger, and 22 measures to prevent from indirect danger or disadvantage, 5 coercive measures arising from the use of surveillance technology, and 7 from the use support material. Application of coercive measures concerned 107 residents residing in 30 units.

Program effects

The proportion of coercive measures that were ended during and after the intervention period was 40.4% in the intervention group and 20.3% in the control group. The variance across units was significant (z = 2.05, p = .04); the variance across residents was not significant (z = 1.11, p = .27). The ICC correlation at the level of units was .25 and .06 at the level of residents. An ICC larger than .05 suggests that the dependencies due to the clustering cannot be ignored, and multilevel analysis is indicated (Hox et al., 2017). Analyses focusing on the degree of reduction of coercive measures before and during the intervention period, i.e. all registered cm, show a significant positive effect of the program on reduction of coercive measures (b = 1.42, t = 2.874, p = .009) (table 1), that is, in the intervention group the proportion of coercive

measures that were ended was significantly larger than in the control group. 9.3% of the variance in reduction across coercive measures nested within residents and units is explained by the intervention.

Irrespective of condition (experimental or control), coercive measures in the category of measures preventing from direct danger were more often reduced (b = 1.14, t = 2.286, p =.032) while coercive measures in the category of measures that used ergonomic material to physically support the resident were less often reduced (b = -1.00, t = -2.01, p =.045) (table 2).

Table 1: Multilevel analysis reduction of cm comparison of intervention and control group

Coercive measures	b (se)	t	p
all registered cm	1.43 (.49)	2.90	.009
cm registered before intervention period	1.77 (.84)	2.12	.048

Table 2: Multilevel analysis of reduction per subset of cm in comparison with the subset surveillance technology (irrespective of condition)

Subset	b (se)	t	p
cm physical support	-1.00 (.50)	-2.01	.045
cm direct danger	1.15 (.50)	2.29	.023
cm indirect danger	-.16 (.34)	-.46	.641

In order to address the alternative explanation for reductions of coercive measures by the increase of awareness and consequently registration of coercive measures, additional analyses were carried out. This analysis focused only on the reduction of coercive measures (n = 234) recorded prior to the intervention period. Analyses focusing on the degree of reduction of the coercive measures recorded before the intervention period also showed a significant reduction of coercive measures (b = 1.77, t = 2.12, p = .048) (table 1). 10.9% of the variance in reduction across coercive measures nested within residents and units is explained by the intervention.

Conclusion and discussion

The study shows that a multidisciplinary intervention program affects the reduction of coercive measures at care units of a large health care organization. Program effectiveness did not differ by type of coercive measure. Coercive measures to prevent from danger were most often reduced, while ergonomic supports that restricted motion were reduced least often, irrespective of experimental group. Using a controlled trial design, the current study confirmed the effectiveness (Schreiner, 2004; Williams & Grosset, 2011) of multicomponent approaches to reduce coercive measures which are applied to protect from harm resulting from challenging behavior or other risks related to intellectual disabilities. The present study focused on a broad interpretation of coercive measures and shows that the impact of such a program extends to all forms of coercive measures.

The program involved campaigning to raise awareness of coercive measures and systematically register the use of these measures at the organizational level, augmented in the experimental group with multidisciplinary consulting at the residential care team level and multidisciplinary intervention at the resident level. None of these program elements on its own were assumed sufficient to reduce coercive measures on a large scale (Deveau & McDonell, 2011; Schreiner, 2004; Williams & Grosset, 2011). The effectiveness of the multidisciplinary expert team should therefore be interpreted against the background of these organization-wide efforts. It is known that care practices arise in interaction between resident and support staff members (Stelk, 2006), requiring an integrated effort to reduce coercive measures by altering organizational context, care staff practices, and resident behavior. The importance of making registration of key care practices part of routine care has been previously demonstrated (Deveau & McDonell, 2011; Huckshorn, 2004; Schreiner, 2004; Williams & Grosset, 2011). In the present study, the registration system made it possible for the multidisciplinary expert team to know how many and which coercive measures were applied and reduced. The finding that assignment to the multidisciplinary expert team program accelerated the reduction of coercive measures over and above any effects that the

organization-wide changes might have had underscores the potential of an integrative approach. Empirical testing of synergetic effects of program components at different levels would require trials involve multiple care organizations.

During the intervention period, more coercive measures were recorded in the experimental group than in the control group. The intervention effect might thus be partly due to increased awareness and registration of the coercive measures that were actually used registered prior to and during the intervention period. This would be in line with findings of a study on explanation of an increase in registration after the implementations of a new law and regulations in Norway (Sondenaa, Dragsten, & Whittington, 2015). In order to separate the effects of the program through awareness raising and through altering care practices, the current study additionally tested the experimental effect on coercive measures that were already registered before consultation by the multidisciplinary expert team commenced. The program effectiveness was also statistically significant for this subset of coercive measures.

Several limitations should be mentioned. First, although the multidisciplinary approach had been developed prior to the study and the multi-disciplinary team had a sufficient number of complementary experts, running the multidisciplinary team required coordination, partly provided by the first author. Program effectiveness evaluation was therefore not independent from program implementation. Second, quantitative data on duration and frequency of application were missing from the registration. Because phasing out of coercive measures can also be done by reducing duration and frequency of their application, intervention effects might be underestimated. Third, the broad definition of coercive measures can lead to different interpretations of forms of measures. Despite close involvement of the expert team in registering coercive measures, this may still have affected the registration.

The present study demonstrated the effectiveness of a multidisciplinary approach for reducing coercive measures. These promising effects await replication across as well as within care organizations. Although the program was protocol-based and

standardized, effects may be associated with qualities of the team experts as well as the specific context of the care organization, which already had implemented organization-wide awareness and registration campaigns. It may be of theoretical interest to apply experimental control to these contextual factors to test their effects on program effectiveness. However, to add insight into implementation of care innovations, effectiveness across organizations may also be tested when interventions are conducted to optimize the organization-specific implementation factors (May, Johnson, & Finch, 2016).

Appendix A: Overview of coercive measures and subsets

Coercive measure	Total	% of total	Nr. of residents applied to	% of residents applied to	Subset
Audio surveillance (either within resident's private room/ and/or in the general care unit)	50	11.7	43	40.2	ST
Limited acces to rooms/area's by locked doors in the care unit	31	7.2	21	19.6	ID
Locking cupboards, wardrobes, kitchen cabinets, refrigerator	30	7.0	22	20.6	ID
Locking the outer doors (to prevent the resident or other residents from leaving the care unit)	30	7.0	26	24.3	ID
A form of surveillance technology which detects a door being opened (used either within a resident's private room and/or general care unit)	29	6.8	27	25.2	ST
Jump suit which cannot be torn and/ or prevents residents taking of their clothes	29	6.8	18	16.8	ID
Types of beds where the resident is not able to get out of (bedrails, Poseybed, bedbox)	26	6.1	23	21.5	SU
Belt/posey vests (weel)chair	24	5.6	19	17.8	SU
Locking the bedroom door	24	5.6	21	19.6	ID
The resident not being allowed beyond the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)	15	3.5	15	14.0	ID
Resident is not allowed at or outside the institutional grounds without supervision (supervised by support staff or surveillance technology)	12	2.8	10	9.3	ID
Physical restraint (parts of the body being held down)	12	2.8	12	11.2	DD
Being confined to one's own room with the door locked	11	2.6	10	9.3	DD
Limiting the use of media (radio; tv; magazines), either in choice or in set times	9	2.1	9	8.4	ID
Locked windows	9	2.1	9	8.4	ID
Closing access to the garden	9	2.1	6	5.6	ID
Monitoring the resident by keeping a close eye on him through other means (such as the window or door)	9	2.1	5	4.7	ID
closing off the water supply	8	1.9	5	4.7	ID

Coercive measure	Total	% of total	Nr. of residents applied to	% of residents applied to	Subset
Mechanical restraint of feet and/or legs	5	1.2	5	4.7	SU
Camera/video surveillance (either within resident's private room and/or in communal part(s) of the building)	5	1.2	4	3.7	ST
Mechanical restraint of arms/hands	5	1.2	4	3.7	DD
Under mattress bed alarm system which can detect a resident leaving their bed	5	1.2	5	4.7	ST
Very strict rules/ agreements such as having to follow a specific day program, having fixed times and amounts with regard to eating and drink, strict rules on when to shower and sleep	4	0.9	4	3.7	ID
Resident had to stay in a room (other than his own) with the door locked	4	0.9	3	2.8	DD
Limiting the use of internet (i.e. a fixed amount time, or only within a specific location (within sight of the carer), or limited access to certain websites)	3	0.7	3	2.8	ID
Stretcher with bed rails or shower stool for in the shower	3	0.7	3	2.8	SU
A movement detector (used either within a resident's private room and/ or in the general care unit)	3	0.7	3	2.8	ST
Locking all the doors	3	0.7	3	2.8	ID
Mechanical restraint of trunk by belt/ harness (other than used in wheelchair)	3	0.7	2	1.9	SU
All forms of medication administered under coercion	3	0.7	3	2.8	DD
Limiting the use of (mobile) phones (having to hand in your phone to the staff at certain (set) times, only being allowed to call someone under supervision or at certain (set) times	3	0.7	3	2.8	ID
Limiting visitation (either receiving or visiting) of family friends and others	2	0.5	2	1.9	ID
Orthosis used in bed, resulting the resident is not being able to move	2	0.5	2	1.9	SU
Adjusted lights, so that the resident cannot turn off the light themselves	1	0.2	1	0.9	ID
Blanket which can't be torn	1	0.2	1	0.9	ID
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for short term forms of seclusion	1	0.2	1	0.9	DD

Coercive measure	Total	% of total	Nr. of residents applied to	% of residents applied to	Subset
Resident is not allowed to be on the institution area without permission of staff carers	1	0.2	1	0.9	ID
Limiting the receiving and sending of letters/mail	1	0.2	1	0.9	ID
Inspection of mobile phone; checking messages and calls	1	0.2	1	0.9	ID
Strip-searching	1	0.2	1	0.9	DD
Having to wear a (fall) helmet	1	0.2	1	0.9	SU
The resident being confined to a room/ area of the unit without the doors being locked (hallway, own bedroom)	0	0.0	0	0.0	DD
Very strict rules with regard to the use of cigarettes, alcohol or other substance use	0	0.0	0	0.0	ID
No interactions with other clients without supervision	0	0.0	0	0.0	DD
Set times for resting	0	0.0	0	0.0	ID
Very strict rules with regard to sexuality/intimacy	0	0.0	0	0.0	ID
Restricting participation in traffic	0	0.0	0	0.0	ID
The resident not being allowed within and outside the institutional grounds without permission	0	0.0	0	0.0	ID
Inspection of private room, cupboards, refrigerator etc.	0	0.0	0	0.0	ID
Locks on shoes	0	0.0	0	0.0	ID
Intensive one on one care	0	0.0	0	0.0	DD
Matrass attached to the bed	0	0.0	0	0.0	ID
Permanent supervision in communal area's	0	0.0	0	0.0	ID
Use of 'Swedish belt' in bed (bed belt)	0	0.0	0	0.0	ID
Resigning a client to a chair/stool on which he or she has to remain seated without being allowed to get down	0	0.0	0	0.0	DD
Having to wear gloves in order to prevent a resident from scratching themselves (form of self- harm)	0	0.0	0	0.0	DD
hands under the table during mealtimes	0	0.0	0	0.0	ID
Not being allowed to cycle unsupervised	0	0.0	0	0.0	ID
Limiting the amount of things that can be collected	0	0.0	0	0.0	ID

Coercive measure	Total	% of total	Nr. of residents applied to	% of residents applied to	Subset
Wearing pyjamas with socks sewn on tot hem	0	0.0	0	0.0	ID
Putting the weelchair on the brakes so that the resident is not able to ride off	0	0.0	0	0.0	SU
Seclusion (for a certain amount of time) whereby the resident is isolated from others in a room specifically designed for long term forms of seclusion	0	0.0	0	0.0	DD
Jumpsuit which includes a lock at the back to prevent the resident taking off his clothes	0	0.0	0	0.0	ID
Administration of all forms of medication without informing the resident (e.g. crushing and mixing medication into foods)	0	0.0	0	0.0	ID
All forms of nutrition (food and liquids) administered under coercion	0	0.0	0	0.0	DD
Resident is not allowed within the institutional grounds without permission	0	0.0	0	0.0	ID
The resident not being allowed to enter certain communal areas (of the general care unit) without permission	0	0.0	0	0.0	ID
The resident not allowed outside and within the residential grounds without surveillance (either under supervision of support staff or through the use of surveillance technology)	0	0.0	0	0.0	ID
Belt/body harness used in wheelchair	0	0.0	0	0.0	SU
(Wheel) Chair with tabletop to prevent residents from getting out of the chair	0	0.0	0	0.0	SU
Deep tub chair to prevent a resident from getting up	0	0.0	0	0.0	ID
Use of wheelchair brake which cannot be removed by the resident	0	0.0	0	0.0	ID
A tilting chair which prevents residents from getting out of the chair	0	0.0	0	0.0	ID
A weighted down blanket preventing the person from getting up	0	0.0	0	0.0	ID
A form of surveillance technology which can detect a resident getting out of their chair	0	0.0	0	0.0	ST
Inspection of bags and jacket/clothes	0	0.0	0	0.0	ID
The resident always being under supervision of the support staff	0	0.0	0	0.0	ID
Total	428	100.0	107	100.0	

Chapter 6

General discussion

The main purpose of this dissertation was to contribute to a better understanding of how coercive measures are used in the care for people with intellectual disabilities. Previous work has suggested that coercive measures are regularly used in professional care (Fitton & Jones, 2018; Romijn & Frederiks, 2012;). However, systematic evidence on how often coercive measures are used is scarce (Fitton & Jones, 2018). Evidence for the effectiveness of interventions at the level of care organizations to reduce the use of coercive measures is scarcer still (Schreiner, Crafton, & Sevin, 2004; Williams, 2011). The studies in this dissertation addressed these gaps by recording how often coercive measures were used in daily practice, by testing how using these coercive measures was associated with characteristics of residents, professional carers, and settings, and by conducting an effectiveness trial of a multidisciplinary program for reducing coercive measures in residential care for people with intellectual disabilities. The studies were conducted in the Netherlands and took place in parallel with a social and political debate concerning the right of self-determination of people with intellectual disabilities. In the dissertation features of the Dutch legal framework for the use of coercive measures have been highlighted, specifically with regard to the criteria for the daily registration of coercive measures.

The studies in this dissertation used a broad definition of coercive measures as any measure that is restrictive for the resident in a specific situation (Dörenberg et al., 2018; Romijn & Frederiks, 2012). This broad definition covers a wide range of practices, including but not limited to practices defined in the current and future Dutch laws. The upcoming law focuses on 'resistance' to care by the person with the intellectual disability or his or her legal representative (Steen, De Schipper, & Frederiks, 2016). Chapter two showed that a reliable registration of coercive measures under a broad definition is only partly feasible. Chapter three discussed the importance of a clear definition and standard formulated measures as part of the mandatory registration in the legal framework. Chapter four reported on a negative association that was found between the resident related factor level of communicative and social functioning and coercive measures. Aggressive and destructive behaviour as well as self-

injurious and stereotyped behaviour were associated with coercive measures that are applied at direct and unforeseen danger. Finally, results of an effectiveness trial of a multi component program on the reduction of coercive measures was reported in Chapter five. The program focused on increasing awareness of support staff members and professionals and registration at the organizational level, multidisciplinary consulting at the residential care unit level, and multidisciplinary intervention at the resident level.

Finally, in this last chapter the main findings are summarized, integrated, and discussed. These findings should be considered in the light of the strengths and weaknesses of the study and are therefore described. Theoretical implications and future research directions are addressed, and the implications for clinical practice are discussed.

Summary of main findings

Reliability and feasibility of full registration of coercive measures applied in daily care for people with intellectual disabilities.

Quantitative data on the use of coercive measures within care organizations provide starting points for reducing coercive measures use (Huckshorn, 2004; Romijn & Frederiks, 2012). Data provide insight into usage patterns of coercive measures and risk factors, helping to design interventions for reduction (Huckshorn, 2004). However, the field of practice uses a wide variety of often incompatible instruments that operationalize diverging and sometimes unclear definitions (Romijn & Frederiks, 2012). Standardized lists and criteria could lead to reliable and comprehensive registration of the use of coercive measures (Huckshorn, 2004; Matson & Boisjoli, 2009; Webber, McVilly, & Chan, 2011).

Chapter two examined whether registration of the use of coercive measures can be standardized and leads to reliable data, taking into account the context and purpose of the potential coercive measure. Reliability of daily registrations of support staff members was tested against registrations of independent observers and informants and results were validated by a panel of stakeholders. Using a flexible research design (Dellinger & Leech, 2007), the study aimed towards optimization of a registration system that was both reliable and meaningful and would therefore have the greatest chance of successful implementation. Reliability was tested comparing routine registration by care staff to registration on selected days by trained observers as well as other members of the care staff team. The success of implementation of the routine registration system was tested by comparing registration of coercive measures to file records of residents.

Results show reliable registrations for 25 out of 57 types of coercieve measures. The study made clear that despite standardized definitions for each coercive measure (Matson & Boisjoli, 2009; Williams, 2010), registration that covers the broad definition of coercive measures is due to yield unreliable and variable prevalence outcomes. Reflections of stakeholders on unreliable outcomes yielded

the possibility of variable awareness among support staff members of coercive measures and high level of difficulty of identifying coercive measures within the complex context of long-term group care for people with often severe and multiple disabilities. The final part of the study showed the success of the implementation of a mandatory routine registration system by comparing registration of coercive measures to residents' care records. Agreement was conditional on the registration of coercive measures in the registration system. 84% coercive measures were identified and talked through during training and agreement was reached on 46% of coercive measures. In conclusion it has become clear that a routine and adequate registration of the use of coercive measures is feasible, at least for a subset of coercive measures.

Legal criteria for registration considered in more detail.

Registration of coercive measures is a leading and mandatory component of the Dutch Care and Coercion Act (Staatsblad, 2018, 36), which will enter into force in 2020. Mandatory registration is one of the reasons why the introduction of this Act will have far-reaching consequences for professional care for people with intellectual disabilities. The Act sets out criteria for the identification and registration of coercive measures and thus contributes to better legal protection for people with intellectual disabilities (Frederiks & Steen, 2018). Chapter three described a viewpoint that is based on reflections by experts with broad scientific and practical knowledge in the field of care for people with intellectual disabilities. Experts focused on the criteria set by law, the description of categories of care practices which should be registered, and the way in which registration would be influenced by environmental and other factors.

Unclear definitions of coercive measures may explain (Matson & Boisjoli, 2009; Webber et al., 2011) low reliability of data on the use of coercive measures, limiting the utility of these data to monitor, test and, if necessary, adjust coercive practices. Also in the Netherlands there is a great deal of confusion and discussion about the concept of coercive measures. The current Psychiatric Hospital Act (Wet Bopz) does not provide a definition of coercive measures, but lists a number

of concrete care practices as coercive measures, such as physical and mechanical restraint and seclusion. Under the influence of societal and political debate, field parties and regulators have advocated a broader view of coercive care (Romijn & Frederiks, 2012). The Care and Coercion Act is based on the term 'involuntary care', which refers to all forms of care that is resisted by the resident or a representative. In addition to the criterion of resistance by the resident or representative, the act formulates nine categories of involuntary care as a guideline for registration. However, it is unclear to what extent this gives direction to a uniform registration. Even when people agree on which practices constitute involuntary care, the judgment in individual cases is likely to depend on multiple characteristics in the context in which care is provided rather than a simple absence or presence (Matson & Boisjoli, 2009). Research results show that experts subscribe to the importance of standardized reporting of coercive measures. However, the definition and the nine categories as set by the legislator are insufficient to ensure uniform, consistent, and reliable registration of involuntary care, and therefore of coercive measures. An expert meeting was held which concluded that many considerations to determine coercive measures remain unclear, which is in line with ongoing international debate (Cairns et al 2011; Carpenter, Langan, Patsios, & Jepson, 2014). Although opinions of experts varied, they unanimously stated that residents' resistance to care must in any case be recorded. They also concluded that the administration of fluids, food, or medication and application of physical restraint, separation or seclusion should always be recorded, regardless of resistance by the client. These findings demonstrate the need for more concrete and clear definitions of involuntary care in legislation, to protect the legal position of residents.

Associations between resident and support staff related factors and the use of coercive measures.

Chapter four addressed the lack of comprehensive and integrated insight in the use of coercive measures and associated factors in long term care organizations (Fitton & Jones, 2018). Past research has identified various associated factors, but these studies were often

limited to a single factor or selected coercive measures (Fitton & Jones, 2018; Webber, Richardson, & Lambrick, 2014). Factors found in one study were often not replicated in other studies, if the criteria for coercive measures changed or additional factors were included. To contribute to further integration of disparate findings, this study tested the hypothesis that residents' challenging behavior, communicative adaptive functioning, attachment behavior, and staff's attributions and self-efficacy were each uniquely associated with residents' exposure to coercive measures. Also, it was determined to what extent the associated factors varied according to the type of measures that were considered, distinguishing between measures which served a protective function and measures serving operational needs. Chapter four revealed an association between lower scores on communication and socialization functioning on the one hand, and higher number of coercive measures on the other. Challenging behavior such as aggressive and destructive behavior as well as self-injurious and stereotyped behavior was associated with coercive measures applied at direct and unforeseen danger. Against expectations, attachment behavior was not associated with coercive measures. Also, variation of the use of coercive measures across units was only partly explained by staff characteristics as attribution on the stability of CB was associated with the total of coercive measures applied.

In conclusion, this study confirmed the association of resident related factors and the use of coercive measures. Notable was that this association was found in the context of a broad set of other client and staff characteristics that, despite earlier findings and theory, were not associated with coercive measures.

Multidisciplinary reduction of coercive measures for people with intellectual disabilities.

Systematically eliminating or reducing the use of coercive measures is seen as a standard for good care (Deveau & McDonell, 2009). Both practice and scientific studies show encouraging examples of initiatives concerning the reduction of coercive measures (Schreiner et al., 2004; Williams & Grosset, 2011). Nevertheless, systematic information is lacking about the effects of interventions to reduce

coercive measures. Implementing a structural change in professional care requires breaking through ingrained patterns (May, Johnson, & Finch, 2016). Such patterns may involve interrelated practices of how people work together, such as support staff, residents and professionals. Patterns of action, which include the use of coercive measures, are formed, are reinforced, and thus continue to exist through these interactions. A multi-component approach (Williams & Grosset, 2011;Schreiner et al., 2004) may influence the various facets of professional care simultaneously, maximizing the chance that coercive measures may be discontinued. It is as yet unclear to what extent effects of interventions focused on single interactions or problems can be extended to a complex of interactions involving multiple residents and units. In line with Schreiner et al (2004) and Williams and Grosset (2011) Chapter five reports on the effects of a multi-component approach on the reduction of coercive measures. Chapter five demonstrates the effects of a multi-component approach on the number of coercive measures employed. A program was developed aimed at awareness and registration at the organizational level, multidisciplinary consulting at the residential care team level, and multidisciplinary intervention at the resident level. The main objective was to test the effect of this program on the use of coercive measures. Effects were determined using a clustered randomized controlled trial. For the coercive measures subjected to the experimental condition, a multidisciplinary expert team was deployed. The expert team worked in systematic and close cooperation with the team of support staff and professionals associated with each residential unit. Central to this systematic work was the registration of coercive measures in the mandatory registration system and the consultation plan. This made it possible to monitor the effects on the use of coercive measures and, if necessary, to adjust the consultation plan. Within the control group, apart from the implementation of registration, care as usual was provided. Findings showed that coercive measures in units in the experimental group had a higher rate of reduction than coercive measures in units in the care as usual group. Also, during the intervention period, more coercive measures were recorded in the experimental group than in the control group. An alternative

explanation for the intervention effect could be increased awareness of, and thus recording, of coercive measures. In order to differentiate the effects of the program through awareness raising and changes in care practice, the experimental effect on coercive measures that had already been registered before the multidisciplinary expert team started to consult was investigated in the current research. The effectiveness of the program was also statistically significant for this subgroup of coercive measures, increasing confidence that the intervention was indeed effective in reducing actual coercive measures.

Limitations

Several limitations should be taken into account when interpreting the results of the studies. First, limitations concerning the study described in Chapter two concerned the possibility that the observer did not observe all coercive measures, for example when certain coercive measures were applied out of sight and outside the hearing distance of the observer. Another limitation concerns the bias that could have arisen by non-random selection of shifts by the informant and the selection of stakeholders by the researchers. Finally, no specific methods were used to analyze qualitative data on stakeholders' reflections. A limitation of the entire dissertation concerns the reliability of the information on coercive measures. The broad definition of coercive measures that refers to any measure that is restrictive for a resident in a specific situation is not sufficient to indicate coercive measures. The dissertation established a subset of coercive measures that can be measured with at least reasonable reliability. However, the broad interpretation may lead to differences in interpretation between the assessments of healthcare practices by different staff members, which in turn reduces the reliability of the data. A limitation of the study described in the third chapter was the absence of methodological analyses of the reflections of the experts. As a result, the study is limited to a summary of expert opinion that legislators and policy developers can use to optimize the registration of involuntary care. With regard to the fourth chapter, a number of shortcomings can be mentioned. The first limitation concerns the reliability of the measures of coercive measures. For the purpose of the study, information on the use of 76 coercive measures was analyzed. Reliability data were only available for a 56 measures. These data were derived from the first study described in the dissertation, and indicated that the overview of 56 measures was partly measurable with at least reasonable reliability. Together with the extension to 76 measures, part of the measures is to be known as unreliable and for another part, reliability was unknown. Second, the division of the total in coercive measures into different subsets is partly based on recent studies and partly, due to the broad definition, based on interpretation

and consequently in a sense arbitrary. The third limitation concerns the long-term nature of the collection of information. The constructs assessed with questionnaires could vary over time. And fourth, because of the cross sectional design of the study no conclusion can be drawn on the causality of the associations.

Finally, the effect of the intervention on the reduction of coercive measures was demonstrated in a large care organization in Chapter five. Several limitations should be taken into account when interpreting the effects. It is unclear whether the effect is specific to this organization or can be generalized to other care organizations. One other limitation concerns the lack of insight into how much support and coordination is needed for the implementation of the program. Running the multidisciplinary team required coordination which was not initially included in the development of the program. Findings may therefore also be the result of this coordination and control, and not merely the result of the multicomponent approach. Another limitation refers to the data on coercive measures. These data did not provide information on the duration and frequency of the application. It is possible that changes in the application related to duration or frequency. These nuanced effects are not identified. Finally, the broad definition of coercive measures can lead to different interpretations of forms of measures. Despite close involvement of the expert team in registering coercive measures, this may still have affected the registration.

Implications for future research

The standardization and structural registration of coercive measures has contributed to raising awareness in staff of and more reliable information about the use of coercive measures. However, it remains to be determined which concrete care practices should be identified as coercive measures. The context—such as which resident, for what purpose and under what circumstances the measure is applied—affects the identification of coercive measures. For example, a certain care practice, such as taking a walk under the supervision of a support staff member, can be restrictive in one specific situation (if the resident would have rather walked alone or with a non-staff person) and not in another (if the resident desired company and attention from the staff member. For a resident who is physically disabled or disoriented, walking under supervision is probably an opportunity to give more room for self-determination, while for a young person who wants to be independent this is a restriction of autonomy. Further research can focus on the various conditions that determine when care practices are coercive, such as the moods and desires of the resident, resistance from the resident, the extent to which the resident understands the situation, and the purpose for which the measure is deployed. When support staff members and care professionals include these conditions in weighing care practices in order to indicate coercive measures, more reliable and valid registration of coercive measures could be achieved. In addition, clarifying these conditions could also be an addition to, or a practical interpretation of, the legal obligation to register coercive measures. It also increases the chances that the protection of residents' rights through registration offsets the bureaucratic burden imposed by registration.

In order to advance the state of the art in charting the causes that determine the use of coercive measures, studies using a longitudinal design should be deployed. This also makes it possible to determine the extent to which factors at different levels are interrelated. In addition, further research into such factors offers the possibility to explain certain associations and to investigate the correlation of combinations of factors and the use of coercive measures. Additional

factors can also be studied that provide a better understanding of the conditions under which coercive measures are applied, such as residents' perspectives on the measure. Also, factors concerning additional information about the application of coercive measures and decision making with regard to the application can be added. More specifically, the circumstances in which the measure was applied are important to record and may moderate associations between coercive measures and staff and context factors. Not all coercive measures are used as a last resort (Deveau & Leitch, 2015). It is known that coercive measures are used for purposes beyond residents' safety (Matson & Boisjoli, 2009). Based on a broad definition the current study has identified 76 measures which, in addition to protecting against indirect and direct danger, are characterized by restrictions arising from the use of physical support material or surveillance technique used to organize care. Follow-up research can determine the conditions under which a coercive measure has been applied and the reason for its application. The reason of application can be specifically requested. In addition, the multidisciplinary decision-making process can be investigated. It has been found that debriefing after the application of physical restraint leads to a decrease in the use of restraint (Deveau & Leitch, 2015). However, no information is yet available on forms of multidisciplinary decision-making in which the emphasis is on minimizing the use of coercive measures.

Finally, the effect of a multi-component approach on the phasing out of coercive measures should be tested with more healthcare organizations in order to investigate the generalizability of the effect.

Implications for practice

The findings presented in this dissertation are particularly relevant to practice in residential care for people with intellectual disability. Findings support systematic registration of coercive measures as feasible, offering a way to increase awareness of support staff members and professionals of the use of these measures. By registering coercive measures, support staff members become aware of which measures they may apply as a matter of routine. It may also contribute to norm setting, meaning that the right to self-determination becomes more appreciated and translated into concrete terms of coercive measures. However, change in norms was not assessed in this study and therefore awaits further research.

In addition, reliable information about coercive measures contributes to the identification of units that may require extra attention and to evaluation of effects of interventions in care practice. Registering the daily application of coercive measures thus contributes to the changes in coercive care practices that are pursued through policy, legislation, and programs to improve quality of care. It is therefore recommended to develop and implement registration systems for residential care. In the course of implementation, attention must be paid to training support staff members and professionals in the identification of coercive measures, which should lead to a more reliable and complete registration. Training in the registration of coercive measures is essential in order to achieve a complete and accurate registration. Without proper training, it is likely that the benefits of registration will not be realized. The importance of training in registration and also the development of unequivocal guidelines for registration are emphasized by the finding that the criteria for registration set by the Dutch legislator are partly unclear. Although the legislator formulates starting points, these do not appear to give sufficient direction for a uniform registration. A comprehensive an accurate registration of coercive measures gives professional care the opportunity to analyze and monitor the use of coercive measures. It gives the possibility to map certain resident and context related factors

and to adapt interventions to these factors. Effects of interventions can also be monitored by means of the registration system.

The intervention study shows that accelerating the phasing out of coercive measures is possible. The multi-component approach aims at several interrelated facets of care that are bound to lock each other in place. These patterns were purposefully disrupted by deploying a multidisciplinary expertise team. While also in the control group coercive measures were reduced, the results of the experimental group showed reduction at a more rapid pace. It is therefore recommended that a multidisciplinary team of experts be set up and trained within organizations. By intervening according to the multi-component approach, a phasing out of coercive measures can be achieved in less time, limiting the exposure of residents to these coercive measures.

General conclusion

The dissertation contributes to the realization of the right to self-determination for people with intellectual disabilities in daily care practice. By means of a systematic registration more understanding has been gained on the use of coercive measures in residential care for people with intellectual disabilities and its main predictors. Also, the effect of a multi-component approach on the reduction of coercive measures were demonstrated. Thereby, the study led to both an important contribution to scientific knowledge and a direct change in healthcare practice.

The broad interpretation of coercive measures was converted into an overview of standardized measures. Findings concerning reliability of daily registration showed a subset of coercive measures that were recorded with reasonable reliability, and that could provide the basis for routine registration of the use of coercive measures. This registration can be used to improve care and protect the rights of persons with intellectual disabilities, which is in accordance with the objectives of the upcoming Care and Coercion Act. Experts reflected on the criteria set by the regulator and emphasized the importance of a clear definition and criteria on the statutory registration obligation. Subsequently, due to this systematic obtained information on coercive measures concerning a large sample it was possible to determine a comprehensive and integrated overview of a set of resident and support staff related factors and the overall use of coercive measures as defined in its broadest way, and divided into measures that serve a protective function against direct and indirect danger. A low level of communication determined the overall use of coercive measures. Challenging behavior was found to predict the use of coercive measures which are applied to prevent from direct, unforeseen, high risk danger and measures used to prevent from indirect, not acute, danger. Finally, a multidisciplinary intervention program can accelerate the reduction of coercive measures at care units of residential care for people with intellectual disabilities.

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Appendix

Dankwoord
Curriculum Vitae
Publications

Dankwoord

Na brede en veelzijdige ervaring in de zorg voor mensen met een beperking besloot ik begin 2013 me in het vakgebied te willen verdiepen door middel van wetenschappelijk onderzoek.

Ik was sterk gedreven door mijn ervaringen die ik in de dagelijkse zorgpraktijk had opgedaan.

Eerst als begeleider van mensen met een verstandelijke beperking, en later tijdens mijn werkzaamheden als orthopedagoog werd ik steeds bewuster van en kritischer over hoe zorg aan kwetsbare mensen wordt verleend. Ik leerde dat vrijheidsbeperkingen soms routineus worden toegepast, ik werkte succesvol aan het afbouwen van ingrijpende vrijheidsbeperkingen, en zag dat ze soms binnen korte tijd weer opdoken in de dagelijkse zorg.

Het gebruik van vrijheidsbeperkingen was voor mij een raadsel. Ik had zoveel vragen, waarbij ik vooral wilde weten óf en hoe het structureel anders kon. Het onderzoek gaf mij de mogelijkheid antwoorden te vinden. Het heeft mij veel inzicht gegeven, geleid tot de ontwikkeling van kennis en richting gegeven aan veranderingen in de dagelijkse zorg.

Een sterke persoonlijke motivatie is weliswaar belangrijk, maar het uitvoeren van onderzoek en het afronden van een proefschrift vraagt om zoveel meer. Veel mensen hebben mij de afgelopen jaren geholpen. Zonder deze hulp was het niet gelukt. In dit laatste hoofdstuk wil ik graag de gelegenheid nemen om deze mensen te bedanken.

Allereerst diegenen die mij hebben begeleid in het uitvoeren van het onderzoek en het schrijven van het proefschrift. Zoals de bekende uitdrukking luidt kon ik verder kijken doordat ik op schouders van reuzen stond. Wetenschappelijke reuzen, goede leraren, met veel kennis en ervaring en bovenal een enorme steun op de nodige momenten.

Maroesjka, dank je wel voor je begeleiding. Met jouw persoonlijkheid en ervaring in het uitvoeren van onderzoek lukte het om steeds weer de juiste stappen te zetten. Als ik (te) lang op een zijspoor bleef stuurde je bij. Wanneer ik vast liep in eindeloos veel ideeën stelde je precies de juiste vragen waardoor ik weer gefocust

was. Je leerde me wetenschappelijk schrijven, het onderzoek stap voor stap uit te voeren en was er op de momenten waarop het nodig was. Bovendien was het gezellig; we hebben veel gepraat en gelachen. Dank!

Brenda, dank voor je enorme kennis over de rechten van mensen met een beperking. Het beschermen van deze rechten is wellicht de essentie van het onderzoek. Jouw kennis en kritische blik waren daardoor onmisbaar. Daarnaast dank voor je kalme wijze van begeleiden; op sommige momenten relativerend zonder het doel uit het oog te verliezen. En bovendien dank voor de gezellig momenten op de congressen en je humor!

Carlo, dank voor je kennis, de inspiratie en uitdaging. Ik heb veel bewondering voor je opmerkzaamheid en analytische vermogen. Jouw reacties op een vraag of voorstel waren altijd scherp en goed doordacht; het werd er altijd beter van. Ik heb onwaarschijnlijk veel van je geleerd. Dank.

Marleen, ik ben je veel dank verschuldigd. Allereerst voor je grote bijdrage aan de wetenschappelijke methode en statistische analyses van het onderzoek. Het was niet eenvoudig en je schroomde niet om me keer op keer te helpen en je te verdiepen in alle analyses. Je hebt eindeloos veel geduld gehad, je was uitermate grondig en hebt het onderzoek daarmee een heel stuk verder gebracht. Dank daarvoor.

Heel graag wil ik 's Heeren Loo bedanken. Het is belangrijk dat door middel van onderzoek zowel wetenschap als praktijk kunnen ontwikkelen. 's Heeren Loo ziet dit belang en maakt dit mogelijk.

In het bijzonder wil ik Bas bedanken. Het onderzoek kreeg een gedegen plek in de organisatie waardoor de continuïteit was gewaarborgd. Als ontwikkelaar van de afdeling Wetenschappelijke Ontwikkeling en Kennismanagement en de verbinding tussen 's Heeren Loo en VU was dit jouw verdienste. Daarnaast wil ik graag de mensen van het eerste uur, Kees Erends en Gijs Bierens en later Timon en Marjolein, bedanken. Dank voor het erkennen en aanwakkeren van het belang van onderzoek naar dit vraagstuk. Marjolein, ergens halverwege het onderzoek (optimistisch als ik ben dacht ik al bijna klaar te zijn) leerden we elkaar kennen. Ik wil je graag bedanken voor

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Lieve Daniëlle, ik ben je enorme dank verschuldigd. Het is al bijna zes jaar vaste prik; elke woensdag nemen we samen alle vraagstukken en ontwikkelingen rond het thema vrijheidsbeperkingen door. Mijn onderzoek was een vast agendapunt en zo werd jij bijna vanzelf landelijke coördinator van het expertiseteam. Hiermee heb je een belangrijke bijdrage aan het onderzoek geleverd. Daarnaast ben je een hele fijne sparringpartner, zowel voor alle werk gerelateerde issues als al het andere lief en leed. Je was en bent een enorme steun.

Lieve Moniek, in één woord 'Wauw'! Ik herinner me nog de dag dat je mijn kamer binnenkwam. Je wilde graag het onderzoek voor je Master binnen mijn project uitvoeren. Dat was het begin van onze ontzettend leuke samenwerking. Ik had al gauw in de gaten dat je een zeer waardevolle aanvulling op het uitvoeren van mijn project was. Gelukkig kon je na je afstuderen nog een tijd werken binnen mijn project. Ik kijk met veel plezier terug op onze lange dagen, en ben trots op de enorme berg werk die we samen hebben verzet. Hopelijk kunnen we onze samenwerking nog een tijd voortzetten!

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De leden van de promotiecommissie, dr. Vivianne Dörenberg, prof. dr. Petri Embregts, dr. Gerda de Kuijper, prof.dr. Annette van der Putten en prof.dr. Heleen Riper ben ik erkentelijk voor het lezen en beoordelen van mijn proefschrift en voor hun deelname aan de oppositie.

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En dan: mijn lieve Hendrik Jan. Ik zeg geen woord teveel als ik zeg dat ik dit zonder jou niet had kunnen doen. Ik heb diepe bewondering voor jouw eindeloze steun en zorg voor mij en onze drie kinderen. Dank dat ik jouw vrouw mag zijn.

Curriculum Vitae

Baukje Schippers (May 1981) has varied experience in professional care for people with disabilities. From 1999-2003 she studied physiotherapy at the Saxion Hogeschool in Enschede. During this study she worked as a staff member with non-congenital brain injury. Subsequently she worked as a physiotherapist, mainly also with people with non-congenital brain injury. From 2004 she studied pedagogical sciences at the University of Utrecht, a study that she completed in 2007 with the master's in Child Rehabilitation - and Disability Care. During this study she worked as a staff member with people with and hearing impairment and people with a intellectual disability and challenging behaviour. From 2007 to 2013 she worked as an child psychologist at various care organizations for people with intellectual disabilities, of which the latest years at 's Heeren Loo. From March 2013 she conducted her PhD research under the supervision of Prof. Dr. C. Schuengel. The results of this research are described in this dissertation. Currently she works as a postdoc researcher at the Collaborative Research Centre 'Intellectual Disabillities', 's Heeren Loo and Vrije Universiteit Amsterdam. She also works as a senior policy advisor at Advisium 's Heeren Loo where she develops and implements policy on involuntary care and other care-related themes.

Curriculum Vitae

Baukje Schippers (mei 1981) heeft veelzijdige ervaring in de zorg voor mensen met een beperking. Van 1999-2003 studeerde ze fysiotherapie aan de Saxion Hogeschool te Enschede. Tijdens deze studie werkte ze als begeleider in een woonvoorziening voor mensen met een niet aangeboren hersenletsel. Vervolgens werkte ze ook als fysiotherapeut voornamelijk met mensen met niet aangeboren hersenletsel. Vanaf 2004 studeerde ze pedagogische wetenschappen aan de Universiteit van Utrecht, een studie die ze afsloot in 2007 met de master Kinderrevalidatie – en gehandicaptenzorg. Tijdens deze studie werkte ze als begeleider van mensen met een auditieve beperking en mensen met een verstandelijke beperking en moeilijk verstaanbaar gedrag. Van 2007 tot 2013 werkte zij als orthopedagoog bij verschillende zorgorganisatie voor mensen met een verstandelijke beperking, waarvan de laatste jaren bij 's Heeren Loo Vanaf maart 2013 heeft zij onder leiding van prof. dr. C. Schuengel haar promotieonderzoek uitgevoerd. De resultaten van dit onderzoek zijn beschreven in dit proefschrift. Momenteel werkt ze als postdoc onderzoeker bij de Academische Werkplaats Verstandelijke Beperkingen, 's Heeren Loo en Vrije Universiteit Amsterdam. Tevens werkt ze als senior beleidsmedewerker bij Advisium 's Heeren Loo waar zij beleid ontwikkelt en implementeert omtrent onvrijwillige zorg en andere zorg gerelateerde thema's.

Publications

Schippers, B., Frederiks, B.J.M., Van Nieuwenhuijzen, M.,& Schuengel, C. (2018). Feasibility and reliability of full registration of restraints in care for people with intellectual disabilities: A study on reliability and implementation *Journal of Policy and Practice in Intellectual Disabilities, 15,* 202-213 doi: 10.1111/jppi.12252

Frederiks, B.J.M., Schippers, B., Huijs, M., & Steen, S. (2017). Reporting of use of coercive measures from a Dutch perspective. *Advances in Mental Health and Intellectual Disabilities*, 11, 65-73.doi: 10.1108/AMHID-11-2016-0039

Schippers, B., Van Nieuwenhuijzen, M., Frederiks, B.J.M, De Moor, M.H.M., & Schuengel, C. In search of factors associated with coercive care for people with intellectual disability: A multilevel analysis. Article in preparation.

Schippers, B., Van Nieuwenhuijzen, M., Frederiks, B.J.M, De Moor, M.H.M., Immers, D.M., & Schuengel, C. Multidisciplinary reduction of coercive measures for people with intellectual disabilities: A randomized trial. Article submitted for publication.

Huijs, M., Schippers, B., Frederiks, B.J.M., & Steen, S. (2017). *Doelgericht registreren in de zorg voor mensen met een verstandelijke beperking.* Amsterdam: VU/VUmc

The application and reduction of coercive measures is a compelling issue in the care for people with intellectual disabilities. Based on the right on self-determination, but also on the risks associated with some applications of coercive measures, there is general agreement on the need to phase out these measures. However, practice appears to be unruly. The structural phasing out of coercive measures appears to be difficult. This is partly due to the limited knowledge concerning the application of coercive measures and effective interventions to reduce these measures.

This research was based on a broad definition of coercive measures: any measure that restricts a person with intellectual disabilities in any specific situation. The results of the study are encouraging. It has shown that a multidisciplinary approach can lead to a significant reduction of coercive measures applied to persons with intellectual disabilities living in residential facilities. The research also showed that routine registration of coercive measures can be partly accurate. A reflection on the future criteria concerning the required registration as described in the Care and Coercion Act ('Wet zorg en dwang') shows that this will not necessarily lead to a reliable and uniform registration. In addition, the study has obtained information on the application of coercive measures and associated factors.

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