

Ethics

Restraint reduction in Sweden

Petra Björne

R&D Coordinator, City of Malmö
Researcher, Lund University



Instrument of Government (Constitution)

- Everyone is protected against the use of coercive or restrictive measures, including
 - Use of restraints
 - Medical interventions
 - Restricted movements
- Legislated exceptions
 - Forensic psychiatric care
 - Compulsory psychiatric care
 - Drug abuse in certain circumstances
 - Etc
- In line with the ECHR and UNCRPD

Community support

- Community support for people with disabilities is never an exception
 - I.e., coercion, restraint or restrictive measures cannot be used
- Some protective measures can be used with the explicit consent of the person
 - Keeping a door locked to guide the person to use another, safer exit
 - Bed rails
- Protective measures without consent are classified as illegal restrictions or restraint

Community support in Malmö



- Department for Disability Support
- Approx. 2400 employees
- Approx. 1600 service users with ID and/or autism
- 800 service users access daily activity services
- 97 group homes

Ethics in the legal system

- Equal rights
 - No allowance for exceptions due to diagnosis
- Provide the opportunity to live like others
- Support is provided in a way that strengthens self-determination and participation
- Consent
 - Equality before the law
 - Capacity for consent
- Presupposition: equality in holding rights and freedoms

And then reality...

- National Board of Health and Welfare
- Health and Social Care Inspectorate
- High profile “media” incidents

- Conclusions:
- Restrictive measures, including restraints, are prevalent
 - Locked areas/rooms/houses
 - High degree of “off-label” medication
 - Belts, clothes, “aids” restrict movements
 - Physical interventions

- Little to no Swedish research on this topic

Disputed humanity

- Autism and ID = conditional rights and freedoms
- Challenging behaviours = relinquishing rights and freedoms

“He is so special, the legislation cannot apply to him”

“She is like no other person you’ve ever met”

“He doesn’t understand the concept, so we have consent to do what is best for him”

“Legislators don’t know anything about this group”

“I’m sending my staff into a war zone”

- Swedish legal system protects “everyone” against undue use of restraints
- Legal certainty
- A person is so “special” that legislation and conventions don’t apply
- Are we then saying that this person is not quite human?

Incident reports

- Mandatory for staff and managers to report incidents and irregularities that put the service user at risk
- Health and Social Care Inspectorate: the majority of reports due to incidents between service users
- Current research project: no reports due to the use of restrictive measures

Incident reports gathered June 1 - November 30, 2018

- Restrictive measures are mentioned, but are not the cause for the report being written
- (The same applies to self-injurious behaviour)

Survey

- Staff and managers in supported accommodation and daily activity services
- What measures are used and how often?
- Why are they used?
- How “intrusive/restrictive” are they?
- Should they be replaced by other forms of support?

Survey (staff)

| What coercive measures are used in the service you work in? | Daily(%) |
|--|----------|
| Locked doors prevent access to communal areas | 32 % |
| The service user can or may not leave the house unless supported by staff | 36 % |
| Locked closets, cupboards, drawers or refrigerators prevent access to private belongings | 38 % |
| Restrictions in use of media, e.g., internet, TV, magazines or movies | 13 % |
| Monitoring via camera, babywatch or similar | 6 % |
| Restricted movements through belts, bed rails, "angel watch" or similar | 36 % |
| Staff hinder the service user physically, by standing in the way or holding back | 38 % |
| The service user is not allowed to meet certain persons | 13 % |
| The service user is given medicine (s)he doesn't want to take | 6 % |
| Restrictions in amount of allowed food or drink | 22 % |

Reducing the use of restrictive measures

- Restrictive measures are part of everyday support and daily routines
- When discussed, focus lies on **what** and **how**, mostly asking “is it legal or not?”
- Should we rather ask **why**?
- Ethics outside of the legal framework
- But within the “creative space” available

Ethics

- What, then, are the ethical questions pertinent when discussing the use of restrictive measures in community support?

Why is the use of restrictive measures (always) wrong?

Why is it important that restrictive measures are (never) used?

Why is it important that a person is not a “war zone”, “a catastrophe waiting to happen”, “completely unpredictable”?

To keep hold of the humanity of a person challenged by the logic of service provision, we must keep hold of our own humanity.

Are we, then, prepared to see “their” reactions as no distinct from “ours”

Petra Björne

Department for Disability Support
SE-205 80 Malmö

petra.bjorne@malmo.se

