



Mediating the interface between voluntariness and coercion: A qualitative study of learning disability nurses' work in medical examinations of people with intellectual disability

Linn Ebeltoft Sparby MHS, PhD-Student^{1,2} | Nina Olsvold PhD, Associate Professor³ | Aud Obstfelder PhD, Professor⁴

¹Centre for Care Research, North, University of Tromsø, The Arctic University of Norway, Tromsø, Norway

²Department of ReHAbilitation, Finnmark Hospital Trust, Kirkenes Hospital, Kirkenes, Norway

³Faculty of Health, VID Specialized University, Oslo, Norway

⁴Department of Health Sciences in Gjøvik, NTNU, Gjøvik, Norway

Correspondence

Linn Ebeltoft Sparby, Finnmark Hospital Trust, Kirkenes Hospital, Department of ReHAbilitation, Kirkenes 9915, Norway.
Emails: linn.sparby@uit.no;
linn.ebeltoft.sparby@finnmarkssykehuset.no

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Abstract

Aims and Objectives: To gain knowledge of prevention and use of restraints in provision of medical care to people with intellectual disability. To this end, we explore how learning disability nurses in community services support the individual through medical examinations when facing resistance.

Background: Despite increased focus on limiting restraints, there is a lack of knowledge of how restraints are prevented and used in the delivery of physical health care to people with intellectual disability.

Design: We used an ethnographic comparative case design ($n = 6$).

Methods: The study was carried out in Norway. The analysis is based on data from semi-structured interviews, participant observation and document studies, in addition to health sociological perspectives on how to support individuals to make their body available for medical examination and intervention. The SRQR checklist was used.

Results: Learning disability nurses strove to ensure that examinations were carried out on the individual's terms, supporting the individual in three phases: preparing for the examination, facilitating the examination and, when facing resistance, intervening to ensure safe and compassionate completion of the examination.

Conclusions: Supporting the person was a precarious process where professionals had to balance considerations of voluntariness and coercion, progress and breakdown, safety and risk of injury, and dignity and violation. Through their support, learning disability nurses helped to constitute the "resistant" individual as "a cooperative patient," whose body could be examined within the knowledge and methods of medicine, but who could also be safeguarded as a human being through the strain of undergoing examination.

Relevance to clinical practice: The article sheds light on how restraints are used in the medical examination and treatment of people with intellectual disabilities and demonstrates the significance of professional support workers' contributions, both

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in facilitating safe and efficient medical care and in ensuring the least restrictive and most compassionate care possible.

KEYWORDS

challenging behaviour, intellectual disability, learning disability nursing, physical examination, primary care, restraint

1 | INTRODUCTION

For health professionals, it can be challenging to deal with situations where people with intellectual disability are actively resisting necessary medical examination and treatment (Heslop, Marriott, Hoghton, Jepson, & Noble, 2014; Moon & Graber, 1985). Intellectual disability is characterised by significant limitations in cognitive functioning and adaptive behaviour emerging during childhood (Emerson & Einfeld, 2011), and some individuals lack or have reduced capacity to make decisions about health matters (Goldsmith, Skirton, & Webb, 2008). Over the past decades, national and international policies, legislations and guidelines have been introduced to ensure the same range, quality and standard of medical care to people with intellectual disability as that provided to others, as well as to prevent and regulate the use of restraints (Hughes & Lane, 2016; UN, 2006). The principle of autonomy entails that health professionals should provide health care on a voluntary basis, based on the patient's understanding and consent (Beauchamp & Childress, 2009). The legal and ethical frameworks differ between countries, but current guidelines tend to emphasise that restraints should only be used, if at all, to ensure care to individuals who lack capacity to make decisions on the relevant health matter, and then only as a last resort in the person's best interest (Deveau & McDonnell, 2009; Heyvaert, Saenen, Maes, & Onghena, 2015). The use of restraints infringes on the individual's autonomy and may cause psychological and physical harm to the patient, the professional and their relationship (Heyvaert et al., 2015; Mérineau-Côté & Morin, 2014; D. W. Perry, White, Norman, Marston, & Auchoybur, 2006). Thus, when an individual is expected to resist necessary medical care, professionals face a dilemma. They either respect the individual's autonomy, and fail in their duty to provide care in accordance with the person's needs, or they respect their duty and risk harming the individual by using restraints (Mohr, 2010). Despite increased focus on the need to limit the use of restraints, there is still a gap in the research on how restraints are used, and indeed prevented, in medical care of people with intellectual disability (Sparby, Olsvold, Bogetun, & Obstfelder, 2016). Knowledge of what professionals actually do when expecting and facing a person's resistance to medical examination and treatment is important in order to succeed in limiting the use of restraints and enable professionals to deliver high-quality medical care in the least restrictive way possible.

What this paper adds to the wider global clinical community?

- The study advances our understanding of how restraints are prevented or minimised during medical examination and treatment of people with intellectual disability.
- In particular, the study provides insight into the importance of tailored and compassionate support in order to succeed in limiting the use of restraints, but also in preventing negative outcomes of restraint use.
- We recommend that health and learning disability professionals collaborate to balance and reconcile considerations for clinical work with the individual's need for support. This is vital in order to provide the least restrictive and most compassionate care possible and prevent the risk of injuries and violation.

1.1 | Background

People with intellectual disability tend to experience more health problems, but poorer access to medical health services (Alborz, McNally, & Glendinning, 2005; Backer, Chapman, & Mitchell, 2009; Krahn et al., 2006; Williamson et al., 2017). As a consequence, they are more likely than others to live their lives with unrecognised and unmet health needs (van Timmeren, van der Putten, van Schrojenstein Lantman-de Valk, van der Schans, & Waninge, 2016). Regular health screening in primary care is seen as an efficient means to identify unmet health needs (Baxter et al., 2006; Robertson, Hatton, Emerson, & Baines, 2014). However, from the perspective of professionals, ensuring some individuals' cooperation with medical examinations can be challenging (Kupzyk & Allen, 2019; Lennox, Diggins, & Ugoni, 1997; Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012). When accessing health services, many individuals with intellectual disability struggle to communicate their health needs and symptoms of pain and illness, to understand what is going on and to follow the doctor's instructions (Hart, 1998; Wullink, 2009; Ziviani, Lennox, Allison, Lyons, & Mar, 2004). For some individuals, sensory impairment or physical disability may put further strain on the ability to cooperate with the examination. Moreover, some individuals may feel anxious and hesitant to undergo the examination (Edwards &

Northway, 2011; Perry et al., 2014) or display challenging behaviour, such as aggression or self-injurious behaviour (Emerson & Einfeld, 2011). They may also experience lack of knowledge and failures of services to make reasonable adjustments (Ali et al., 2013; Tuffrey-Wijne et al., 2014), such as adapting communication or offering home visits. In turn, these matters may impede the doctor's possibility of carrying out a satisfactory health assessment as a basis for diagnosis and treatment, as well as jeopardising the safety of the examination (Lennox et al., 1997; Romer, 2009). Thus, in some of these cases, professionals use restraints to ensure safe and efficient examination and treatment (Bridgman & Wilson, 2000; Romer, 2009; Sparby et al., 2016).

People with intellectual disability are particularly vulnerable to restrictive interventions (Mérineau-Côté & Morin, 2013). The use of restraints, defined as any chemical, physical or mechanical means of controlling a person's behaviour (Rickard, Chan, & Merriman, 2013), is an ongoing concern in provision of social and physical care to people with intellectual disability (Newton, 2009; Sparby et al., 2016; Van der Meulen, Hermsen, & Embregts, 2016). Going to the clinic, many individuals with intellectual disability depend on support from family members or professionals involved in their everyday care, for instance learning disability nurses (Alborz et al., 2005; Manthorpe & Martineau, 2010). When the use of restrictive interventions is being considered, it is important to ensure that support is delivered in the least restrictive way possible. In this regard, provision of tailored support is of vital importance in facilitating the person's cooperation and preventing anxiety and challenging behaviour (Edwards & Northway, 2011; MacArthur et al., 2015; Slevin & Sines, 2005). Learning disability nurses have expertise in adjusting support to meet the needs of people with intellectual disability. When supporting a person with intellectual disability on a daily basis, they get to know the particular person well and gain extensive experience in how to tailor communication and interaction, as well as the physical surroundings. Thus, knowledge of how learning disability nurses work to support a person through a medical examination may be particularly useful in shedding light on issues of restraint use, and restraint prevention, in medical care delivery to people with intellectual disability.

1.2 | Aim

To contribute to our understanding of the prevention and use of restraints in provision of medical care to people with intellectual disability. To this end, we explore what learning disability nurses working in community services do to support individuals with intellectual disability during medical examinations when resistance is likely to occur. The study was conducted in Norway where learning disability nurses are licensed health professionals who have a bachelor's degree specialising in supporting individuals with disabilities. The research team consisted of a specialist learning disability nurse with broad clinical experience from local and specialist habilitation services and two general nurses/sociologists with broad social science research

and teaching background as well as clinical experience from general nursing. Empirically, we based our analysis on six ethnographic case studies of people with intellectual disability seen as resisting physical health care and their associated web of care. Theoretically, we draw on health sociological perspectives that shed light on the body and how professionals work to support a patient through medical examinations. These perspectives show that medical examinations of any patient require the individual to cooperate with the doctor and the context in specific ways, thereby letting his or her body become an object of medical attention. However, as completing a medical examination is a fragile process, professionals continuously work to support the individual, aiming both to ensure completion of the examination and to safeguard the individual's dignity (Gardner & Williams, 2015; Heath, 1986; Maseide, 2011; Strauss, 1985).

1.3 | The context

The empirical context for the study is Norway. As in many Western countries, health services have the main responsibility for giving medical care to people with intellectual disability, while day-to-day support is provided by community services. In situations where individuals with intellectual disability resist necessary medical care, legislation on restraint use in physical healthcare delivery is involved. In these situations, health professionals responsible for medical care delivery have authority to decide on the use of restraints when specific legal requirements are met. In such cases, they mainly have to consult with the patient's closest relatives and, when using intrusive strategies, other relevant professionals. Learning disability nurses in community services have no formal role in decision-making on restraints in medical care, but as they often assist the individual when accessing health services, some will become involved in situations where restraints are used.

1.4 | Theoretical framework

Since the era of Hippocrates, medicine has had an aspiration to devote itself to treating disease (Fox, 2012). To pursue this aspiration, doctors have to work on the patient's body. The purpose of any kind of medical examination is to record and measure in a reliable way the patient's bodily state, functioning and capacity (Maseide, 2011), with the aim of diagnosing and treating disease. Medicine operates with at least two conceptions of patients' bodies: the natural "objective body" and the subjective "social body" (Maseide, 2011). The typical focus of medicine is the natural, *objective body*, composed of biological entities (Freidson, 1970/1988; Maseide, 2011). However, the patient is not just a natural body, but also a person or *social body* who experiences the examination and is expected to cooperate with the doctor (Maseide, 2011). In order to allow medical work to be carried out, many medical procedures presuppose that the objective body is "separated" from the social body, through so-called "separation practices" (Harré, 1991), such as the use of the "clinical gaze" (Foucault, 1973, in Maseide, 2011), professional

body techniques and anaesthetics (Maseide, 2011). The separation of the social body from the objective medical body *transforms* the patient into a clinical object suitable for medical investigation and knowledge production (Heath, 1986; Maseide, 2011).

In general terms, giving and receiving medical care involve effort from both the patient and the health professional. In order for the doctor to make a diagnosis, the patient has to be able and willing to *cooperate* with the doctor's efforts (Maseide, 2011; Parsons, 1964). In this regard, the nature of medical procedures often requires the patient to communicate with the professionals, accept "hands-on" examination and to be examined with technological equipment (e.g. gastroscopy). While some procedures require the patient to actively move and position the body or body parts, other procedures require the patient to cooperate passively, by lying or sitting still (Maseide, 2011). To allow oneself to be examined by a doctor requires trust, and mental as well as physical effort. The patient has to be able to endure painful, sometimes frightening and discomforting examinations while restraining impulses to scream or pull the body away (Strauss, 1985). In turn, by taking control of their bodies and behaviours, patients temporarily render themselves as disciplinary objects for medical work (Heath, 1986). However, leaving control over one's body to health professionals can occasionally be challenging for all patients. Thus, in order to ensure continued cooperation during the examination, health professionals direct attention to the individual as a social body. In doing so, they do what Strauss and colleagues term *sentimental work* (Strauss, 1985), negotiating the patient's acceptance of the medical procedures by establishing trust, informing the patient what is going on, giving comfort and helping the person to keep calm and composed. Typically, when negotiating with the patient, clinicians work to safeguard the patient's autonomy by continuously navigating shifts in consent and, if necessary, altering the course of the examination trajectory, for instance by modifying pace and direction. Thus, they work to guide the patient towards a "dual goal," always directed towards completing examinations, but also letting the patient experience control within a respectful consultation (Cook & Brunton, 2015).

2 | METHOD

2.1 | Study design and participants

This study was part of a larger ethnographic study exploring prevention and use of restraints in physical healthcare delivery to people with intellectual disability. A comparative case study approach was employed as this allows detailed investigation of social processes within context, using multiple sources of data (Hartley, 2014). In order to explore professionals' challenges in both depth and scope, we sought to include individuals with intellectual disability who tended to resist health care and who had different abilities to make health decisions. Each case included an individual with intellectual disability and an associated web of care: a relative/legal guardian, a learning disability nurse/support worker, and the local policy framework. Two cases included doctors, one case included a dentist, and

several cases included support unit managers and various support workers. The intellectually disabled individuals were recruited in cooperation with local and specialist habilitation services, health authorities and user organisations. Local learning disability nurses, familiar to the individual, provided information and obtained written consent from relatives or guardians, and the individuals themselves if possible. Further, they selected relevant informants and arranged interviews and observations in relation to each case.

The individuals with intellectual disability participating in the study, five men and one woman, were aged between 29–48 and had complex and continuing health and social care needs. They were diagnosed with profound/severe (4) or moderate/mild (2) intellectual disability, various genetic syndromes or developmental disorders, and were considered as displaying challenging behaviour. All individuals had various physical, mental and/or behavioural health issues, such as epilepsy, diabetes, reflux, chronic constipation and depression. The individuals lived in supported living units, receiving varying degrees of support.

2.2 | Data collection

Data were collected by semi-structured interviews, participant observation and reading of relevant documents. The first author, who is a specialist learning disability nurse, was present in the supported living units for up to five days. During this time, she conducted interviews and field conversations and made observations of interactions between individuals with intellectual disability and support workers, and read relevant documents, such as local procedures for health supervision and restraint use. Interviews and field conversations were conducted according to interview guides with individuals with intellectual disability, relatives and professionals. With intellectually disabled individuals, the first author conducted field conversations as considered appropriate and conducted an interview with one participant who gave informed consent. For this interview, in order to ensure understanding and voluntariness, the first author tailored communication (Cambridge & Forrester-Jones, 2003) and encouraged the person to signal "pause" or "stop" with a red card if wanting a break or to terminate the interview. All recorded interviews were transcribed in full. Observations were made in everyday situations, oriented towards mapping ongoing interactions in context. Due to ethical reasons, observations were not made during medical examinations as this was considered to involve too much strain on the individual. Data from other observations, interviews and documents, along with the researchers' experience from similar situations, provided the basis for analysis of the support work.

2.3 | Data analysis

The data analysis was inspired by Tjora's (2019) stepwise deductive inductive strategy. First, interview transcripts, memos and observation logs were read individually and, as a whole, focusing on gaining a general impression of how learning disability nurses worked.

Next, the textual material was coded using codes textually close to the data. These codes were subsequently categorised into themes and further analysed by drawing on sociological concepts (Heath, 1986; Maseide, 2011; Strauss, 1985). The analysis proceeded in an iterative manner, moving back and forth between the research question, texts and theory. Comparative analysis between the case study narratives generated themes that cut across cases. To ensure rigour, the first author regularly discussed interpretations of the data with the co-authors. Further, to maintain a reflexive approach, the first author either recorded or wrote her reflections on the research process and discussed these with the other authors. These discussions also proved valuable to deal with emerging research ethical issues.

2.4 | Ethical considerations

The study was approved by the Regional Ethics Committee of Northern Norway. In a research context, people with intellectual disability are considered a vulnerable group, and researchers should ensure adequate protection (WMA, 1964). The research protocol included a separate plan for managing research ethical concerns, which outlined detailed procedures for recruitment, information, capacity assessment and consent. Accordingly, the researchers aimed at ensuring a responsible research ethical practice throughout the planning, execution and presentation of the study (Guillemin & Heggen, 2009). In the article, all informants have been anonymised and given pseudonyms. The Standards for Reporting Qualitative Research (SRQR) checklist was used to guide the construction of this article (see File S1).

3 | RESULTS

When supporting a person with intellectual disability through a medical examination, learning disability nurses strove to ensure that the examination was conducted on the individual's terms as much as possible. This was considered imperative in order to ensure that the examination would succeed, and proceed with minimum restriction and maximum care and consideration. In doing so, they focused on *arranging a suitable examination setting* and *providing direct assistance* in ways that could allow completion of the examination, primarily based on voluntariness, but also, if necessary, by use of restraints. The work proceeded in three phases (see Table 1). First, before going to the clinic, learning disability nurses made preparations to facilitate the upcoming examination. Second, during the visit to the clinic, they worked to facilitate an examination based on voluntariness. Third, when facing the individual's resistance, they intervened to ensure completion of the examination in the safest, least restrictive and most compassionate way possible.

3.1 | Preparing for the examination

Learning disability nurses knew from experience that the individual's arrival at the clinic and the doctor's attempts to make an

examination could cause anxiety, distress and resistance. Thus, *before going to the clinic*, they *prepared* for the examination, aiming to achieve the individual's cooperation. Planning ahead was necessary to ensure that the examination could proceed on the individual's terms as much as possible. This was considered crucial in order to succeed with the examination, but also to prevent any use of restraints that otherwise might be necessary. The preparations consisted of two elements: *encouraging adjustments of the examination setting*, and *informing and preparing the individual* before the examination.

3.1.1 | Encouraging adjustments of the examination setting

Learning disability nurses in leadership or contact roles attempted to arrange the examination setting to fit the particular individual's needs and to promote the person's coping with the stressful situation. In doing so, they focused on *support workers' assistance to the individual*, *the physical examination context*, and *the doctor's examination strategy*. First, when planning how to assist the person at the clinic, they assigned personnel, arranged transportation and discussed how best to proceed. In order to succeed with the examination, it was especially important that the individual was accompanied by experienced personnel who knew him or her well. This was confirmed by Jenny who appreciated being supported by familiar staff:

Jenny says that she prefers being accompanied by the contact nurse. She used to be hesitant about examinations, but after being accompanied several times by the contact nurse, she feels calmer and sometimes chooses to attend a consultation by herself, particularly for dental checks.

From the first author's field notes.

The accompanying personnel had to be competent in giving practical and emotional support to enable the person's cooperation on his or her own terms, but also needed to be able to deal effectively with any resistance or challenging behaviour that could jeopardise the examination:

In these situations, it's very important that only people who know Frank accompany him. Then he will usually feel more secure. Those of us who know him, we know how to relate to the situation at hand, what's important in order to succeed. So I think that's crucial. That is, if you don't know him, it will take a lot to succeed.

Carl, learning disability nurse employed as primary support worker.

Often, the person was assisted by one or more learning disability nurses or support workers who knew the person and his or her health situation well. However, some individuals could sometimes be assisted

TABLE 1 The learning disability nurses' support work when facing the individual's resistance

Themes	1. Preparing for the examination	2. Facilitating the examination	3. Intervening to ensure safe and compassionate examination and treatment
Indirect support	a. Encouraging adjustments of the examination setting	a. Coping with the examination setting	a. Managing the examination setting
Direct support	b. Informing and preparing the individual before the examination	b. Assisting the individual during the examination	b. Restraining and safeguarding the individual

by newly hired or temporary staff with little knowledge of the person's needs and what was required to succeed.

Secondly, it was important that the *physical context of the examination* was adjusted in particular ways to prevent anxiety and challenging behaviour and facilitate cooperation. For some, this could imply that the doctor attempted to conduct minor check-ups in the individual's home environment. When the person needed to go to the clinic, the context could be adjusted by estimating longer consultation time, minimising waiting time or offering alternative entrances, examination rooms or waiting areas. For some, this could even imply that the doctor's instruments needed for the examination had to be concealed or removed:

We'll let the doctor know: it's best if you don't wear glasses and remove your watch, pens, scissors and that stethoscope that dangles around your neck. Because John will just touch and throw those things away.

Jill, learning disability nurse/manager.

Thirdly, the doctor's *examination strategy* could either facilitate or hinder the individual's cooperation with the examination, requiring professionals to make adjustments in their interaction. In this regard, the nurses emphasised taking time and communicating in plain language directly to the individual, or for some, keeping a distance or being careful when touching. Suitable adjustment to prevent challenging behaviour and meet the person's needs could be crucial to succeed with the examination and to ensure the safety of the individual, professionals and medical equipment:

The learning disability nurses have told me not to use too much physical force or try to hold him. You have to talk carefully and steer him gently into the examination room and down into the dental chair. If you use force and try to restrain him, he will hit you right back. He will stop cooperating, and you won't get him into the chair.

Christopher, dentist.

3.1.2 | Informing and preparing the individual before the examination

Before going to the clinic, the learning disability nurses *informed and prepared the individual* about the upcoming examination, aiming to

ensure the person's cooperation in going to the health facility and undergoing the examination. Giving information was crucial in order to succeed with the examination. Information had to be tailored and given in a way the person could understand. As these individuals often appeared anxious, the nurses tried to reassure, motivate and persuade them, sometimes making promises about subsequent rewards. It was considered important, but difficult or even impossible to ensure that some of them understood. For some, information had to be given particularly carefully and was sometimes even withheld in order to ensure the examination. Just being told what was going to happen could be enough to provoke panic, and the attempt to go to the clinic could break down even before leaving home, as this nurse's account shows:

It's hard because when Frank realizes we're going to the clinic, he won't even get in the car. So, should we avoid telling him where we're going? Should we at least try to drive there and see if he comes along inside or not? But that isn't quite right. The right thing to do is to inform him about what's going on, but as soon as he knows, he won't come along. So that is a dilemma.

Anna, learning disability nurse employed as primary support worker.

3.2 | Facilitating the examination

At the clinic, the learning disability nurses focused on ensuring that the examination could proceed on the individual's terms as much as possible and attempted to give support based on voluntariness, aiming to help the individual to cope with the examination. Despite their preparations, it was difficult to anticipate how the person would cope with the stressful situation in the unfamiliar surroundings of the clinic. Therefore, during the visit at the clinic, the nurses continuously monitored and took account of the health professional's approach, the physical context and the individual's reactions. This was considered crucial in order to ensure that the examination could take place on the individual's terms and to limit or prevent any use of restraints. The work to facilitate the examination at the clinic consisted of two elements: coping with the examination setting and assisting the individual during the examination.

3.2.1 | Coping with the examination setting

The clinic was a context of narrow corridors, crowded waiting areas, uniformed personnel, busy time schedules and unfamiliar practices, equipment, sounds and smells. In these surroundings, the person could become increasingly distressed, for instance when waiting for extended periods of time in crowded and noisy waiting rooms, when locating the right place for the examination or when being exposed to frightening medical equipment in the examination room or laboratory. It could be difficult to achieve the necessary adjustments to meet the individual's needs, and unforeseen delays and changes could occur. Although the learning disability nurses attempted to address these issues as they occurred, the individual's cooperation for the examination could easily break down, sometimes even before entering the examination room:

We get there, and I know Peter can't wait in the waiting room for two hours. When he arrives, everything has to be ready. Otherwise, he turns the waiting room upside down. But that's how it turned out the last time as well. He repeats 'home, home' and 'done, done', and this keeps on escalating.

William, teacher employed as primary support worker.

The possibilities of making adjustments were also limited by considerations of the doctor's examination and diagnostic work. The adjustments of procedures, equipment use or localities considered necessary to ensure the person's cooperation could not always be made without compromising the doctor's possibilities of performing the examination in a safe and responsible manner. For instance, the doctor could not always draw on routine procedures or equipment such as blood pressure monitors, stethoscopes or X-ray machines. In turn, this could limit the likelihood of reaching a correct diagnosis as a basis for treatment decisions:

I never get to talk to him, and I barely get to examine him because he resists any kind of handling. Listening to his chest sounds and so on, that's never completed in the [regular] way. I can't ask him to do exercises included in diagnostic procedures. For instance, if you want to examine a neurological condition, you tap reflexes, you ask the patient to raise their right hand, left hand, close their eyes tightly and so forth. It's not just that he resists, but he doesn't have the ability to cooperate in this way. And that means that you don't succeed with the examination.

Harold, doctor.

3.2.2 | Assisting the individual during the examination

In the examination room, the learning disability nurses worked to assist the person in the interaction with the doctor. Typically, the

doctor took the lead by giving information and trying to proceed with the examination, by asking questions, telling what to do, looking, touching and using medical equipment. Some examinations required the individual to sit or lie still, while others required more active cooperation, like breathing in and out, opening the mouth or raising the hands. For some, medical procedures could be performed in a more routine manner, while for others, doctors had to make ongoing adjustments of procedures, for instance by working faster, keeping a distance or refraining from touching the person or using equipment. During the examination, the nurses provided cognitive, practical and emotional support to help the person to understand and cooperate in accordance with the doctor's instructions. Typically, they explained what to do, guided the person to move and position the body and offered emotional support to prevent panic and to ensure that the person stayed calm and composed during examinations, by reassuring, comforting and encouraging the person to keep going.

We talk all the time, and it's good if we repeat: 'Now the doctor has said [what to do]. It's not going to hurt. You won't feel it'. Sometimes, my arm has been stiff because it takes time, and he wants you to hold him exactly this way or that. He needs some security when he feels so insecure.

Jill, learning disability nurse/manager.

All through the examination, the nurses had to be alert to the person's reactions and prevent the person from interfering with the examination or risking the safety of the person, professionals or medical equipment. Aiming for their support to be based on voluntariness and on the individual participating on his or her own terms, the nurses had to give room for the individual's particular way of coping with the situation, but always had to monitor and be ready to control the person's actions:

We aim to manage the examination without any use of restraint and ensure that it proceeds on his own terms. So we have to control what's going on, but also allow him to keep on doing his own things.

Fred, learning disability nurse/assistant manager.

Sometimes, the professionals' joint efforts resulted in a successful examination, often after considerable adjustment to meet the individual's needs. However, even when skilfully tailored, the efforts to ensure the individual's acceptance of the medical examination could risk breaking down. In these cases, the doctor and the learning disability nurses had to decide whether to accept the individual's refusal or resistance and cease further attempts at examination - or to proceed despite the individual's resistance.

When it's something he really doesn't want to do, he becomes agitated and rips his clothes off, and sends a clear message that he doesn't want this. We had to terminate. (...) We had to calm down and say 'we're

not going to the doctor after all. We understand that you don't want this, and we'll go back home as soon as you're calm.'

Magnus, learning disability nurse/assistant manager.

3.3 | Intervening to ensure safe and compassionate examination and treatment

When an individual's health was at stake, and examinations risked failing, or had actually failed, it was more urgent for everybody involved to safeguard the individual's health and ensure completion of the examination, diagnosis and often treatment. The individual could be ill, injured or in pain. In order to be sure to succeed in safely providing necessary medical care, professionals now took *more control* over the conditions surrounding the examinations, as well as over the individual's behaviour. When a decision was made to conduct examinations despite the individual's resistance, the learning disability nurses strove to ensure that this was done in the safest, least restrictive and most compassionate way possible. The work consisted of two elements: *managing the examination setting*, and *restraining and safeguarding the individual*.

3.3.1 | Managing the examination setting

Aiming to ensure completion of medical care, professionals put in a great effort to arrange particular conditions for the examination that could prevent, but also overcome, the individual's resistance. For some minor check-ups, they decided to use the supported living unit as the site for the examination, for instance in an office or in the individual's bed or favourite chair. Being in a familiar environment could ease the emotional strain for the individual, but it was also easier for professionals to ensure a safe examination. Occasionally, the physical context was modified specifically to overcome the individual's resistance in order to ensure the examination, but also to enable that the examination could be done in a safe and compassionate way with minimum restriction.

In order to ensure safe transportation, John's vehicle was fashioned with seatbelts and doors he could not open by himself, and 'unbreakable glass' in the windows. This vehicle was occasionally used by the doctor or laboratory workers to ensure safe blood sampling. Whereas use of manual restraint could lead to aggression and injuries, being strapped in the seatbelts and held by his arms, John was calmer and unable to cause harm.

From the first author's field notes.

It was not always possible to arrange conditions at home or at the local clinic that could adequately ensure examination and treatment in a safe and responsible way. More extensive, specialised medical examination and treatment had to be done at the hospital,

often under general anaesthesia. These interventions required the presence of certain specialists and equipment, technology and infrastructures. Learning disability nurses often requested necessary adjustments and that various medical and dental examinations and treatments were coordinated and done under the same anaesthesia, aiming to facilitate treatment and minimize strain. However, it was up to health professionals to plan for hospitalisation and interventions, and learning disability nurses often had to accept and make the best out of conditions considered to be extremely challenging for the individual.

3.3.2 | Restraining and safeguarding the individual

When facing the individual's resistance, restraints could be decided upon and used either in ad hoc manner in emergency situations, or as a result of detailed planning after previous failed attempts to provide care. Typically, professionals drew on three main strategies to circumvent or overcome the person's resistance to the examination: holding or manually restraining the individual, oral sedation and general anaesthesia.

Generally, manual restraints were used only with individuals with severe intellectual disability, typically for minor examinations or blood sampling, but also to prevent harm in emergency situations. The learning disability nurses usually held the individual, typically by the arms, while the doctor performed the medical procedure. Restraining the arms hindered the person from moving in unwanted ways, removing equipment, leaving or causing harm to self, others or expensive equipment. The use of manual restraints raised moral concerns. Although it could ensure the safe and efficient completion of the examination, it could also result in escalation of panic and aggression. In turn, this could compromise safety and lead to increased use of force or the failure to perform the examination in a responsible way. When restraining the person, it was of key importance to remain in control, but also use minimum force. For the individual, being restrained was clearly stressful, and the examination could easily turn into violation. In order to minimise discomfort and ensure compassionate use of restraint, it was crucial to help the person understand and cope emotionally with the situation, for instance by comforting and encouraging the person, and explaining the necessity of the use of restraint to safeguard his or her health.

You don't always succeed in doing examinations voluntarily. Sometimes, you just have to say: 'Now I have to hold your hand, John, until this is over. You'll feel a little prick. You've done this before a lot, but I'll hold your hand tightly, and you can pinch me.'

Jill, learning disability nurse/manager.

Another way of trying to circumvent or overcome resistance was to give oral sedatives to the individual prior to examination or surgery. The goal of oral sedation is to produce a lightly sedated, relaxed,

more cooperative patient that is easier to manage (Appukkuttan, 2016). Sedatives were sometimes prescribed by the doctor, or more commonly by dentists, and administered by the learning disability nurses before examinations. The nurses considered sedatives gentler for the person, but nevertheless a form of restraint. For individuals with mild intellectual disability, sedatives were only used in agreement with the individual. For those with severe intellectual disability, the nurses occasionally concealed the medicine in favourite food to prevent the person from spitting it out, often causing ethical concerns. However, the medication did not always work as intended in helping the person to cooperate with the examination. The effect was uncertain, and some individuals did not calm down, but became agitated or fell asleep, jeopardising the safety of the examination and the individual's dignity:

After several failed attempts to go to the dentist, he got a drug that we should give him before consultations. However, the first attempt failed: he got the pill, but got so tired that he couldn't get out of bed. The second attempt succeeded, and he could sit in the chair for a couple of minutes. But then his patience ran out, and there was no point in making him sit there any longer. Because then he acted out.

Anna, learning disability nurse employed as primary support worker.

In many cases, particularly for those with severe intellectual disability, hospitalisation and the use of general anaesthesia were required to ensure the safe and efficient completion of more specialised and invasive examination and treatment. However, provision of these interventions at the hospital could be problematic. For the individual, being at the hospital could be confusing and frightening, and learning disability nurses took action to reassure the individual by giving information and comfort, and for some, giving sedatives. Despite this, at the hospital the individual often became increasingly confused and anxious, and professionals could struggle to get the person ready for examination or surgery. In such cases, several of the nurses had been involved in restraining the person while health professionals administered anaesthesia. In these often chaotic situations, they kept trying to help the individual:

When he was about to have general anaesthesia, he got very anxious and tried to get away. So we had to hold him, all of us, including the doctors, and those who knew him best tried to have contact with him and keep him calm so that the doctors could give him an injection or mask to get him under anaesthesia.

Carl, learning disability nurse employed as primary support worker.

After the use of restraint, the nurses often took further steps to support the individual, by attempting to address and rectify the

emotional and relational damage that followed the use of restraint in examination and treatment:

When Peter has been under general anaesthesia, he shouts a lot and clings to us. He enters the hospital voluntarily, but he resists having the mask put on, and we have to hold him until he falls asleep. Afterwards, we've tried to explain why we do this to him. He's frustrated and angry. And that's fully understandable after what we've done to him.

Ada, sister/learning disability nurse.

4 | DISCUSSION

The transition from subjective personhood into a clinical object for medicine can be challenging for any person. For people with intellectual disability, the process can be even more challenging as many may struggle to communicate, understand what is being said and cooperate as the doctor expects (Wullink, 2009; Ziviani et al., 2004). When an individual is ill, in pain, anxious or confused, the process of undergoing examinations may be *unbearable*. Supporting people with intellectual disability expected to resist examination, learning disability nurses attempted to help them to cope with this strenuous process to enable them to render their body accessible for examination. In doing so, they strove to ensure that the examination was accomplished on the particular individual's terms as much as possible. In this regard, they tried to tailor examination strategies and contexts, and to assist the individual in ways that could enable voluntary cooperation with the examination. As research shows, it can be difficult to anticipate and meet each individual's needs for adjustments and support (Tuffrey-Wijne et al., 2014). Despite the nurses' attempts to encourage an examination on the individual's terms, it was highly uncertain whether they would succeed in their efforts, and whether the individual would manage to undergo the examination or not. Sometimes, the individuals accepted the doctor's examination, while on other occasions, the clinical work would break down and become "disarticulated" (Strauss, 1985).

In response to their difficulties in safeguarding the individual's health, professionals often, either planned or as an emergency response, decided to draw on increasingly restrictive physical and chemical interventions, aiming to progress with the examination and to ensure the safety of the individuals themselves, clinicians and medical equipment. Accordingly, the learning disability nurses did not merely work to ensure voluntariness, but also participated in the use of restraints to overcome resistance and prevent the individual from interfering with medical interventions. The nurses acknowledged the necessity of restraint to safeguard the individual's health, but also questioned whether more could have been done to avoid use of restraints. Their participation in restraint use caused moral concerns, particularly about the strain and risk of trauma this could involve for the individual (Heyvaert et al., 2015). In these pressing

situations, the nurses emphasised the importance of *the way* restraints was carried out. While some ways could be respectful and preserve the individual's dignity, other ways could result in trauma, humiliation and breaches of trust. Thus, when involved in restraint use, learning disability nurses attempted to address the individual to promote understanding and coping, both during restrictive interventions and afterwards. This could be seen as attempts to make restraints acceptable to the individual (Van der Meulen et al., 2016) in order to proceed with the examination, but also as taking action specifically to prevent, limit and rectify any physical, emotional and relational damage.

In order to complete a medical examination and reach a diagnosis, the doctor needs a "cooperative patient" (Maseide, 2011) as well as a suitable "diagnostic space," a physical context arranged to facilitate the diagnostic work (Gardner & Williams, 2015). Research emphasises the importance of individualised support to ensure cooperation on examinations (Edwards & Northway, 2011; MacArthur et al., 2015). Both when preparing for, and during, the examination, the learning disability nurses attempted to give direct support and to encourage doctors to adjust and align their medical knowledge, practices and spaces to the individual. By doing so, they aimed to prevent anxiety and resistance from occurring at all and to prevent a sequence of behaviour from escalating into aggression (primary and secondary prevention, see Harris, Cornick, Jefferson, & Mills, 2008). There was no clear point at which restraints were initiated. Rather, this depended on the efforts from everybody involved to exhaust the possibilities of support strategies and person-centred adjustments of the examination practices and contexts. When medical interventions failed, this often seemed to be the result of a seemingly unbridgeable *gap* between the knowledge, practices and physical spaces necessary to prevent resistance and enable the individual's cooperation, and those necessary to enable the doctor's diagnostic work. A sociological perspective on the body and healthcare work allows us to shed light on the use of restraint in this situation. From this perspective, professionals' use of preventive strategies and subsequent use of physical and chemical restraints could be seen as various "separation techniques" (Harré, 1991). These techniques worked in increasingly efficient ways to "bracket" the individual's resistant social body, thereby making the natural, objective body available for medical examination and diagnosis. Thus, for professionals, the use of restraints ultimately made the individual into an often pacified "cooperative patient" who could be successfully examined within the context of the clinic or general hospital. In this way, the use of restraints helped to bridge the gap between the individual's and the doctor's need for support to accomplish the examination, aligning the individual with a medical approach.

While the doctor's main focus was generally to examine, diagnose and treat disease in the *objective body*, the learning disability nurses attended to the individual as a *social body* to give support through the hardships of the examination. In doing so, they supported the person *indirectly* by trying to make suitable arrangements of professionals, strategies and spaces, in other words facilitating a "diagnostic space" (Gardner & Williams, 2015) and *directly* by helping

the person to understand what was going on, to practically position the body as requested (*body positioning work*), by helping the person to stay calm (*composure work*) and by helping the person to deal with pain and restraint use (*comfort work*; Strauss, 1985). The support work was played out over time as a process: from the initial preparations (preparatory work, Heath, 1986), proceeding with the ongoing support provided during the examination and ending with the *rectification work* (Strauss, 1985) after the examination to restore any physical, emotional and relational damage caused by the process. By attending to the social body, the nurses worked to *mediate* between the doctor and the individual (MacArthur et al., 2015; Slevin & Sines, 2005). When doing so, the nurses always had to take into consideration both the doctor's need for a cooperative patient and a suitable "diagnostic space" to succeed with the examination, and the individual's needs for settings and practices that could help him or her to cope. This placed great demands on the nurses' support of the individual, particularly when using restraints. Thus, to deal with these sometimes conflicting considerations, they strove towards a "dual goal" (Cook & Brunton, 2015); they continuously had to balance and reconcile considerations for progress in the medical work on the natural body with considerations for the autonomy and well-being of the individual as a person or social subject. Moreover, when using restraints, they intensified the work to protect the individual, aiming to minimise discomfort and ensure the most compassionate care possible, as is evident in this statement from a learning disability nurse: "You don't always succeed in doing examinations voluntarily. Sometimes, you just have to say, 'Now I have to hold your hand, John, until this is over'."

4.1 | Limitations

Case study design is criticised for relying on small samples, thus having limited possibilities to make generalisations (Hartley, 2014). Our interpretations rely on detailed examination and comparison of cases, as well on theoretical perspectives on the body and healthcare work directed towards any patient, regardless of diagnosis or disability. Thus, we maintain that our interpretations allow for *analytical generalisation* and may be characteristic of, and transferable to, similar cases and processes (Tjora, 2019).

5 | CONCLUSION

The overall aim of this article is to improve our understanding of prevention and use of restraints in provision of medical care to people with intellectual disability. Drawing on health sociological perspectives on the body and healthcare work, this article demonstrates how learning disability nurses in community services support individuals with intellectual disabilities through medical examinations in the face of resistance. To support the anxious and hesitant individual through medical examinations is a precarious process, and the boundary between voluntariness and coercion can be unstable and

blurry. The work can all too easily break down, resulting in delays in treatment, the use of increasingly restrictive strategies, and risk of harm and violation. By supporting the individual, learning disability nurses helped to constitute a “cooperative patient” and a suitable “diagnostic space” (Gardner & Williams, 2015), thereby also facilitating the doctor’s work to provide a safe and responsible examination. However, in doing so, the nurses faced continuous and contradictory demands of rendering the individual’s body as a medical object while retaining the integrity and dignity of the person (Heath, 1986). We suggest that when supporting the “resistant” individual, the nurses worked to mediate “the interface between voluntariness and coercion,” always having to juggle and balance multiple and often opposing considerations: voluntariness and coercion, progress and breakdown, safety and risk of injury, dignity and violation. When working at this challenging interface, learning disability nurses help to ensure that examinations proceed on the individuals’ terms as much as possible. In doing so, they take an important role in ensuring the least restrictive and the most compassionate care possible.

Professionals’ use of restraints in medical care of people with intellectual disabilities is problematic in a human rights perspective. In this article, we have not considered all ethical or legal aspects of these practices, but have instead focused on the situational and relational character of the work to provide medical care and the use of restraints in this context. This should not be seen as an attempt to trivialise the use of restraints or idealise professional practices. Rather, our analysis should be seen as a way of highlighting the practical dilemmas and complexity of the work professionals undertake, as they strive to realise human rights for this vulnerable group of people, aiming to ensure quality and equal access to health care, but also to prevent and minimise restrictive practices. We do not pretend to have any final answers to the challenges that arise in everyday medical practice regarding how to ensure medical examination and treatment in the face of resistance. Indeed, we do not believe that a definitive answer is possible. Nevertheless, we hope that our analysis may be thought-provoking and helpful for stakeholders in ensuring access to quality medical care for this group of patients and arranging for gentle and minimally restrictive examinations. We recommend that professionals in health and community services, along with specialist teams and facilitators if available, collaborate to balance and reconcile considerations for medical work with the individual’s need for cognitive, practical and emotional support. This is vital in order to enable necessary medical examination, diagnosis and treatment in the least restrictive and most compassionate way possible.

6 | CLINICAL RELEVANCE

The article provides insight into the support work done at the interface between voluntariness and coercion, and thereby advances our understanding of prevention and use of restraints in medical care of people with intellectual disability. Knowledge of these practices may prove valuable to ensure efficient and safe delivery of health care,

but also to ensure the least restrictive and most compassionate care possible.

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CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

ORCID

Linn Ebeltoft Sparby  <https://orcid.org/0000-0002-3765-3465>

Nina Olsvold  <https://orcid.org/0000-0002-3297-6943>

Aud Obstfelder  <https://orcid.org/0000-0001-8263-6560>

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SUPPORTING INFORMATION

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