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Disability-specific Forms of Deprivation of Liberty: Causes, Obstacles, and Levers for Change

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Compulsory hospitalisation in psychiatric facilities and the placement of adults with disabilities –most of whom have a psychosocial or mental disability– in medico-social residential institutions are situations that are often traumatic and painful for the persons involved and their families, as well as healthcare professionals. According to a United Nations (UN) report on the rights of persons with disabilities, these situations may constitute deprivation of liberty specifically based on the existence of a disability, running contrary to Article 14 of the Convention on the Rights of Persons with Disabilities. Based on interviews conducted with the stakeholders involved in these situations (persons with disabilities, family members, representatives of Non-Governmental Organisations working with persons with disabilities, health and social care professionals, directors of healthcare institutions and social services, policy makers, and in France, the General Inspectorate of Places of Deprivation of Liberty (Contrôleure Générale des Lieux de Privation de Liberté)), this study aims to gain a better understanding of the reasons for these situations and the ways they can be avoided.

People's right to freedom and security (the right to not be arbitrarily detained) has been recognised as a fundamental and universal human right since the Universal Declaration of Human Rights (UDHR). This right was reaffirmed when France ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) in 2010. However, by law this right may be subject to restrictions in the interest of public health or public security. Article 14 of the CRPD stipulates that the existence of disability alone cannot justify deprivation of liberty. However, according to the report issued by the UN Special Rapporteur on the Rights of Persons with Disabilities (see "Sources", p.2), forms of deprivation of liberty specifically based on a disability are practiced in most countries (Flynn et al., 2019), even though many of them have introduced policies and care and support practices to promote independent living within a mainstream environment. Individuals are considered to have been

deprived of their liberty when they are confined in a place or a closed institution without their free and informed consent, or when they are under continuous supervision and control, and are not free to leave. Deprivation of liberty is considered to be based on the existence of a disability when it is authorised by laws, regulations, or practices on the grounds of an actual or perceived disability, or when there are places of confinement that are specifically for people with disabilities. Two situations in which individuals are deprived of their liberty due to a disability, as defined by the UN, are studied here: involuntary hospitalisation in psychiatric facilities, and institutionalisation in medico-social residential institutions (see insets "Sources", p.2, and "Method", p.6). There is a legal framework for involuntary hospitalisation and it requires the authorisation of a liberty and custody judge (juge des libertés et de la détention). Institutionalisation is often justified by a need for specialised care or support, but this is not always desired by the person concerned.

In her report on the situation of people with disabilities in France, Catalina Devandas-Aguilar, the UN Special Rapporteur on the Rights of Persons with Disabilities, criticised these residential institutions for restricting the freedom of people with disabilities by segregating and isolating them from their communities, denying their choice of and control over living and support arrangements, and significantly restricting their day-to-day decisions (UN, 2019).

A brief description of these situations in France will be followed by an explanation of what triggers them and a description of the obstacles to and levers for the full enjoyment of the right of persons with disabilities to freedom and security.

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Around 200,000 adults are deprived of their liberty in France, as defined by the Convention on the Rights of Persons with Disabilities (CRPD)

According to the UN, approximately 200,000 adults are currently deprived of their liberty due to a disability in France. Based on data from the 2014 Social Establishments (*Établissements Sociaux*, ES) survey conducted by the French Directorate for Research, Studies, Evaluation and Statistics (*Direction de la Recherche, des Études, de l'Évaluation et des Statistiques*, DREES), roughly 120,000 adults are institutionalised in medico-social residential institutions for adults with disabilities¹, that is to say without taking into account semi-residential stays (day or night care) and individuals who have been temporarily institutionalised, who have freedom of movement. Most of the residents have intellectual or mental health disabilities (Bergeron, Eilideman, 2018), in contrast with persons with disabilities who live at home, whose most common functional limitations are motor and sensory impairments (Espagnacq, 2015). The average length of stay, which varies according to the institution, is relatively long—ten years in residential facilities, specialist care homes (*Maisons d'accueil spécialisé*, MAS), and residential care homes (*Foyers d'accueil médicalisé*, FAM). Most persons with disabilities have resided in several institutions.

In 2018, there were 80,000 involuntary hospitalisations in psychiatric facilities. Although consent to care is an indispensable condition for any therapeutic treatment (Article L.1111-4 of the *Code de la Santé Publique*), French legislation also provides for the use of compulsory care in the event of severe psychiatric disorders (Coldefy, Fernandes, 2017). Certain criteria must be met for involuntary hospitalisation: the existence of a psychiatric disorder, dangerousness to self or to others, and the need for care or treatment that has been identified by healthcare professionals. In 2018, 80,000 out of the 424,000 people who were hospitalised in psychiatric facilities were hospitalised without their consent, that is to say one person in five.

It is important to note that involuntary hospitalisation and institutionalisation in medico-social residential institutions are

¹ In 2014, 144,100 disabled adults were institutionalised in these institutions, and furthermore, 81% of the 146,600 places in adult care centres were residential.

distinguishable from each other insofar as compulsory hospitalisation generally constitutes an emergency solution, while institutionalisation may be a longer-term solution. However, as far as the issue of deprivation of liberty is concerned, many triggers, obstacles, and levers—identified during the interviews that were conducted—are common to both situations.

Deprivation of liberty due to a disability is a controversial notion

The very notion that a person institutionalised in a medico-social residential institution or hospitalised without consent in a psychiatric facility could constitute deprivation of liberty due to a disability was the subject of much debate during the interviews. The UN's definition of deprivation of liberty—a place which a person with a disability is not free to leave at will—is not shared by all the healthcare professionals, directors of institutions, and even the families and friends. Many people who were contacted and who had experienced one of the situations in the study, did not wish to participate in the survey, as they did not feel that the issue of deprivation of liberty was relevant to them. This notion receives greater recognition in the field of psychosocial disability and psychiatry, where it is subject to a legal framework. Hence, most of the interviews conducted dealt with the subject of psychosocial disabilities.

Various points of view were expressed. For some, the institutions in which people resided without their consent were perceived as care facilities aimed to protect them and provide them with vital services and support. Thus, involuntary hospitalisation of persons with disabilities in psychiatric facilities and their institutionalisation in medico-social residential institutions do not constitute a violation of human rights, but rather deprivation of liberty that is necessary in certain circumstances, in the individual's interests, as expressed by this **director of an institution**:

"In my view, a person who dies "free" on the roadside because he/she did not want to receive treatment... it's not a step forward for that person."

Legislation is often referred to by policy makers and professionals to justify involuntary hospitalisation, as well as a doctor's duty to protect the life of the person and provide the necessary care:

"It almost amounts to the principle of rendering assistance to a person in danger, by forcing the person to receive treatment which, a priori, he/she does not want to endure, does not want to receive."

Policy maker

For others, certain institutions ensure that persons are informed of their rights and receive care based on their needs and cannot automatically be considered as places in which people are deprived of their liberty. This is the case, in particular for hospitalisation in a forensic "Unit for Difficult Patients" (*Unité pour malades difficiles*, UMD) following a ruling exempting the person from criminal responsibility, which, for the **healthcare professionals interviewed**, is preferable to a prison sentence:

"When people with psychiatric disorders are not judged to be irresponsible for their actions and are sentenced to imprisonment (...) they are not able to reach the prison's objectives and work. Prison guards are often attacked (...). These people are being penalised; there are many cases like this in French prisons."

For others still, institutionalisation in medico-social residential institutions was perceived more as a "non-choice" resulting from a lack of alternative solutions aimed at self-reliance rather than deprivation of liberty. This echoes Catalina Devandas-Aguilar's observations on the situation of people with disabilities in France; in her view, despite laws designed to promote independent living for persons with severe disabilities, residential and institutional solutions are all too often favoured over responses that promote active citizenship, social inclusion, and community participation. She believes that current efforts to address the needs of persons with disabilities focus on addressing the individual's impairment rather than on transforming society and the individual's environment to ensure accessible and inclusive services as well as community-based support (UN, 2019). This observation was shared by a **policy maker**:

"There is a tendency for persons with disabilities to remain in institutions and it is not considered necessary to help them gain independence. The State should help the institutions and service providers to work towards that end. The solution isn't to "close" the institutions' doors (...), but rather to "open" them and make it possible for institutionalised persons with disabilities to realise their projects in life, preferably living at home, and sometimes also in a sequential way (...), involving solutions that combine periods at home and in an institution with support services."

"The medico-social field fails to recognise the existence of social confinement, whereby people live exclusively in an institution... it's the solution that's used to address the problem of reduced autonomy, and which kills people."

The lack of alternative solutions may impact the willingness to deinstitutionalise people with disabilities. Some of the families and persons with disabilities thought that the situation of people with disabilities went beyond the debate on human rights. They described their sense of powerlessness when they endured painful experiences in a mainstream environment: their solitude, rejection, the lack of awareness about disabilities, the lack of interest, the difficulty in helping a relative or friend to have a better life, or ensuring that a child has access to education. Hospitalisation and institutionalisation are often the last resort, "the least worst solution...", as stated by a **service user representative**:

"The parents and legal guardians decide to institutionalise them and choose to do so because there is no other solution. (...) And forcing autistic people to live collectively when they have difficulty establishing relationships with other people is an aberration. In the specialist care homes (MAS), etc., people are forced to eat together and they are required to participate in various activities. There's no respect for the person's lifestyle or preferences. (...) Requiring people to engage in activities which they're not interested in instead of learning to recognise a person's preferences is also a form of "non-choice", a deprivation of liberty, and an infringement of people's rights."

Furthermore, what does "consent" mean for example in certain cases of intellectual disability or multiple disabilities, which make it difficult to identify a person's needs or desires? Sometimes these practices end up being tolerated and people end up resigned. Certain respondents promote a medical model of disability to justify this violation of people's freedoms.

Lastly, some of the people interviewed thought that these forms of treatment were discriminatory human rights violations and deprived them of their freedom to choose where they live and their freedom of movement. Furthermore, these situations are often characterised by other violations of people's rights, such as the right to information, the right to communication, and the right to dignity, which are regularly reported by the General Inspectorate of Places of Deprivation of

Liberty (*Contrôleure Générale des Lieux de Privation de Liberté*, CGLPL, 2020), families, and persons with disabilities:

"The most fundamental right –the right to be informed of one's rights– is very often not respected, either because it is considered that the person is not in a fit state of mind to understand their rights and that this can be done later, but later never comes, or because persons are informed of their rights by healthcare workers who have a limited knowledge of patients' rights, and who explain everything too quickly, because they're not convinced that patients should be informed of their rights."

General Inspectorate of Places of Deprivation of Liberty (CGLPL)

"In France, a patient in seclusion who is restrained cannot be visited. They can't be dressed either. They're not dressed. They stay in pyjamas."

Family member

"(...) I think this may infringe upon a person's dignity. It's something that I find difficult to talk about, even with people close to me. They'd be shocked if they knew I was restrained..."

Person with a disability

"The more you ask for, the worse it gets. Asserting rights, of which one has little understanding, is seen as a sign of illness that has to be treated with medication..."

Person with a disability

Other people who were interviewed recognised that there was discrimination against persons with disabilities and said that it was due to ignorance, stigmatisation, and the lack of alternatives to institutionalisation.

The main factors that trigger deprivation of liberty

A review of the literature and the interviews showed that deprivation of liberty is more clearly acknowledged in the field of psychiatry, where it is subject to a legal framework, than in the medico-social sector. There are many factors that trigger deprivation of liberty of persons with disabilities because they depend on the person's individual situation (persons who receive support, isolated individuals, persons under guardianship, persons living independently, persons living in their parents' home, etc.), and are linked to the nature of the disability (motor, mental, sensory, etc.) and the place of deprivation of liberty (a hospital, an institution, or at home). A major life event, a lack of family support, an inappropriate solution in an emergency situation, precautionary meas-

SOURCES

This study is part of a programme of international research conducted by the Centre for Disability Law and Policy – National University of Ireland, Galway, during the period 2018–2019. The protocol for the study of the factors that trigger deprivation of liberty and the levers to prevent deprivation of liberty developed by the Centre included all types of disabilities and was used in various countries. The scope, the survey method, the number of stakeholders and types of stakeholders to be interviewed and the interview grids were the same in the various countries that participated in the study. In France, the people and families that were willing to be interviewed were mainly affected by psychosocial disabilities (bipolar disorders, schizophrenia, anorexia nervosa, etc.) and behavioural disorders such as autism and pervasive developmental disorders (PDD). Only adults were interviewed. The full report from this project (CDLP, 2019) contributed to the 2019 United Nations (UN) report on the rights of persons with disabilities (UN, 2019).

ures, and the social stigmatisation of disabilities are the main triggers of deprivation of liberty.

A crisis caused by an external event often triggers the deprivation of liberty process

Some of the people interviewed stated that a particular event –a personal experience or family event– or a mental health crisis resulted in deprivation of liberty. Most often, they referred to a cause external to the crisis (loss of employment, a relationship break-up, etc.), whereas the healthcare professionals stated that the person's physical or mental state of health (decompensation, non-compliance with treatment, inappropriate or violent behaviour, addiction, etc.) was most often the cause:

"The reason for involuntary hospitalisation is often due to a crisis situation, which means that the person is a danger to himself/herself or others. (...) The other reason is that they are often people who've been under psychiatric treatment and there's been a break in their treatment, they've stopped their treatment. (...) Another contributing factor is that they're not able to give their consent to treatment because a characteristic of a mental illness is denial (...) or inconsistent consent, that is to say they say "yes", then "no" five minutes later, and then "yes"..."

Healthcare professional

In these emergency situations, the prevention of suicide and self-mutilation, in particular, is often used to justify compulsory hospitalisation, even though forcing someone to receive treatment in a closed institution can constitute an additional traumatic experience and impede the person's recovery.

Insufficient involvement of people and family members is also a factor

A lack of information and interest in the persons concerned and their families not only undermines the family and the person concerned, but also the medical and support teams, which can result in deprivation of liberty. For the persons with lived experience:

"There's never a two-way discussion where you could at least communicate and understand why you were in that state. In both directions –when they spoke to me and I spoke to them. It was a vicious circle– the system throws you in the psychiatric wringer."

Person with a disability

Families unanimously expressed their dissatisfaction with the lack of information about the decision-making process and the alternatives to hospitalisation and institutionalisation, particularly in crisis situations. Lacking support or sufficient social or financial support, families and friends, who are on the brink of exhaustion and can find no other solution, often make a request –directly or through healthcare or medico-social professionals– for treatment and support. This results in compulsory hospitalisation, institutionalisation, as explained by this **service user representative**:

"The person's family is at the end of their rope and completely isolated, and the families don't know what their rights are, so they can't defend their family member, and the people themselves even less so."

And these **parents interviewed**:

"In retrospect, we can see how lacking in knowledge we were... the forced hospitalisation took us completely by surprise; we didn't realise that we'd become involved in a vicious circle (...). I'd never do that again..."

Some overprotective families "force" their relatives to live a life of dependency, depriving them –unintentionally or not– of their liberty (outings, visits, means of transport, etc.):

"In view of the constraints imposed by the situation and the families' inability to help disabled family members to become autonomous, the only solution they come up with is institutionalising them."

Policy maker

In certain cases, the family may even feel that they have been "manipulated" by healthcare professionals, and even misinformed about the consequences of involuntary hospitalisation. It is then very difficult to undo everything and wind the

clock back, which is distressing for the families and the persons concerned, and leads them to feel emotionally and socially insecure due to the involuntary hospitalisation process:

"Before signing the documents, as part of the process, we didn't realise that we were about to force our son to go to an institution. We called a doctor to get our son treated. There was no need for compulsory hospitalisation. He wasn't violent or suicidal. He wasn't seriously overwhelmed."

Family member

"The family's at the end of their rope, they've always coped on their own, so it's immensely painful for them: the family members feel helpless when faced with the fait accompli, they're told that they've done everything they could and that they can no longer cope with the person. They agree without understanding the consequences, because they're told that they're placing themselves and the person in danger."

NGO representative

Hence, according to Mirfin-Veitch et al. (2003), the families think that they won't be able to look after their child in the long term, particularly as the support schemes and services do not fulfil their needs, and they feel guilty.

A lack of knowledge about the characteristics of a disability and the compartmentalisation of the sectors may lead to deprivation of liberty

Deprivation of liberty also occurs when the person does not receive care that is appropriate for their particular disability (poor treatment of somatic problems, in particular, and behavioural problems), especially when healthcare professionals are not trained to do so (lack of time and resources, inadequate training, no continuing training). This **family** told us about their experiences:

"The things that triggered [involuntary] hospitalisations were small acts of violence: kicking and slapping... but that's where it stopped, they were small acts of aggression. They were often in reaction to something because we weren't able to reassure her [autistic person] at a given time. We shouted at her and made her feel anxious because we didn't know what else to do... We then got attacked in return. And that's what triggers compulsory hospitalisation... You have to remain calm instead and not try to force them to do anything. And that changes everything..."

A view shared by this **service user representative**:

"In these situations, everyone feels helpless. There is little awareness in adult psychiatry

of the issues related to the behaviour of disabled persons. It turns out that acts of violence are often and quite simply caused by a deprivation of essential human rights. Frustration leads to acts of violence, which are also linked to the fact that these people do not know what their rights are and are unaware that they can receive support that would enable them to manage their disability, and have access to specialised and mainstream services."

These situations exacerbate the person's already difficult situation and sometimes lead to restraint or seclusion measures that are traumatising, as explained by a person who experienced this treatment during a stay in a psychiatric facility:

"They thought that I had to be kept away from the others for my own good (...). And I had already had traumatic experiences in my childhood. It was awful (...) They should have spent more time trying to help me and listening to what I had to say... But they strapped me onto a bed and put me in seclusion; there was no one to talk to. People walked past my room and saw me through the window, tied down like that. It was terrible. I felt like an animal in a cage. That's not care, it was definitely something else. It had a considerable impact on what followed..."

Person with a disability

Several health and social care professionals highlighted the fact that the lack of coordination between the health and medico-social sectors in France is a factor that leads to deprivation of liberty. The resulting lack of resources, time, and sometimes motivation to deal with violent situations and behavioural problems, while respecting people's right to freedom, is an aggravating factor:

"When faced with situations that they can't deal with (autism or the prevention of behavioural problems), medico-social institutions very often turn to psychiatry, because healthcare professionals aren't trained to deal with such situations."

NGO representative

Stigmatisation, a paternalistic model, and a medical approach to disability often lead to deprivation of liberty

Negative representations and the fear associated with persons with disabilities in France are major obstacles to their freedom. In this **healthcare professional's opinion**:

"Disability is viewed negatively in France; the capacity for autonomy is underestimated in society and the French system is paternalistic. Everything is based on fear and overprotection, which dissuade people from seeking autonomy."

The stigmatisation of disabled people, which can lead to disability-specific deprivation of liberty is often based on the idea that disabled persons are incapable of living in the community and must receive specialised care in an institution (Eyraud, Velprey, 2015; Boente, 2017; Show, Priebe, 2013). Underlying this prejudice is the unsubstantiated idea that persons with psychosocial disabilities are intrinsically inclined to be violent (McAleenan, 2013; Stuver et al., 2014; Lovell, 2005). Yet, studies have shown that disabled people are more likely to be victims of violence than violent towards others (Desmarais, 2014). Stigmatisation exists at all levels of society: in neighbourhoods, education, employment, home ownership, sexuality, parenthood, and access to shops and standard healthcare. A large proportion of the population believes that disabled people are not capable of living in society (Chow, Priebe, 2013). Most of the people interviewed experienced this stigmatisation:

"Discrimination varies according to the different pathologies: schizophrenics are viewed as being dangerous and uncontrollable, and so are people who suffer from bipolar disorders; and people who suffer from depression have a lack of willpower. People with mental health issues are always viewed in a negative way."
Director of an institution

"These days, to avoid stigmatisation, we prefer to put people away and out of sight, lock them up away from the rest of the world, and resort to the former approach of using mental asylums."
Policy maker

"People reject anything they aren't familiar with. The family abandoned us as well. We're seen as having all the genetic defects in the world and as not being respectable; this happens to a lot of families with autistic children or children with disabilities."
Family member

Self-stigmatisation is in fact also prevalent amongst persons with disabilities:

"And all these people decide at some point that that's it, you're "disabled"; they take a long-term view and there's a fatalistic attitude towards your condition. That's why the system is stuck in a rut. That's why they can deprive disabled people of their liberty whenever they want to (...)."
Person with a disability

All these factors contribute to deprivation of liberty or prevent disabled people from gaining access to the "mainstream" world.

The medical approach to disabilities was highlighted by both healthcare professionals and disabled people as an obstacle:

"An illness or a disability?... in the case of psychosocial disability, (...) the medical authorities always (...) decide what's going to happen; no services will do anything for you if the psychiatrist doesn't move on it. But in the case of a person with a motor or physical disability, it's possible to reach a full agreement with a doctor before deciding on services or an institution. (...) It's not a question of "psychosocial disability", but rather of providing support for the "mentally ill" (...). They play with words but it's still a medical model and not a disability model."

Person with a disability

Lastly, some of those interviewed believed that we should be wary of a policy of 'inclusion' that is taken to an extreme, which may hamper efforts to advance inclusion for persons with disabilities or lead to the abandonment of severely disabled people:

"(...) There is a risk policies will benefit mildly disabled people; this is what I've heard from the ministerial departments and government officials, who say that there will always be institutions for severely disabled people. But we can't implement a policy of segregation. (...) I think there's an increasing danger of this, and I didn't think about it before... because (...) the notion of inclusion didn't exist before."

NGO representative

The levers to prevent deprivation of liberty

Information and support for the persons concerned and their families, an initial safeguard to prevent deprivation of liberty

One of the study's most significant findings is that support for both disabled people and their families is essential to reduce the instances of deprivation of liberty. Although it is often families who initiate the process of deprivation of liberty, they are also often the best way to avoid it, oppose it, and get the person out of an institution.

Whatever their background, all those who were interviewed highlighted the collective need for information on disabilities and the rights of persons with disabilities in order to reduce the instances of deprivation of liberty:

"Information and raising awareness amongst relatives are essential when the first crisis occurs."
Family member

People who have experienced the various forms of deprivation of liberty look to non-profit organisations for help with legal matters and support in their social and working lives:

"The last time I was hospitalised without consent, I was able to get out thanks to advice and legal action taken by an association for the defence of patients' rights. (...) There should be more organisations that help people to recover, so that they can get their lives back and go to places where they can meet others."
Person with a disability

The involvement of persons with disabilities and their families in the care pathway helps anticipate and manage crises as early as possible

Psycho-educational and educational therapy programmes are being developed for persons with disabilities, their families and friends in certain services, which often make it possible to avoid a crisis and involuntary treatment:

"Programmes for persons with disabilities are also important. They need to be trained themselves (psycho-education, cognitive re-mediation). People will then be able to tell themselves when something is going wrong."

Family member

At the same time, research has shown that peer group activities make it possible for persons with disabilities to express themselves and foster empowerment (European Network on Independent Living, ENIL, 2014). Programmes to help families gain a better understanding and appreciation of their family member's disability also contribute to finding solutions:

"The whole family was trained, including the other children, and we were able to discuss the situation with him (our son) and tell him that it would be a good idea if he went to a clinic and he agreed."
Family member

To prevent crisis situations and avoid involuntary hospitalisation, several people mentioned the importance of upstream support and the establishment of advance directives in psychiatry.

"Advance directives are very important, and so is prevention. Support needs to prevent these breakdowns that lead to involuntary hospitalisation. We need to be supported in a positive way, particularly when it comes to personal, family, and, of course, social independence, and, above all, freedom of thought because that's never mentioned..."

Person with a disability

A national study is currently being conducted –simultaneously in Marseille, Paris and Lyon– on 'psychiatric advance directives' (PADs). PADs enable persons with disabilities to write, share instructions, and designate people of trust as a precau-

tionary measure. That way, their choices and preferences concerning drug treatment and non-medical related instructions can be made known and respected if crisis situations occur that alter their ability to make judgements. Their main aim is to reduce the frequency of hospital readmission, particularly on an involuntary basis (Maitre et al., 2013). Mainstreaming the use of psychiatric advance directives is one of the recommendations put forward by the General Inspectorate of Places of Deprivation of Liberty (CGLPL) in its report on psychiatric treatment without consent and fundamental rights (CGLPL, 2020). They exist in several Western countries and can take various forms: in particular, joint crisis plans.

These informational, training, and support systems for persons with disabilities and their families make it possible to better anticipate acute crises (warning and early crisis management systems) and provide the time required to "negotiate" hospitalisation or treatment with consent, rather than compulsory hospitalisation for security reasons, as explained by the General Inspectorate of Places of Deprivation of Liberty (CGLPL), the healthcare professionals interviewed, persons with disabilities, and their families:

"If someone had taken the time to discuss the situation with him the first time around to persuade him to receive treatment, things could have been different. The first involuntary hospitalisation wasn't justified. It happened because we were at a total loss. We were told that we didn't have a choice. We were distraught when we saw our son like that... We trusted them." Family member

However, many solutions put forward by the people interviewed would make it possible to avoid or leave places in which people are deprived of their liberty due to a disability. Behind the supposed need to hospitalise people in a mental health facility or another institution often lies a lack of healthcare options and adequate support².

"(...) A lack of healthcare options is sometimes used as an excuse to say that nothing else is possible." Healthcare professional

The development of alternative –including non-medical– structures would foster the autonomy of individuals with disabilities

Based on experience abroad, local emergency services may be a solution to care for persons with disabilities undergoing a crisis (Gooding et al., 2018). The deployment of non-medical mobile emergency

teams and accommodation can help prevent involuntary hospitalisation. In this type of structure, persons with disabilities receive support and counselling to defuse the situation and help them recover and reintegrate society and the work force:

"The hospital should quickly dispatch someone –a team– to assess the situation and whether there's another way to handle the situation instead of hospitalisation. No one comes, so the situation just gets worse. We're often just left with the option of calling an ambulance or the police... We don't know what to do." Family member

"We now have something that has worked extremely well with the psychiatric sector (...), a transitional structure to enable persons with disabilities to have a different experience and live as independently as possible. You need breathing room, space and temporary accommodation centres. (...) But there are so few of these structures." NGO representative

These specific places adopt an approach that is different to that of traditional psychiatric treatment which does not always meet the needs of persons with disabilities:

"We need a social approach with peer helpers, non-medical people who aren't always on the lookout for symptoms... it is much more support that is needed; psychiatry's outlook would be changed –there'd be a focus on the person's suffering and not the treatment. Drug treatment isn't the answer– if it were we wouldn't be looking for other solutions." Person with a disability

"In Paris there's a special centre for schizophrenic people that uses cognitive remediation techniques and has, in fact, also been used by autistic people. (...) In Lyon, there are similar initiatives (...). These initiatives are good and reassuring for the future in terms of reintegration into society and support for persons with disabilities." NGO representative

In several countries, coercion-free and non-medical community programmes for persons in extreme distress are alternative solutions to hospitalisation (respite centres, temporary care and accommodation centres, etc.). There are less residents than in hospitals, they live in a homely environment and have more contact with people outside the centre and the staff, which is often composed of peers, and the care provided is less dependent on medication. Obuaya et al. (2013) have shown that such programmes make it possible to reduce the number of compulsory hospitalisations and increase the rate of people's satisfaction:

METHOD

This qualitative study was based on nineteen individual interviews with stakeholders in the fields of disability and deprivation of liberty, falling into seven categories: the General Inspectorate of Places of Deprivation of Liberty (CGLPL), two policy makers, two directors of health care institutions and social services, two NGO representatives, two health and social care professionals, three families of people with disabilities, and seven people with disabilities who have experienced deprivation of liberty.

Without aiming at statistical representativeness, this qualitative study highlights certain barriers and levers that exist in France in situations that constitute disability-based deprivation of liberty and gives priority to the views of the people concerned, family members and friends.

The interview method that was chosen –semi-structured interviews– allowed for plenty of leeway in the interviews to enable interviewees to discuss other issues of concern. The ideas and concepts mentioned by the interviewees were classified in order to identify a maximum of similar and different issues until the emergence of new issues.

Each interview was conducted by an interviewer while an observer took notes. The interviews lasted between 50 and 90 minutes. Two distinct interview grids were used according to the type of stakeholder interviewed. The subjects addressed were the following:

Disabled people and families

- The **factors triggering** deprivation of liberty
- The **person's experiences** once they were in the deprivation of liberty system
- **Leaving or not leaving** institutional care
- **What was needed and what should have been done** during treatment

Policy makers, directors of institution, NGO representatives, and health and social care professionals

- The **person's experiences** according to the type of deprivation of liberty:
 - Involuntary hospitalisation and treatment
 - Diversion from the criminal justice system
 - Institutionalisation
 - Home confinement
- **Good practices** in terms of health care and social rehabilitation support

"That's the challenge ... supporting the creation of a wide range of possibilities: "supported living" that's somewhere between an institution and the person's home to combat the problem of people being locked up. We are faced with "de facto" deprivation of liberty, it's not forced."

Policy maker

"The lack of solutions for families regarding "alternative" or transitional accommodations on a voluntary basis can also lead to placement in an institution or a hospital against the person's will..."

NGO representative

A **director of an institution** who was interviewed went so far as to suggest that the "inclusive" and "compensatory" approach, which can stigmatise people with disabilities, should be replaced by a more positive approach that focuses on a person's skills and not on their disabilities and limitations:

"We're just starting to realise that people with disabilities can be an asset and a source of enrichment, but it's a completely new idea. In France, it really is a compensatory system based on the idea of providing support and assistance, and coming to their aid."

Training healthcare professionals, promoting responsiveness to disabled people's needs, and dissemination of good practices

All those who were interviewed agreed on the need for training of healthcare professionals. A policy maker stated that "there's still a lot of room for improvement" in terms of training staff and that we are at a "relatively early stage of learning how to better support and be responsive to the people concerned". The lack of staff trained to deal with people with disabilities can lead to a form of interference by staff in these people's life plans. This goes back to the recommendations of the General Inspectorate of Places of Deprivation of Liberty (CGLPL), both in terms of the initial training of healthcare professionals on the topics of recovery, peer support, and patients' rights, and also continuing training that makes it possible for practising healthcare professionals to update their knowledge and skills.

A director of an institution noted that every time she went to work in a new group home for people with disabilities, there were people who remained locked in their rooms, which is against the law. The staff thought they were dangerous. This director underlined the absolute need for staff training in order to avoid these

situations, both to disseminate "solution-orientated" approaches and to learn how to manage their emotions, as well as in terms of management and team responsibility. She highlighted the qualifications deficit and the situation of the staff in medico-social institutions, who are sometimes experiencing serious personal difficulties themselves and are unable to help residents with their future life plans. The presence of peer mediators in the health and medico-social teams can also contribute to a better assessment of the person's needs and difficulties, and facilitate relations with staff.

The obstacles that need to be overcome to limit deprivation of liberty

Many of those interviewed put forward concrete suggestions to foster freedom of choice and inclusion, and ensure this approach in the long term. These suggestions included transitional accommodation, specific community services (such as housing assistance, home help services, peer support services, etc.), innovative independent living facilities, integration of groups in mainstream services or full and direct use of such services, training, and so on.

The regulations, the fungibility of funding, and collaboration between the health and social sectors must be developed

These solutions require the development of the regulations and the fungibility of funding. The lack of resources and the financial structure currently implemented are an obstacle to reducing the instances of deprivation of liberty:

"In France, there are three main sources of funding to care for persons with disabilities: the Social Security system, the Regional Health Agencies (Agences Régionales de Santé, ARS), and the departmental councils (Conseils Départementaux). This is a barrier to independent living for disabled people, because, again, people who can't move from one scheme to another, because it's not the same funder, are compartmentalised."

NGO representative

"France operates in a very compartmentalised and sectorial way, everyone works in silos and there's a real health culture with sector-specific funding, and the same goes for the medico-social sector. It's an "institutional" culture; inclusion and inclusive environments are only just beginning to be considered."

Director of an institution

It is, for example, very difficult to amend regulations in order to build on what people with disabilities know and enjoy doing. Initiatives are often limited by the regulatory aspects and a lack of coordination:

"In France, all the regulatory aspects are major obstacles. For example, in a specialist care home, you can't prepare meals with the residents. (...) The residents lose the habit of going shopping and making themselves something to eat... Then, when you want to leave an institution, you have to learn how to do everything all over again. You've unlearned everything you knew how to do..."

Director of an institution

"The medico-social and health services blame each other but the persons themselves have no choice in anything."

NGO representative

One of the **policy makers** interviewed wondered what could be done with a health policy that aims to reduce involuntary hospitalisations to an absolute minimum, whereas in certain situations, he believed that involuntary care was being used to manage the effects of the shortage of alternative solutions and the insufficiency of upstream interventions. He thought it was all the more regrettable because:

"(...) the organisation of healthcare that could reduce the use of compulsory hospitalisation is undoubtedly more advantageous for the State and Social Security budget than its non-organisation, that is to say that the palliative measures that are implemented cost more than what a good or better organisation of our health care system would cost. (...) Quite clearly, there's a lack of facilities, the approach is so hospital-centric that we only think in terms of institutions, both upstream and downstream."

"We don't have an independent living in the community culture in France. Much remains to be done, even if an accommodation unit would cost the same as an institution..."

NGO representative

State action and a change in the way we perceive disability are required

These changes can only be brought about through policies for persons with disabilities. The French government has shown political willingness to improve the situation. The sectorisation of psychiatric services and, more recently, the five-year strategy for the transformation of medico-social services (2017–2021) and the "no one left behind" support programme for persons with disabilities ("*Réponse accompagnée pour tous*" initiative) are intended to be a step in that direction. The aim of this last scheme is to prevent any break in

the life pathways of individuals with disabilities, formulate inclusive solutions, and improve service provision in order to better meet the needs of people with disabilities. However, as stated by certain interviewees, the scheme is inadequate and there is little change on the ground. Although a process of deinstitutionalisation has been initiated in the French psychiatric sector and the medico-social sector, it has remained incomplete, due in particular to the lack of resources allocated to the community to provide accommodation for these people and enable them to live in a mainstream environment.

There is a trend to develop day centres and intermediate solutions that lie between living in an ordinary home and an institution, but the developments are slow and the number of individuals with disabilities living in institutions remains high in France. The number of places in accommodation centres continued to rise between 2014 and 2018 (+5.5%, i.e. 8,000 additional places (Bergeron, Dauphin, 2020).

Another major obstacle is the way society perceives persons with disabilities. There is general agreement amongst healthcare and medico-social professionals, policy makers and directors of institutions, NGO representatives, family members and persons with disabilities themselves that there needs to be a real change of attitude. Many challenges thus remain with regard to information, awareness raising, support, training, coordination between sectors, the organisation of care, and also human, financial, and legislative resources.

* * *

These barriers to the autonomy of persons with disabilities raise questions in terms of equal rights, including the fundamental right of freedom to choose how you want to live your life. Between protection and overprotection, when and how should the state intervene? When does institutionalisation become deprivation of liberty? If it is not possible "to protect without force", should we accept "to force in order to protect" (Velpry et al., 2018)? How can individuals with disabilities be included in society without further discrimination?

Despite the growing acknowledgement of the fact that deprivation of liberty is a violation of human rights at an international level and stances in favour of the inclusion of individuals with disabilities in society,

there has been little change in attitudes and practices. As stressed by the majority of interviewees, legislative changes, particularly in France, must be accompanied by a radical change in attitudes based on a citizen-centred vision of individuals with disabilities. Moving towards the abolition of closed institutions and the prohibition

of compulsory treatment would not be enough to foster the inclusion of individuals with disabilities or the necessary support for their families if alternative solutions are not provided in the community and people's perception of disability does not change. ♦

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