Journal of Policy and Practice in Intellectual Disabilities

Journal of Policy and Practice in Intellectual Disabilities doi: 10.1111/jppi.12399

The Use of Restrictive Measures in Community Services for People With Intellectual Disabilities in Sweden

Petra Björne[*,†], Roy Deveau[‡], Peter McGill[‡], and Lena Nylander[§,¶,‖]

*Department for Disability Support, Malmö, Sweden; †Department of Clinical Sciences, Lund University, Lund, Sweden; ‡Tizard Centre, University of Kent, Canterbury, UK; §Department of Clinical Sciences/Psychiatry, Lund University, Lund, Sweden; ¶Gillberg Neuropsychiatry Centre, Institute of Neuroscience and Physiology, Sahlgrenska Academy, Gothenburg University, Gothenburg, Sweden; and ‖VUB-Team, Psychiatric Clinic, Lund, Sweden

Abstract

Background: Community services for Swedish people with intellectual disability (ID) are intended to support self-determination and integrity. Legislation does not allow the use of restrictive or coercive measures.

Aim: The aim of this study is to identify the extent of, rationale for, and strategies staff believe would reduce the use of restrictive measures in group homes and daily activities services for people with ID.

Method: A survey was sent to all staff in group homes and daily activities in one large Swedish municipality. The survey comprised four Likert style questions and one free text question, addressing the type of and reasons for restrictive measures, and how much staff value their replacement. A total of 250 surveys were completed.

Results: A third of staff reported that some restrictive measures were used daily or weekly, primarily to protect and support service users. Adequate numbers of staff, better service design, and training were considered necessary for change.

Conclusion: Staff report structural reasons, such as staffing, resources time, lack of training, and supervision for using restrictive measures. Staff see reducing the use of restrictive measures as requiring structural changes with engagement from the whole organization.

Keywords: community services, intellectual disabilities, policy, practice, restrictive measures, staff

Introduction

In services for people with ID, the use of restrictive measures, including coercion and restraints, is prevalent, especially when behaviors are perceived as challenging (Mérineau-Côté & Morin, 2013; Webber, McVilly, & Chan, 2011). Reducing the use of restrictive measures is a human rights issue (Karim, 2014).

Good leadership within organizations and services appears to be associated with less use of restrictive measures (Stubbs et al., 2009). Leadership focused upon providing good quality care and reducing restrictions is required at all levels in an organization, including strategic senior levels (Deveau, Gore, & McGill, 2020) and frontline practice leadership (Deveau & Leitch, 2020; Deveau & McGill, 2016).

The use of restrictive measures has a significant negative impact on the quality of life of people with ID (Heyvaert, Saenen, Maes, & Onghena, 2015; MacDonald, McGill, & Deveau, 2011; Mérineau-Côté & Morin, 2014) as well as on staff well-being (Mérineau-Côté & Morin, 2014) and can cause injuries (Williams, 2009). People with ID might experience a physical intervention as being punished, although the intentions of staff were to protect the person from harm (Fish & Hatton, 2017). Panic, fear, and lack of power are feelings connected to physical interventions, which might lead to increased challenging behavior (Hawkins et al., 2005; Lambrechts et al., 2008; MacDonald et al., 2011; McGill, Murphy, & Kelly-Pike, 2009; Sanders, 2009). Service users who have been exposed to physical interventions might be traumatized (Hughes et al., 2019; Wigham & Emerson, 2015).

Preventing and replacing restrictive measures with other forms of support seems likely to require organizational engagement, such as managers providing practice leadership to support staff, and a continuous focus on quality development. Every instance of the use of restrictive measures must be analyzed, and feedback and support for direct care staff to change their methods provided (Ferleger, 2008; LeBel et al., 2010; Luiselli, 2009). Close cooperation with other stakeholders, such as advocacy groups, families, and experts, is also necessary (Anthony & Huckshorn, 2008; LeBel et al., 2010).

Swedish Legislation on Restrictive Measures

The Swedish Instrument of Government states that every person is protected against measures that are restrictive or

Received November 24, 2020; accepted September 27, 2021
Correspondence: Petra Björne, Department for Disability Support, 205 80 Malmö, Sweden. E-mail: petra.bjorne@malmo.se

coercive. Such measures include confining a person to a small area, both indoors and outdoors; submitting someone to involuntary medical procedures; limiting access to personal possessions; the use of mechanical restraints, such as belts; the use of locks with the intent to lock someone in. Such measures can only be used if supported by additional legislation, for example, legislation regulating prison sentences or compulsory psychiatric care. Community treatment orders govern the relationship between the psychiatric care provider and the patient, and do not affect the responsibilities of staff providing community support. Living with an ID or autism and accessing services do not constitute exceptions to the Instrument of Government.

The aim of services and staff is to enable persons with ID to live like other citizens, as independently as possible, with a high degree of integrity and self-determination (SFS, 1993). Community services can be provided only with the consent of the person including measures used to protect the person from harm.

The use of a belt to assist the person to be well-positioned in a wheelchair is permissible and not legally considered a restraint as long as the service user consents to this aid. If aids are used to facilitate access to objects or activities and the service user is comfortable with and consents to this, it is permitted. Using the same aids with the purpose to hinder mobility is illegal. To avoid confusing legal aids and illegal restraints in this study, it was stressed that a belt, bed rail, or other such device be used with the intent to reduce the person's mobility.

The use of such measures in community services in Sweden has not been studied, except for one publication with a focus on physical restraints (Lundström, Antonsson, Karlsson, & Graneheim, 2011). Current knowledge about the use of restrictive measures in Swedish services for people with ID stems from government administration, such as the National Board of Health and Welfare (2016, 2018) and the Health and Social Care Inspectorate (2019). Despite the strong legal framework outlined above, restrictive practices, including restraints and seclusion, are known to be frequently used in services for people with ID, with a negative impact on their quality of life (National Board of Health and Welfare, 2018). The National Board of Health and Welfare (2016, 2018) and the Health and Social Care Inspectorate (2017, 2019) have identified the need for further actions to minimize the use of restrictive practices.

Aim

This study is part of a larger project (Björne et al., 2021) examining factors that hinder and facilitate organizational change in support for people with ID whose behavior is described as challenging. This change includes the reduction of restrictive interventions, to enable the intentions of the legislation of supporting a self-determined life. In this paper, the term ''restrictive measures'' is wider in scope than physical interventions, including social rules and dietary requirements, in addition to physical restraints and coercion. Some of these measures might be legal, depending on whether the service user consents to them. Given that service provision and the legal framework in Sweden differs from that of other countries, context-specific knowledge in this field is crucial for service development.

The research questions were:

1. From the sample given, what restrictive measures do staff report using?
2. Do staff consider them important to reduce?
3. What organizational changes do staff identify would contribute to the reduction of restrictive measures?

Method

The research was approved by the Swedish Ethics Review Authority, registration number 2018/838. Participants were informed in an e-mail and when opening the survey about voluntary participation, how data were to be handled, confidentiality, and a contact person for GDPR. They consented by completing and submitting the survey.

Setting

The research was conducted in a large Swedish municipality that manages all group homes and daily activity centers for people with ID. Group homes vary in size and form, depending on the support needs of the person. All service users have their own, albeit often small, apartment, with living room, bedroom, kitchen or kitchenette, and bathroom. In addition, there are communal areas, shared by those living in the group home. The apartment can be part of a house shared by four to six persons, staffed around the clock, or apartments, where support is provided through a mobile team.

Daily activities are offered at centers, with a high degree of support, to smaller groups or individual placements integrated in a workplace. This group overlaps with, but is not identical to, those living in group homes.

The legislation and the organizational structure do not differentiate between people with ID and/or autism. As the survey was sent to all staff who support people with ID and/or autism, some may support those with autism without ID. Nor do administrative records differentiate between different living arrangements or degree of support in daily activities. For the sake of simplicity, the terms "group home" and "daily activities" will be used, irrespective of the degree of support provided.

Participants and Procedure

The local intranet was used to inform staff about the research project and the survey. The Human Resources department compiled e-mail lists for staff in group homes and daily activities services, excluding those with temporary employment. A survey, using Microsoft Forms, was sent to all direct care staff, ($n = 1175$) in group homes and daily activities, who support people with ID and/or autism. Each person received an e-mail with information and a personal link that could only be used once. In the e-mail, information was given about the research project, the survey being voluntary, how anonymity was being handled, and who to contact if there were questions. When

TABLE 1
Respondents

	Staff daily activities services	Staff supported living	Total
Women	65	124	189
Men	22	32	54
Non-disclosure/other	2	5	7
Total	89	161	250

opening the survey, the respondent was informed that he/she consented to participate by answering the survey.

The survey was open for 2 weeks, with a reminder sent after 1 week. Since responses were not tracked, the reminder was sent to everyone on the original e-mail list.

One hundred and sixty-one staff in group homes (18%) and 89 staff in daily activities services (34%) completed the survey.

Survey

The survey included five questions. The first listed 10 examples of commonly used restrictive measures, asking respondents to indicate on a Likert scale if the measures were used daily, weekly, monthly, yearly, or not at all. Examples were taken from the research literature, local incident reports, and national reports.

The second question listed 10 examples of common reasons for using restrictive measures. These were sampled from the research literature, discussions with direct care staff, and the research group. The third question asked how restrictive the 10 examples of measures were perceived, and the fourth asked how important it was to replace each measure with other interventions. There was room to comment following each question and to give examples of other restrictive measures and reasons for their use. Lastly, a free text question asked for suggestions about what needed to be done at an organizational level to prevent the use of restrictive measures.

Analysis

Results were compiled in tables and graphs, using Excel.

The free text answers (generally short and concise) were copied into a Word document under each question. They were read repeatedly and categorized according to content. The free text answers were often very similar in nature and were summarized as general themes and are presented as such below, for example, "staff reported" or "respondents suggested". Where a small number of respondents mentioned a particular theme, the numbers are provided, for example, "One staff said."

TABLE 2
The use of restrictive measures, n = number of respondents for each listed example

What restrictive measures are used in the service you work in?	*n*	Daily (%)	Weekly (%)	Monthly (%)	Yearly (%)	Not used (%)
Locked doors prevent access to communal areas	250	32	4	4	7	54
The service user cannot or may not leave the house unless supported by staff	247	36	5	3	2	53
Locked closets, cupboards, drawers, or refrigerators prevent access to private belongings	249	38	1	1	2	58
Restrictions in use of media, for example, internet, TV, magazines, or movies	247	13	3	2	1	80
Monitoring via camera, babywatch*, or similar	249	6	0	0	0	93
Restricted movements through belts, bed rails, "angel watch"**, or similar	248	22	2	1	1	74
Staff hinder the service user physically, by standing in the way or holding back	248	4	8	7	8	73
The service user is not allowed to meet certain persons	248	8	3	2	3	85
The service user is given medicine (s)he does not want to take	247	4	0	3	3	89
Restrictions in amount of allowed food or drink	249	24	6	7	4	58

*"Babywatch" is an auditory monitoring device. **"Angel watch" is a device used to hinder the service user from opening a seat belt.

TABLE 3
The purposes for using restrictive measures, n = number of respondents for each listed example

To what purpose are these measures used?	*n*	Very common (%)	4 (%)	3 (%)	2 (%)	Not common (%)
To protect service user from harm	234	59	14	8	3	17
To protect other service users from harm	234	36	15	12	6	31
To protect staff from harm	231	16	11	13	11	49
To protect the public from harm	229	16	10	8	10	56
To support physical health of service user	227	47	17	6	4	26
To protect mental health of service user	229	40	16	9	7	28
To prevent sexual abuse	226	15	3	4	6	73
To prevent self-injurious behavior	229	26	11	10	7	45
To prevent "outward" challenging behavior	228	32	13	12	9	34
To meet wishes of relatives	229	12	3	13	11	61

Results

The majority of the respondents (76%) were women, which reflects the gender profile in services for people with ID (see Table 1). In the current municipality, approximately 75% of staff supporting people with ID are women.

Use of Restrictive Measures

Results are jointly presented for all staff (see Table 2), as the responses were similar, with the exception of using cameras for monitoring service users, which were not used in daily activities services.

The most commonly reported restrictive measures were preventing access to communal areas through locked doors (36% daily or weekly), similarly preventing access to private belongings (39%) and preventing a service user from leaving the house without support (41%). In free text answers, staff additionally mentioned the practice of locking a wheelchair or "placing it tactically", food being locked in the staff refrigerator, and keeping cigarettes and money locked away. Rules for the communal areas were applied, which might prevent service users from having full access. Staff also mentioned the practice of locking gates (similar to a baby gate) to contain challenging behaviors and occasionally locking an outdoor gate with a padlock that would normally be open. Locking medication in a special cupboard was also mentioned, with staff expressing uncertainty whether this was a restrictive measure or not (this would depend on the assessment made by the GP).

Two respondents commented that there was a big difference between standing in the way of a person, hindering their access

TABLE 4
Restrictiveness, n = number of respondents for each listed example

Which measures are most restrictive for the service user?	*n*	Very restrictive (%)	4 (%)	3 (%)	2 (%)	Not at all restrictive (%)
Locked doors prevent access to communal areas	246	47	13	22	8	9
The service user cannot or may not leave the house unless supported by staff	243	39	14	23	11	13
Locked closets, cupboards, drawers, or refrigerators prevent access to private belongings	244	55	10	16	9	11
Restrictions in use of media, for example, internet, TV, magazines, or movies	245	56	16	11	6	10
Monitoring via camera, babywatch, or similar	244	67	7	13	3	9
Restricted movements through belts, bed rails, "angel watch," or similar	244	50	16	14	8	12
Staff hinder the service user physically, by standing in the way or holding back	241	66	11	15	2	6
The service user is not allowed to meet certain persons	243	58	16	12	5	8
The service user is given medicine (s)he does not want to take	242	57	15	12	6	11
Restrictions in amount of allowed food or drink	244	43	23	22	6	6

to a room, another person or a desired object, and holding on to the person. One claimed that standing in the way cannot be wrong as they do it several times a day.

Purpose of Using Restrictive Measures

Table 3 shows how commonly the listed purposes were identified by respondents for the use of restrictive measures. The most commonly (i.e., very common or common) noted purposes were to protect the service user (73%) or other service users from harm (51%) and to support the physical (64%) and mental (56%) wellbeing of the person. Potentially harmful events that were noted by staff included falling from a balcony due to epilepsy, climbing out of high windows, and walking into the street, not heeding traffic.

In free text answers, staff mentioned that restrictive measures were used at the wish of or with the consent of the service user, and only used to benefit the person. Specifically, staff noted:

- Restrictions concerning food and drink were being applied as part of the municipality's policy on health to prevent service users eating too much sugar or snacks between meals.
- Locked refrigerators reflected communal living, ensuring enough food to go around, or preventing a service user from eating something dangerous.
- Locked doors were related to congregate settings, preventing negative interaction between service users or one accessing another's belongings.

Staff also noted that restrictions were sometimes used routinely over a long period without questioning their continuing need. Some staff raised concern that individual staff might apply measures to handle their own feelings, though the nature of these feelings (e.g., fear, anxiety) was not clear.

Some staff mentioned that they only applied restrictive measures that were mandatory under forensic or compulsory psychiatric care legislation.

Restrictiveness

As Table 4 shows, all the restrictive measures listed were considered by many staff (the majority in most cases) to be very restrictive for service users.

The question on leaving the house (rated 4 or 5 by 53%) led to staff comments that some people are unable to leave due to their physical disabilities and/or may not be able to move outdoors safely due to cognitive disabilities. These issues may explain the relatively high numbers of staff (compared to other items) who rated being prevented from leaving the house without staff as not very restrictive.

Staff also commented that the use of restrictive measures was a symptom of a staff group being dysfunctional with one participant equating the use of such measures without service user consent as using violence. Having to live according to the routines and structures in congregate settings and being hindered from living according to personal preferences and dreams due to lack of resources, such as insufficient staffing, are seen as the most restrictive measures.

Other staff commented that giving medicine against the will of the person or putting him/her on a diet was not restrictive, as the person did not understand consequences due to their intellectual disability. A diet prescribed by a doctor or dietician was described as mandatory, with Prader-Willi syndrome (in which there is a "compulsion" to eat) being mentioned.

Replacing Restrictive Measures

Table 5 shows staff ratings of the importance of replacing restrictive measures with other supports. Monitoring is mentioned by 6%, and only by staff in group homes. Thus, although it seems that the use of cameras is uncommon, 73% consider it very important to replace monitoring devices by other support. Similarly, although reported as uncommon, giving medicine without consent of the service user is seen as very important to replace. Not being allowed to meet certain persons (77%), restricting movements, either by physical aids (68%) or staff actions (81%) are also considered important or very important to replace.

Free text comments suggested that ignoring the competence, initiative, and preferences of a service user was restrictive. It was considered important to reduce measures that limited the service user's self-determination. Examples ranged from serious ones, such as not being allowed to come home from the daily activities center at will, or not being allowed to use private money according to preferences, to seemingly trivial examples, of being prevented from placing their purse in a favored place. The apparent triviality does not preclude potential negative impact on the person with ID.

Staff also expressed frustration with the use of restrictive measures:

> "Excuse me, but what century are we talking about, unless it is a forensic ward." (Staff group home)

What Is Needed for Change?

In the last question, staff were asked to give their views of what was needed to change the use of restrictive measures. Thirty-eight staff in daily activity services and 79 staff in group homes answered, their responses being summarized below under the headings of Staffing, Training and Supervision, Design of Services, Values and Legislation.

Staffing. The most common answers were related to staffing, that is, sufficient, experienced staff with appropriate knowledge and training, time for reflection, planning, and supervision. For example:

> "Most often more staff and more experienced staff!" (Staff daily activities)

TABLE 5
Importance of replacing restrictive measures, n = number of respondents for each listed example

Which restrictive measures are most important to replace with other support?	*n*	Very important (%)	4 (%)	3 (%)	2 (%)	Not at all important (%)
Locked doors prevent access to communal areas	241	50	18	15	7	10
The service user cannot or may not leave the house unless supported by staff	239	51	14	20	6	8
Locked closets, cupboards, drawers, or refrigerators prevent access to private belongings	240	53	17	14	9	8
Restrictions in use of media, for example, internet, TV, magazines, or movies	240	50	20	13	9	9
Monitoring via camera, babywatch, or similar	239	63	10	10	8	8
Restricted movements through belts, bed rails, "angel watch," or similar	238	55	13	16	5	12
Staff hinder the service user physically, by standing in the way or holding back	240	70	11	9	3	7
The service user is not allowed to meet certain persons	236	58	19	11	4	9
The service user is given medicine (s)he does not want to take	236	63	14	11	4	8
Restrictions in amount of allowed food or drink	239	52	19	18	6	5

> "MORE regular staff! That is the ONLY way to improve a workplace. Fewer temp workers who don't really know the service users and lead to reduced continuity." (Staff group home)

Training and supervision. Staff referred to a range of training/supervision needs including knowledge about disabilities; legislation; values; awareness about restrictive measures; and alternative methods, including structured teaching, low-arousal, cognitive and communicative aids. For example,

> "[This requires] well developed pedagogical aids, communicative and cognitive support, and adapted environments. Everything tailored to each individual's needs and preferences. To achieve such a goal, resources such as time, competence and well-planned environments are required. We lack in all three resources today, and therefore staff out in the services don't have the right conditions to design the right support for each individual service user." (Staff daily activities)

Design of services. The location and design of services were mentioned repeatedly as problematic including, communal living and lack of effective choice over who to live with. Restrictive measures were sometimes reported to prevent interactions that "could" lead to behaviors considered challenging or to prevent harm due to environmental influences, for example,

> "Sometimes personal belongings are locked in a cupboard because another service user might take/touch things that don't belong to him." (Staff daily activities)

> "Many daily activity centres and their rooms are not at all suitable for daily activities, thinking about layout, thin walls, etc." (Staff daily activities)

> "Maybe an environment without traffic could have enabled the service user to leave and be more independent outdoors. The buildings and their placement make a big difference in working with restrictions." (Staff daily activities)

Values and legislation. Some respondents argued that restrictive measures were not negative. Standing in the way of a service user was proposed as a tool to reduce sensory overload, which supports the person in being focused and not distracted by all that is going on. Others argued that some restrictions, including food and drink, were appropriate given the person's lack of understanding of consequences. Defining restrictive measures was therefore considered difficult:

> "As in all contexts we usually start with ourselves when we define and value, which e.g. could lead to a lack of what we see as a restrictive measure can in itself be restrictive for the service user." (Staff group home)

That is, not applying restrictive measures might be restrictive, probably due to lack of support. However, several

respondents were concerned more broadly with the values involved in the use of restrictive measures.

> "As soon as one erodes the spiritual and physical freedom of a service user, one must beware." (Staff group home)

Discussion

The results presented here are part of a broader project to identify organizational factors that act as facilitators and barriers to improving the quality of services for people with ID whose behaviors challenge. Improving the quality of services requires "organisational readiness for change" (Weiner, 2009), including change efficacy and change valence, that is, if members of the organization value the (intended) change; and contextual factors, such as organizational cultures and practices.

The survey investigated what restrictive measures were used, for what purpose, and how much the organization, as perceived by staff, values their reduction. The results from the survey show that:

- Many of the restrictive measures, including locked doors and physical hindering are reported to be used daily/weekly by more than one-third of staff.
- The main reasons given for usage are to protect service users (self and others) and to support physical and mental wellbeing and are used with "consent", in accordance with "policy".
- Most measures are considered restrictive and should be replaced.
- Staff perceive a range of requirements for change, including more/better staff, training/supervision, service redesign, values/legislation clarification.

Restrictive Measures and their Justifications

The Swedish legislation providing support and service for people with ID is based on self-determination, integrity, and independence; it also requires staff to ensure the physical and social wellbeing, and safety of the service user. Support can only be provided with the consent of the person, including the use of protective measures. Consent must be documented and revised continuously, and the least restrictive support provided. Consent can be revoked at any moment. Doctors, trustees, or relatives cannot consent to, or prescribe the use of restrictive measures for adults with ID supported in the community. It is therefore notable that staff seem to defer to external authority, such as doctors or dieticians, when justifying the use of restrictive measures.

Thus, staff negotiate between conflicting goals, being well aware of the moral dilemma between honoring a person's self-determination and keeping them safe. Are staff aware of their power to define and negotiate what constitutes good (and legal) support and what is needed to keep the service user safe? From the point of view of staff, it might seem reasonable, even recommendable, to lock a door to keep someone from unsafely venturing out in traffic or to act as a barrier between two persons to prevent altercations and injuries. The measure "Staff hinder the service user physically, by standing in the way or holding back" elicited the comment from staff that standing in the way was done every day, as this was needed. Standing in the way of a person could be interpreted as a pedagogical support, by staff positioning themselves as a reminder of direction and purpose during an activity. However, from the point of view of the service user, if staff regularly block the service user's path, staff retain the power to "manage" the service user, and impose their interpretation of suitable and unsuitable patterns of behaviors. Well-intended measures can still have a negative effect on a person being restricted in movement, independence, and self-determination. Although a restricting act proposes to keep a person from harm, it can cause stress and a sense of abuse for the service user, which has a negative psychological impact on those affected (Hughes et al., 2019; Northway et al., 2013; Wigham & Emerson, 2015). The repeated use of some restrictive measures shown in these results suggests that staff are not provided with support and advice to reduce or replace them with less restrictive approaches (see Deveau & Leitch, 2018). The results also indicate that when staff use a measure frequently, then it is not perceived as restrictive, also suggested recently by Embregts et al. (2019).

Change

Policies and legislation that protect the freedom of a person accessing community support do not necessarily have a bearing on everyday support (Northway et al., 2013; Northway, Davies, Mansell, & Jenkins, 2007). Staff consistently mentioned the need for additional resources to change their practice and reduce the use of restrictive measures. Such resources included more staff, adequate training and supervision, buildings, and environments that are adapted to the needs of people with ID. Given that people with ID are supported in congregate settings, thought must go into who shares common spaces. Therefore, the whole organization must be engaged in the support of people with ID (Ferleger, 2008; LeBel et al., 2010; Luiselli, 2009), so that long-term financial, physical, and social planning builds the foundation for staff in their everyday support for people with ID. Supporting staff to apply complex values and principles into daily practice requires practice leadership from immediate managers (Deveau & Leitch, 2020; Deveau & McGill, 2016). Providing necessary environmental contexts, for example, housing and finances, requires strategic leadership.

Limitations of the Study

The main researcher works in a senior position within the organization and is associated with training and supervision in support for people whose behavior is described as challenging. This potentially introduced biases, for example, staff aware of restrictive measures being illegal may have given socially acceptable answers. However, given the frustration expressed in the free text answers, and the experience that staff are forced to use restrictive measures due to structural or organizational causes,

those that have answered seem to be aware and honest about measures used.

While the restrictive practices considered in this study reflected incident reports to include practices that staff were likely to recognize, it is unlikely to provide a completely comprehensive list (Schippers, Frederiks, van Nieuwenhuijzen, & Schuengel, 2018). The survey did not include questions whether service user consent had been sought. However, staff mentioned this, and this should be explored further.

The reliability of surveys on personal practice regarding behaviors described as challenging is problematic. For example, practices that are part of the everyday support or seemingly innocuous may go unrecognized and practices that are illegal may go unreported.

The researcher's position may also have made respondents wary of answering the survey, in case their answers were not treated confidentially. To make them feel safe in answering, staff were not asked where they work. Therefore, it is not known if the answers were clustered to a few services. However, most services encompass fewer than 15 staff suggesting responses were from across many services.

Although staff report a pervasive use of restrictive measures, it is not possible to draw any conclusions on how many service users are affected, or if restrictions are more common in services for people whose behaviors are described as challenging.

Conclusion

Staff continuously negotiate legislation that is complex in its application in everyday situations.

The use of restrictive measures appears widespread, despite strong and clear legislation and policies forbidding their use. The measures are used to protect service users from harm and seem often to be applied with the best intentions. Many staff identify a lack of resources, including staffing and adapted environments, as key factors in causing the use of restrictive measures, and lack of knowledge and time in preventing changes in support. Access to support for staff, by training, guided reflection, supervision, and leadership is crucial to limit such restrictions.

Acknowledgments

The main author is financed through FORTE, research grant 2018-01336. Mats Jansson and Judith Timoney provided input on the results. Alexandra Emanuelsson commented on an early draft of the paper. Three anonymous reviewers have provided thoughtful and thorough feedback.

Conflict of Interest

The authors have no conflict of interest to declare.

References

Anthony, W. A., & Huckshorn, K. A. (2008). *Principled leadership in mental health systems and programs*. Boston University Press.

Björne, P., Deveau, R., & Nylander, L. (2021). Passing laws is not enough to change staff practice: The case of legally mandated "incident" reporting in Sweden. *Journal of Intellectual & Developmental Disability*, (*46*)2, 186-196. https://doi.org/10.3109/13668250.2021.1873751

Deveau, R., Gore, N., & McGill, P. (2020). Senior manager decision-making and interactions with frontline staff in intellectual disability organisations: A Delphi study. *Health & Social Care in the Community*, *28*, 81–90. https://doi.org/10.1111/hsc.12842

Deveau, R., & Leitch, S. (2018). *Person centred restraint reduction: Planning and action*. Birmingham: BILD Publications.

Deveau, R., & Leitch, S. (2020). Implementation of policy regarding restrictive practices in England. *Tizard Learning Disability Review*, *25*, 1–8. https://doi.org/10.1108/TLDR-05-2018-0016

Deveau, R., & McGill, P. (2016). Practice leadership at the front line in supporting people with intellectual disabilities and challenging behaviour: A qualitative study of registered managers of community-based, staffed group homes. *Journal of Applied Research in Intellectual Disabilities*, *29*, 266–277. https://doi.org/10.1111/jar.12178

Embregts, P. J., Negenman, A., Habraken, J. M., de Boer, M. E., Frederiks, B. J., & Hertogh, C. M. (2019). Restraint interventions in people with moderate to profound intellectual disabilities: Perspectives of support staff and family members. *Journal of Applied Research in Intellectual Disabilities*, *32*, 172–183. https://doi.org/10.1111/jar.12519

Ferleger, D. (2008). Human services restraint: Its past and future. *Intellectual and Developmental Disabilities*, *46*, 154–165. https://doi.org/10.1352/0047-6765(2008)46[154:HSRIPA]2.0.CO;2

Fish, R., & Hatton, C. (2017). Gendered experiences of physical restraint on locked wards for women. *Disability & Society*, *32*, 790–809. https://doi.org/10.1080/09687599.2017.1329711

Hawkins, S., Allen, D., & Jenkins, R. (2005). The use of physical interventions with people with intellectual disabilities and challenging behaviour – The experiences of service users and staff members. *Journal of Applied Research in Intellectual Disabilities*, *18*, 19–34. https://doi.org/10.1111/j.1468-3148.2004.00207.x

Health and Social Care Inspectorate. (2017). Vad har IVO sett? [What has the Inspectorate seen?].

Health and Social Care Inspectorate. (2019). Vad har IVO sett? [What has the Inspectorate seen?].

Heyvaert, M., Saenen, L., Maes, B., & Onghena, P. (2015). Systematic review of restraint interventions for challenging behaviour among persons with intellectual disabilities: Focus on experiences. *Journal of Applied Research in Intellectual Disabilities*, *28*, 61–80. https://doi.org/10.1111/jar.12095

Hughes, R. B., Robinson-Whelen, S., Raymaker, D., Lund, E. M., Oschwald, M., Katz, M., … Nicolaidis, C. (2019). The relation of abuse to physical and psychological health in adults with developmental disabilities. *Disability and Health Journal*, *12*, 227–234. https://doi.org/10.1016/j.dhjo.2018.09.007

Karim, S. (2014). *A human rights perspective on reducing restrictive practices in intellectual disability and autism*. Birmingham: BILD Publications.

Lambrechts, G., Petry, K., & Maes, B. (2008). Staff variables that influence responses to challenging behaviour of clients with an intellectual disability: A review. *Education and Training in Developmental Disabilities*, *43*, 454–473. http://www.jstor.org/stable/23879676

LeBel, J., Huckshorn, K. A., & Caldwell, B. (2010). Restraint use in residential programs: Why are best practices ignored? *Child Welfare*, *89*, 169–187.

Luiselli, J. K. (2009). Physical restraint of people with intellectual disability: A review of implementation reduction and elimination procedures. *Journal of Applied Research in Intellectual Disabilities*, *22*, 123–134. https://doi.org/10.1111/j.1468-3148.2008.00479.x

Lundström, M. M., Antonsson, H., Karlsson, S., & Graneheim, U. (2011). Use of physical restraints with people with intellectual disabilities living in Sweden's group homes. *Journal of Policy and Practice in Intellectual Disabilities*, *8*, 36–41. https://doi.org/10.1111/j.1741-1130.2011.00285.x

MacDonald, A., McGill, P., & Deveau, R. (2011). You squeal and squeal but they just hold you down. *International Journal of Positive Behavioural Support*, *1*, 45–52.

McGill, P., Murphy, G., & Kelly-Pike, A. (2009). Frequency of use and characteristics of people with intellectual disabilities subject to physical interventions. *Journal of Applied Research in Intellectual Disabilities*, *22*, 152–158. https://doi.org/10.1111/j.1468-3148.2008.00483.x

Mérineau-Côté, J., & Morin, D. (2013). Correlates of restraint and seclusion for adults with intellectual disabilities in community services. *Journal of Intellectual Disability Research*, *57*, 182–190. https://doi.org/10.1111/j.1365-2788.2012.01601.x

Mérineau-Côté, J., & Morin, D. (2014). Restraint and seclusion: The perspective of service users and staff members. *Journal of Applied Research in Intellectual Disabilities*, *27*, 447–457. https://doi.org/10.1111/jar.12069

National Board of Health and Welfare. (2016). Insatser och stöd till personer med funktionsnedsättning. Lägesrapport 2016. [Support and service for people with disabilities, 2016].

National Board of Health and Welfare. (2018). Insatser och stöd till personer med funktionsnedsättning. Lägesrapport 2018. [Support and service for people with disabilities, 2018].

Northway, R., Davies, R., Mansell, I., & Jenkins, B. (2007). "Policies don't protect people, it's how they are implemented": Policy and practice in protecting people with learning disabilities from abuse. *Social Policy and Administration*, *41*, 86–104. https://doi.org/10.1111/j.1467-9515.2007.00540.x

Northway, R., Melsome, M., Flood, S., Bennett, D., Howarth, J., & Thomas, B. (2013). How do people with intellectual disabilities view abuse and abusers? *Journal of Intellectual Disabilities*, *17*, 361–375. https://doi.org/10.1177/1744629513509565

Sanders, K. (2009). The effects of an action plan, staff training, management support and monitoring on restraint use and costs of work-related injuries. *Journal of Applied Research in Intellectual Disabilities*, *22*, 216–220. https://doi.org/10.1111/j.1468-3148.2008.00491.x

Schippers, B., Frederiks, B. J. M., van Nieuwenhuijzen, M., & Schuengel, C. (2018). Reliability and feasibility of systematic registration of coercive measures in care for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *15*, 202–213. https://doi.org/10.1111/jppi.12252

SFS 1993:387 Act concerning support and service for persons with certain functional impairments. Retrieved from https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387

Stubbs, B., Leadbetter, D., Paterson, B., Yorston, G., Knight, D., & Davis, S. (2009). Physical intervention: A review of the literature on its use, staff and patient views, and the impact of training. *Journal of Psychiatric and Mental Health Nursing*, *16*, 99–105. https://doi.org/10.1111/j.1365-2850.2008.01335.x

Webber, L. S., McVilly, K. R., & Chan, J. (2011). Restrictive interventions for people with a disability exhibiting challenging behaviours: Analysis of a population database. *Journal of Applied Research in Intellectual Disabilities*, *24*, 495–507. https://doi.org/10.1111/j.1468-3148.2011.00635.x

Weiner, B. J. (2009). A theory of organizational readiness for change. *Implementation Science*, *4*(1), https://doi.org/10.1186/1748-5908-4-67

Wigham, S., & Emerson, E. (2015). Trauma and life events in adults with intellectual disability. *Current Developmental Disorders Reports*, *2*, 93–99. https://doi.org/10.1007/s40474-015-0041-y

Williams, D. (2009). Restraint safety: An analysis of injuries related to restraint of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *22*, 135–139. https://doi.org/10.1111/j.1468-3148.2008.00480.x