**REGIONAL CONSULTATIONS**

“From isolation, invisibility and segregation into inclusion of persons with disabilities in the community. Identifying and overcoming barriers to the successful process of deinstitutionalization”

[*Committee on the Rights of Persons with Disabilities*](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx)

**Outcome of the regional consultation for EU, other Western European countries and other States**

**BACKGROUND**

On 25 May 2021, the Committee held the online regional consultation for countries of the European Union, other Western European counties and other States. There were 89 participants in total: 40 speakers and 49 observers, as well as eight Committee members, and members of the Secretariat. The Committee received 58 written submissions and four videos.

Organizations of persons with disabilities of the following countries were represented: Austria, Belgium, Bulgaria, Czech Republic, France, Germany, Greece, Hungary, Israel, Italy, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, and the United Kingdom of Great Britain and Northern Ireland.

**THEMATIC CONCERNS AND RECOMMENDATIONS IN THE REGION**

In many States, institutionalization, segregation and exclusion remain the norm and the reality for persons with disabilities. Deinstitutionalization process, supported by funding from the European Union, perpetuate institutionalization. Violence against persons with disabilities is rampant in institutions and perpetrators remain unpunished. Support measures and personal assistance continue to be under-developed. Support continues to be provided in institutions. Children with disabilities, older persons with disabilities, persons with intellectual disabilities and persons with psychosocial disabilities are disproportionately affected by institutionalization. Coercion in mental health systems continues to be common. Poverty, lack of accessible services in the community and pressure over families are main factors leading to institutionalization. Austerity measures have significantly affected funding on independent living schemes and pushed persons into institutions. Measures adopted during the Covid-19 pandemic resulted in more isolation and in deaths of persons with disabilities.

The following paragraphs describe the concerns raised and the recommendations (R) raised by participants:

**Legislation (art.19, articles 1-4)**

*Concerns*

* no incorporation of the CRPD Convention into domestic law;
* lack of commitment to implement legislation;
* planned reform of mental health act still focusing on medical approach, justifying coercion and not acknowledging multiple discrimination
* diverse interpretation of the law on independent living at the municipal level due to self-governing;
* law prohibits persons with disabilities placed in institutional settings to apply for social housing and personal assistant;
* draft additional protocol to the Oviedo Convention contradicts the CRPD
* non-enforcement of law
* CRPD not taken into account or misinterpreted, to justify creation of institutional settings
* General Comment No 5 not considered
* Legislation allows for forced commitment in a broad range of circumstances; such as perceived risk to property or emotional wellbeing of relatives
* Not sufficient resources to implement law

*Recommendations*

* the Mental Health Law needs to be repealed (since it is all medical model, about the management of coercion,) and all admissions to mental health inpatient facilities and all outpatient services should be based on the free and informed consent of the person concerned
* The access to appropriate and adequate support to live in the community should be recognized as a fundamental right in the legislation at all level of government and ensured to all persons with disabilities across the country.
* CRPD must be incorporated in domestic law.
* Introduce legislation with a deadline for the closure of psychiatric institutions and sufficient provision of mental health and community-based services and support in conjunction with disabled peoples lead organisations.
* Incorporate the DI commitment into national legislation and introduce clear legal obligations into law
* Continuing to call urgently for an end to law which authorises coercion on the basis of psychosocial disabilities.
* Covid-19 has also highlighted the need to legislate a dedicated law that acknowledges people with disabilities' right to receive welfare and community services to allow them to receive the appropriate support they need in order to be included fully in the community regularly and more so during times of emergency.
* Absolute prohibition of forced treatment and commitment, with a repeal of all legal provisions that authorize any forced or non-consensual interventions or treatments in the mental health system.
* Development of laws and policies that replaces coercive regimes and ensure that all services are based on the free and informed consent of the person concerned, including in emergency situations.
* Legally prevent so-called " associations of persons with disabilities " which directly or indirectly manage establishments with accommodation (or who otherwise violate the CRPD) from being "representative".

**Policy design, implementation and coordination (art. 19, arts. 1-4)**

*Concerns*

* No oversight of Equal Opportunity Body on the implementation of policies by local authorities
* Lack of cross-sectoral cooperation between Health and Social Services, and between public and private providers
* Lack of coordination, DI policy is not managed by a single ministry
* Local authorities fund institutions and oppose DI
* Austerity measures reducing availability of community based services
* Trans-institutionalization
* Long-term processes of DI
* Insufficient efforts to implement policies
* No certainty about competencies and oversight powers of foreseen NHRI
* Previous DI strategy was not enough, a new DI policy still needed
* DI is not a policy priority
* Misunderstanding of independent living by state officers in charge of policy implementation
* Authorities not willing to change the status quo

*Recommendations*

* Design and implement a national de-institutionalization policy.
* Monitor de-institutionalization
* A transition programme from segregating to community -based services should be adopted and adequately funded
* Cease new funding that contributes to further segregation of children.
* Monitor closely how the money invested reflects on the lives of people who were supposed to benefit from these investments.
* Invest directly toward development of mainstream services to enable children to stay with their families – hospitals, kindergartens, schools, social housing –
* DI is managed by a single Government body, both soft activities (education, consultations etc.), as well as management of investments.
* Financial matters should be transparent and allocated to living in the community.
* To end institutionalization, all policy documents should include a definition of the term "community living" stressing personal autonomy and choice.
* The need to adopt strategy of deinstitutionalization – with specific measures, time-frame and budget – is urgent.
* Not to get distracted: Millions in institutions globally and millions more in danger of institutionalisation. Their inclusion must get all attention and resources
* Some people may need “residential care”. What matters is how this is set up, principles it follows, the individual needs; that it leads to inclusion
* Accountability: User-led quality inspections are crucial, with public, easy to understand results; with consequences for providers.
* Promote activity and engagement of policy-makers and service providers. Reward changes and progress in the right direction
* Protect legitimacy of deinstitutionalisation. There is no need to play in the hands of the opposition by using terms such as “deinstitutionalisation in crisis
* Provide policy-makers, funders and service providers with a clear picture of the desired outcome. Trust in their ability to deliver
* People have different roles to play: be that EU experts, national policy-makers or service providers. They have different needs in how they work and what problems they are solving. This needs to be reflected in guidelines.
* Learning from behavioural sciences: What steers people towards institutionalisation? How to turn these choices other way round? “Changing peoples’ mindset” is the toughest job. Changing the way people work and behave is doable; Minds will follow.

**Participation of persons with disabilities (arts 4, 19)**

*Concerns*

* Persons with disabilities not consulted in the establishment of a personal assistant benefit, adopted mainly because of the lobby of associations of parents of persons with disabilities.
* No involvement of organizations of persons with disabilities in policy development on inclusive education
* No participation of young persons with disabilities
* Lack of involvement of organizations of persons with disabilities in DI processes
* Social welfare lobby and services providers are heard, but not persons with disabilities
* Persons living in residential settings afraid to speak, no involvement at all
* More representation of institutions, including Church, in consultations.
* No involvement of children with disabilities and elderly people with disabilities in consultations.

*Recommendations*

* Independent living organisations [run and controlled by disabled people], not just DPOs, should be involved in the policy making process and allowed to introduce self-determination and independent living as bottom-line for disabled people.
* Accessible representation of young persons with disabilities in local, regional, country and international levels.
* Member States should ensure close consultations with and involvement of disabled people, through their organisations, in all stages of ESI Funds use.
* Constantly promoting meaningful, well-funded involvement of organisations led by people with psychosocial disabilities.
* Empowerment is needed, including through assistive technologies, user-led services, accessible social security and other support.
* Need a dialogue with regional governments.
* Autistic persons and their organisations must be consulted in order to understand what accessibility measures they need.
* children to be consulted and their choices respected.

**Discrimination (arts. 5, 19)**

*Concerns*

* Exclusion of children with intellectual disabilities from initiatives to promote inclusive education, as they are considered “unfit to follow the common curriculum”
* Parents of children with autism forced to accept institutionalization of their children
* Children with disabilities at a higher risk of being institutionalized
* Persons with disabilities discriminated to be eligible for DI, they must be employed
* Bureaucratic procedures discriminate against persons with disabilities
* Persons with disabilities overrepresented in residential settings
* State funding to institutions is 30 times higher that funding to independent living
* Persons with disabilities still considered as objects of assistance
* DI excludes older persons with disabilities
* A person with an intellectual, psychosocial disability needs demonstrate a sufficient "functioning level" to have independent living.
* COVID-19 has exacerbated the inequalities that already exist in society
* The right to non-discrimination and reasonable accommodation is only partially implemented in law, and less in practise.
* Children with disability are not considered in DI process.
* Employees of institutions tested positive Covid-19 were hospitalized, while the positive tested children remained locked in the institution.
* People in institutions did not receive information during the pandemic
* People with psychosocial disabilities living in institutions became more isolated and invisible during the pandemic
* Persons with psychosocial disabilities are more likely to be detained in mental health facilities, they are even detained for a lifetime.

*Recommendations*

* Within the DI process, it is necessary to pay careful attention to include all persons with disabilities and all institutions, regardless of their founders.
* Making governments fully accountable for multiple discrimination
* Start with those most likely to be left out: people with complex support needs, people with intellectual disabilities. Make the changes and services work for them first.
* Reforms to child protection must be followed by changes in adult services to avoid people with disabilities who reach adulthood ending up in institutions

**Awareness raising**

*Recommendations*

* Make anti-stigma campaigns
* Calling on governments to publicise the UNCRPD effectively; it is still poorly known.
* Strongly promoting rights-based training which is compliant with the UNCRPD
* The awareness rising activities, stronger voice of persons with disabilities in public debate and inquiries from international monitoring bodies might accelerate the process and generate political will to introduce changes.
* Society needs to be more attentive, informed, concerned.
* Legal obligation of training about autism (and psycho-social difficulties) for all civil servants who have to meet the public.
* With regard to autism and psycho-social disability, the entire population of the area (shops, public services, schools, industries, residents, etc.) must be made aware of how autism functions, especially in order to prevent mocking, rejection or condescension.

**Covid-19 emergency (arts.11, 14, 15, 16, 17 and 19)**

*Concerns*

* During the pandemic isolation was complete because no one could visit a person in a Psychiatric hospital.
* Many people living in residential setting were infected, and died for lack of protection arrangements and adequate staff.
* Persons living on their own were confined and there was more burden on family caregivers
* Persons living with their families were abandoned because of lack of support services
* Significant increase in deaths of older disabled persons
* Statistics shows that number of deaths is a fifth higher than the average for previous years
* Heavy restriction of in-person services
* Government cancelled all home visits, including personal and therapeutic care
* Complete lockdown in psychiatric hospitals
* Staff in institutions overly relied on toxic levels of medications and chemical restrains.
* Lack of information, inability to access support
* Because of confusion between nursing homes and rental homes, tenants of public housing were lockdown, no family visits and no contact with the outside world.
* Institutions offered responses based on financial criterial, living the needs of persons with autism neglected.
* Triage of persons with disabilities living in institutions
* Pandemic has reduced even small achievements from NGOs and showed a lack of cooperation especially between the health and social sector
* Harsh impact on persons living in institutions, urgency to strengthen efforts towards DI
* All touch-based treatments suspended, adversely affecting persons with autism
* Persons with autism torn apart from any familiar environment and routine
* Family or relatives became the main caregivers
* Persons living in institutions had limited or no contact with families
* Many deaths in homes for elderly people.
* People discharged of institutions and sent home were completely cut off from social contacts and left on their own.
* it was difficult to get protective materials such as masks and gloves in the beginning,
* Services have been removed or severely limited during the pandemic
* People with hearing impairments deprived of lip reading due to the use of opaque masks.
* In families, mandatory confinement, teleworking and video classes in inadequate housing conditions, as well as the interruption of rehabilitation sessions and other home support for people with disabilities, generated complex family relationships with situations of exhaustion. Many families were forced to institutionalize family members with disabilities due to worsening physical and mental conditions
* Some people living in group homes, were not allowed to walk around the city alone, to go to the store or coffee alone. Such measures did not apply to their neighbours living in the same street, nor to the employees of the institution or NGO.

*Recommendations*

* During emergencies, the goal must be to get disabled people out of the psychiatric hospital to maintain infection control and avoid the need of unnecessary self-isolation, withdrawal of in person support services that maintain wellbeing during any deadly virus outbreak.
* Isolationcaused by the pandemic highlighted that the residents of institutions need regular counselling and psychological support, even after the coronavirus-emergency.
* Institutions must have emergency plans. They need to be prepared for a new pandemic or any other kind of emergencies. **Preparation to emergency - -** A designated staff member is responsible for the development and implantation of Emergency guidelines in the organization. For organizations that provide services for people with disabilities, the emergency model should consider the Emergency needs of professionals and the Emergency needs of the service users; - Accessible emergency kits for staff and service users in community-based settings. When living independently in the community, group homes, or supportive communities, this is crucial.; - Resiliency program provides emotional and practical tools to prepare emotionally for emergency situation; - Community as a resource – building network and relationships with different actors in the local community can bring much support in times of crisis; - Digital literacy trainings for professional teams and service users.  **When an Emergency Event Occurs: -** Executing protocols and guidelines according to the emergency situation - leaving no one behind; - Communication between all levels of the organization is crucial to provide a quick, efficient and accurate response. Digital transformation and implementation of knowledge management systems can support that; - Support and guidance to professional teams, including emotional support and flexibility in routine. For example – opening a short-term emotional support hotline for staff members/ service users. **3. Emergency Routine: -** Adjusting the programs to the situation – flexibility and creativity as leading concepts. Organizations should provide the services that are needed and keep routine as much as possible, - Accessibility of the services: Moving to online platforms or bringing the services to the people in a proactive way; Assessment - of the resiliency level among staff and service users.

**Legal capacity (arts. 12, 19)**

*Concerns*

* Some 90% of elderly or disabled persons under guardianship or support administration are sent to institutions by the courts, even against their will and the availability of their families to support them at home.
* A Guarantor that deals with people deprived of their liberty, also deals with people "segregated" in services”
* Out of 45.000 persons living under guardianship, almost 4000 being institutionalized in over 442 social homes, in some cases the chief of the home acting as a legal guardian.
* Persons with disabilities abused and institutionalized by guardians,

*Recommendations*

* Clear legal frameworks in place, promoting equal recognition before the law, moving away from outdated substitute decision-making regimes towards Supported Decision-Making. An adequately trained workforce in the judiciary system and in the social care and support services to further promote Article 12 and SDM.
* The system of guardianship must be abolished, and supported decision-making must be strengthened in all aspects of life.
* Providing concrete examples of successful, rights-based alternatives to substitute decision-making and institutionalisation; many people cannot even envisage these.
* A good example is “personligt ombud”, a personal representative that does not overtake legal capacity, which stands in contrast to the practise of using administrators.
* Supported decision-making become the norm. How can people take responsibility over their lives, when not allowed to decide

**Involuntary institutionalization (art.14)**

*Concerns*

* People are transferred to Psychiatric hospitals by police-cars.
* Recently a law has passed, according to which, your family has the power to transfer you to a private hospital using coercion.
* It is very easy to be under involuntary treatment once again every time you quit your medication.
* Most of the people who live with their families come on and off Psychiatric hospitals.
* Those who don’t have somewhere to go, and they need a group home, may wait several months in the hospital, until a home is found for them, which they do not choose, it is just imposed to them.

**Violence in institutions (arts.19, 15, 16 and 17)**

*Concerns*

* Overmedication, restraint, isolation rooms, even beating are used to control people
* They deprive you of your mobile phone, and you cannot access internet.
* People stay in hospitals from one month to several years, especially in the private sector, where institutionalization is a common practice.
* institutionalized children with autism are mistreated by the care staff
* Isolation in residential care facilities and physical restraints systematically adopted against “uncooperative” persons, namely persons with intellectual and/or psychosocial disabilities,
* Children living in group homes: sitting motionless on chairs, couches or benches, or on concrete floors sitting in pervasive inactivity, some rocking back and forth, hitting themselves, biting their hands or poking fingers in their eyes.
* Children kept in cages and cage-like cribs.
* children exposed to emotional neglect, inappropriate and potentially damaging models of behavior,
* Exposure to violence, bullying, and other forms of abuse that are common in institutions
* Risks to depersonalize people with disabilities and not to let them express their interests or wishes;
* People stripped of their dignity.
* During the pandemic, lack of support that resulted in inhuman treatment or even danger to health or lives.
* Women with severe intellectual disabilities gave birth in an institution, sexually abused by one of the employees but the authorities didn’t properly investigated.
* At the beginning we were completely closed for a month and a half, there was a lot of distress. Then they drove us (with the vans) to get a little air.
* Disabled people were tied to bed cages, into tragic health conditions and overmedicalised, among others.
* the indefinite incarceration or threat of placement in institutions,
* the highly intrusive, violent and harmful non-consensual medical interventions
* the enforced administration of mind-altering drugs and electroshock, isolation and restraints,
* the degradation of forced nudity,
* the removal of self-determination, losing the power to control our own bodies and minds, the loss of control over virtually all aspects of our daily life, down to who we can meet and talk to or when we can eat, leaving us powerless in the hands of the medical professionals.
* the infliction of fear, suffering, pain and trauma, are all together creating a torturing environment
* Widespread practice of persons forcefully committed yearly to psychiatric wards
* Forced hospitalization and treatment are commonplace for people with more complex psychosocial situations.
* Forced commitment is neither the last resort, as often narrated. Instead, it is the State's "first line" treatment module for people with more complex needs.
* Prescription of the drug Risperidone to 5 years-old children, with some restrictions that are not respected in practice.
* Number of persons who were forced hospitalized is increasing.
* An unknown number of persons are under forced psychiatric medications, some under the threat of forced hospitalization, others because they cannot find the medical help they need for the drug withdrawal.
* people with intellectual disabilities living in institutions are lonely and have few or no meaningful contacts
* During the pandemic and no one could visit persons living in institutions. People suffer of loneliness and institutionalization.
* The isolation of residents from external visitors lasted even after the easing of confinement measures, transforming residential care facilities into detention places.
* People have been deprived of any social contact outside institutions for an unacceptable period of time (often more than 180 days).
* The everyday life of people with disabilities who live in homes and institutions is often characterized by isolation and separation. No privacy and the self-determined structuring of daily life. Disability is therefore often the result of institutionalization

**Persistence of institutionalization (art.19)**

*Concerns*

* Large number of persons with disabilities continue living in institutions. Number of people institutionalized has increased
* People who are in need of more support are forced to go live in residential care offered in group homes
* Involuntary treatment counts as 60% of hospitalization
* Different OPDs also participate and support the institutionalization of people with functional diversity
* Continuing investment of public funds in the construction of new residential institutions for persons with disabilities.
* 3,4% of persons have access to small family type communities or to community housing, while over 90% live in institutions.
* Regional policies and regulations continue to maintain or bring back to institutionalizing facilities older or disabled persons, mainly those with high support needs.
* Large number of persons with disabilities still in residential care, most of them in old- isolated facilities, together with other 200-300 people in the same place. The conditions are not adequate.
* Most of institutionalized persons do not even know they could request to live in community; they cannot pressure the system, as they do not know of any alternatives. As this is the only known approach, authorities claim that institutions are in demand.
* Aa large numbers of residential care facilities were developed with EU Funds
* The country has replaced a system of large, old orphanages with newer, smaller buildings that are still operating as institutions.
* The system of support for persons with intellectual or psychosocial disabilities remains predominantly institutional.
* Data indicate that there has been even an increase in the number of residential care facilities.
* The State actually built many more institutions, and these are now called ‘Centres for Family-Type of Care’ or ‘Centres for Care’.
* In the 10 last years, the number of institutionalized persons continued to grow.
* In 2018 the country had 108 900 children institutionalized in medico-educational institutes. The criteria for the placement of children in these institutes is, according to the administration document: "deficiencies predominantly intellectual”.

**De-institutionalization (arts, 14 and 19)**

*Concerns*

* Deinstitutionalisation is relocation of large cohorts of disabled children and adults from large to smaller facilities.
* The alternatives options to residential care facilities (small group homes, supported living units, support measures at home, etc.) are still very few and mainly reserved to persons with slight disabilities.
* Lack of progress with deinstitutionalization.
* Building and renovation of large institutions continue, in some cases under the pretext of improving “energy efficiency .
* Protected living is the same with the residential care but at a small scale: still people life is decided by the staff, there is mandatory schedule for 3 meals/day, there is mandatory to have complain box in people’s house or to develop a schedule for a visiting program.
* Even the policy makers who declare that are in favor of DI, the entire system (legislation, administrative, institutional) is built with no vision, and based on institutionalization. Even when independent living initiatives are created, they have to deal with over-regulated & over-professionalized requirements.
* group homes and "community appartements" often determining all aspects of life (e.g., employment) are considered as "community living", if they are in a community and have less than 24 tenants.
* The decision on type of living arrangement is made by the authorities rather than the person.
* Institutions have their own DI related agenda, do not consider people in institutions to be people, only residents. Want to maintain control over persons.
* Small group homes are mushrooming across the continent instead of community support.
* There is still no action plan for De-I. On the contrary, regional governments still build new or renovate segregating institutions by even using European Structural funds.
* In most cases people are institutionalized due to a lack of response to their needs.
* The creation of a deinstitutionalization program for people with disabilities requires: - providing support services, including personal assistance and services provided at home and support products;- Physical and financially accessible housing; -Inclusive education and training and properly paid employment; -Provision of accessible transport; -Integrated and accessible health and rehabilitation services; -Effective monitoring of the deinstitutionalization process with rehabilitation professionals, psychological, social and educational support.
* The State Budgets must reflect the allocations necessary for the full compliance with Article 19
* The basic solution for DI suggested by the big majority of the stakeholders (government, families, traditional disability movement etc) is the supported living homes, so basically small group homes (especially for people with intellectual impairments, autism or with high support needs).

*Recommendations*

* Deinstitutionalisation should not be judged by closure of large institution – smaller ones or families easily replace them – but the conditions created for IL of disabled people, which entails accessible and affordable housing, technical aids, personal assistance (not family care) and accessible environment
* stop incarcerating persons with autism in ‘prisons’ that masquerade as ‘hospitals’, speed up the process of ending the cruel and degrading detention of Autistic people
* Abolish State sanctioned institutionalisation of disabled people.
* Immediately stop construction of new group homes and work to reintegrate children into families and, more broadly, move away from group homes as a placement for any child toward family placement for all children with and without disabilities.
* Moratorium on institutions.
* Prevent people with disabilities from being placed in institutions.
* Institutions must be closed as soon as possible.
* Trainings for the residents before moving them out of the institutions, because they need to be prepared for their new, independent lives.
* Local communities need to be prepared as well in order to properly welcome and include people with disabilities
* Financial resources aiming to fund deinstitutionalization truly support the inclusion and independent living of the people concerned.
* People with disabilities need to be involved in the planning and monitoring of the DI process.
* There is a social care workforce shortage. We need resources not only to train the new professionals but also those who have been working on the field for a long time. DI is creating a new situation for them as well, so they need to be prepared.
* DI should not be led by institutions.
* The DI process must pay careful attention to include all persons and institutions.
* Family members dedicate their lives providing care and support. Family members started many existing community-based services. Families don’t want their loved ones to be institutionalised. Involving them is critical.
* Flexibilization and decentralization must be promoted in all areas of the public: in the way the authorities deal with disabled people, in their scope for decision-making, in services, in living, loving and working.

**Reparations (arts, 19, 4)**

*Concerns*

* There is no remedy and reparation of harm for those who have been institutionalized

*Recommendations*

* Autists who have been incarcerated are given access to counselling services administered by practitioners trained to communicate effectively with their varying and differing communication needs.
* The State should review who bears responsibility for deaths in institutions and introduce effective mechanisms to provide reparations, redress and compensation, as well as guarantees of non-repetition.
* Securing victims of forced psychiatry access to effective remedies and redress, including effective mechanisms to obtain immediate release from any confinement or forced intervention in mental health settings
* Since coercive mental health practices represent patterns of violence against persons with disabilities, reparation is needed on a collective, as well as an individual level

**Support (art.19)**

*Concerns*

* Institutional care is offered in group homes, between 8 to 30 people
* Support is provided by institutions in group homes
* Only basic care is provided to people with intellectual disabilities in institutions
* There is no room for peer support.
* Given the limit of hours and low rate of payment people with high level of support needs and no family to look after them are forced to apply for institutional placement.
* Allocated funds to independent living are scarce, both in terms of number of persons served and of maximum individual fees, thus excluding persons with high support needs
* There is an unfair burden on family carer’s due to lack of support services.
* During COVID-19, many social services faced significant challenges, such as increased expenditures in parallel with unstable or decreased funding, and staff shortages, which put at risk the continuity and sustainability of support.
* During Covid-19 health and safety were prioritized instead of empowering individuals and supporting them.
* Easements were introduced as part of the Coronavirus Act allowing local authorities to relax duties around the provision of care and support . Local authorities have unofficially removed or reduced care.
* People faced large reductions in support, with day services closed, respite care cancelled, and some in-person support replaced by phone calls or support hours cut
* Loss of staff: The pandemic has worsened the staffing situation for disabled people
* The government has constantly forgotten disabled People in receipt of Direct Payments. There were no plans in place for months to provide personalized payments, Covid-19 testing and vaccinations.
* Continuing cuts to funding for social care and support for independent living. Particularly those with learning difficulties found out that their support was reduced without reassessment of their needs.
* Therapies were cancelled and services disappeared without warning or time to react, leading to a sense of bewilderment and anguish amongst autistic individuals
* People do not receive enough assistance; there is only physical support, mental/ emotional/ organizational or other forms of supports do not exist.

*Recommendations*

* Offer wider and more adequate possibilities for providing support and care in people’s own homes.
* Invest in small-scale support systems in neighbourhood communities.
* Ensure that the progress made towards the deinstitutionalisation of social services is not weakened by the onset of any public health crisis.
* A qualified workforce is at the heart of a quality support service delivery. take concrete actions for the upskilling and reskilling of social care and support workers.
* During times of uncertainty, support for autistic individuals should not be withdrawn, but intensified.
* Ensure that the interventions are not standardized, but based on the analysis of the person’s context conditions.
* Provide services that support persons and their families in their own homes, for example personal assistance services. These services must be available for everyone.
* Provide individualized support.
* Provide services must be inclusive and available for everyone. People with complex support needs must not be left out.
* Successful deinstitutionalization depends on availability of personalized, in-home support services for all.
* Individual needs must be taken into consideration and not only a medical approach which is dehumanising. There is a need for a shift from “care” to “self-determination”
* Give persons with disabilities the freedom and flexibility of choosing the type of support (service providers, representative or direct employment).
* One size does not fit all. This applies to institutions, and in the community. There’s no one service suitable for everyone.
* People leaving institutions need support establishing relations, learning about outside world and dealing with the consequences of institutionalisation (including support to cope with violence
* All support must be about establishing independent life in the community based on each person’s needs and choices.
* Introducing pilot projects on the ground, backed with evidence-based research, would serve as "proof of concept."
* People should not be penalised by financial considerations or restrictions due to the mutualisation of services, which should be adapted to the person and not vice versa.
* There is also a need to offer people with disabilities, free of charge and if necessary at a distance, specific training or education to learn how to live independently and better manage life in society, particularly in the case of autism or psycho-social disabilities.
* We need to provide and develop services in the community that respond to the needs of each individual and empowers them. Collective power, collective strength, collective interests, which are also the interests of each individual, are very important. Raising awareness and making a strong, users coalition for deinstitutionalisation is important

**Support- personal assistance (art.19)**

*Concerns*

* Personal assistance is a disability benefit for families to look after their disabled relative. It creates a quadruple unbreakable dependence between the disabled person and her/his family: physical mobility dependence caused by the impairment, emotional one resulting from the family relationships, financial coming from the cash flow into the budget of low-income families, and finally, social due to the control of a relative [as a PA] over the daily activities of the disabled person.
* It is based on the medical model splitting all disabled people in four groups with limited number of PA hours depending on the type and level of impairment. Individual assessment of the needs plays minor role.
* There is actually a scheme that includes PA, but it is very deficient, not based in the CRPD, quite difficult to obtain, subject to several payments charged to the user and not satisfactory at all.
* Personal assistance services are still project-based, non-systemic and limited in budget, duration and territorial availability.
* Introducing a systemic personal assistance service for people with various disabilities is planned up to 2025. Currently these remedies are prepared as projects, which makes taken actions limited in nature.
* Ministries and municipalities, who are responsible for granting personal assistance, are limited by budgets and are not fully taking the individual rights into consideration, including the best interests of the child, as the primary concern.
* The law prohibits persons with disabilities who are currently placed in residential settings, including group homes, from applying for social housing and for personal assistants.
* The state and the municipalities grant health- and care services, in a manner that does not respect self-determination, municipalities often state how or where we should live to receive municipal services.
* Large groups of persons still fall outside the right to select personal assistance benefit, though provided by law. By the end of 2020, only 3679 persons had been granted personal assistance benefit, even though authorities estimates that 14 000 qualify for it.
* A person is given personal assistant benefit with an emphasis on basic needs. Not enough assistance is allocated to participate in society through social activities, work, being a student, democratic participation, etc.
* Municipalities put restrictions on when, where and how the assistance will be given, in addition to whom is accepted as an assistant. By extension, user control is therefore not secured. There are considerable differences between municipalities when executing the scheme and many people are frightened to complain in trepidation of receiving worse services or being deprived of services.

*Recommendations*

* Invest in systems to make personals assistance widely available.
* Legislation on PAs, should set up limits for relatives as assistants.
* Individual assessment of needs should prevail in the procedure of accessing PA and payment should allow recruitment of PAs on the labour market
* Budgets should be increased to find qualified assistants on the labour markets
* Bureaucratic steps should be eased, direct payments should be given to the user, the user should have full choice and control over the hiring process, activities, formation and hours of service s/he needs.
* The current social system based on standardized fees and facilities should be reformed to adopt a system based on individualized projects and budgets, respecting the rights, needs and wishes of every person with disabilities, regardless of the level of the needed support.
* Increase of personal assistance supply to have a wider spectrum to choose.
* We need PAs to be available to provide support outside of counseling settings and regular office hours
* Social housing and personal assistance should be made available to all persons with disabilities without exception.
* PA and community based services need to be expanded. All children and adults with disabilities should be entitled to PA according to their individual support needs.

**Support-budget (art.19)**

*Concerns*

* The budgets involved in direct payment and support in one’s own home are based on the financial level for group home care and therefore are usually not sufficient for independent living.
* Many local authorities chose to increase the charges people had to pay for their support, further pushing persons into poverty and causing some to end their care completely. Telecare support has also faced charging increases.
* If a person is living in residential care, the state spent for each person 2,500-3,000 EUR/month, but if the same person chooses to live independent, the state will spend only 100- 420 EUR/month.
* Most state funding goes to services with institutional characteristics. Even persons who need minimal personal assistance sometimes are forced to live in group homes, because they cannot pay rent.

*Recommendations*

* Fully restore the budgets for individual support systems.
* Adequate funding is needed to facilitate the development of high-quality services
* Prioritize flexible and adequate funding streams to allow services to adapt to meet the evolving needs of the people they support, such as user-centred funding models.
* Prioritize funds and policies aimed at the development of home and community-based services.
* Apply the principle ‘the money follow the person’ put the person in control of his/her life.
* Change the model of allocating money for institutionalizing
* Making sure people have enough money for both a personal budget and then choosing the services to give him/her power and control over his/her life.
* Develop and finance good quality services, for which introducing personal budgets can be a useful tool.
* Emphasize the need to divert funding from hospitals to non-institutional community resources, backed by rights-based research.
* Funding for independent living should be allocated to the person, not the facility. It should also cover housing and living expenses because the person cannot earn them
* The amount of funding should depend solely on the disability and not on where they live.
* Funds should be paid directly to the disabled person, not to "institutions" or providers.
* Needs and self-determination must be brought into a balance that does not focus on the alleged scarcity of resources but solely on the self-determination of people with disabilities

**Services in the community (art.19)**

 *Concerns*

* persons with an intellectual disability living in residential care have to pay an hourly rate of 35 to 40 euro to the care provider for every time they ask to be supported in going to a sports club or other recreational activity of their own.
* Pensions and allowances are so low; that a person cannot take part in the life of the community even if he is very capable (cannot afford a ticket for cinema, theatre, of course travelling).
* Failure to invest into community-based services, such as personal assistance, and accessible housing
* Lack of sustainable funding, current resources being tied up in segregated services.
* The financing of social services is based on an ‘assessment of dependency’ and persons with disabilities have no possibility to control these finances. Institutions are direct beneficiary.
* The financing of social services is based on allowances. People receive a certain sum in order to purchase services, which can only provide a limited level of support. If a person requires a higher level of support, this is only guaranteed in institutions.
* In the health care system, the affordability of home care is ensured only to the extent prescribed by a doctor. This is accompanied by a lack of adequate material support for informal carers. PWDs often have no genuine choice than to live in an institution to access care/services.
* It is important to have a range of supports. At present, few persons with disabilities can access supported decision-making, education or physical and mental health care.
* 1.8 million persons with reduced mobility depend on external assistance to leave their home due to accessibility problems and 100,000 never leave their home due to the lack of accessible and affordable housing or supports
* Authorities funded the construction of an entire “special care village” for long-term placement of people with autism, Down syndrome and other “rare diseases” in a rural village. The authorities point out that the new care village was necessitated by the absence of community-based services for adults with disabilities. The village will be self-contained and cut-off from the community.
* Lack of accessibility, such as the entrance to certain buildings.
* Lack of adapted infrastructures, namely adapted public transportation
* On many occasions, persons are not eligible and are ‘left out’ of resources and either have to rely on services depending of charity or third sector organisations or perpetuate their stay in the hospital occupying a bed they no longer need, collapsing waiting lists and preventing other people who might need treatment.

*Recommendations*

* Create community services, open to society
* Invest in IL, develop community-based services.
* Modify the relevant regulations and quality standards for service provision, which currently are not conducive to ensuring conditions for independent living.
* Public and private money should be strictly invested in services ensuring independent living which respond to the individual needs of the people concerned.
* Every service that wants to support a person with disabilities can’t be pre-determined but it has to start from the choices, preferences and wishes of the person itself and, based on those, it has to be projected, financed, and activated
* The system of financing should allow free choice and control and should prefer community-based services.
* Ensure community mental health services that are based on human rights principles, in particular respecting legal capacity, ending coercive measures and ensuring participation of persons with psychosocial disabilities.
* Provide a range of supports. Efforts should be made to enhance access to justice, guarantee the provision of reasonable accommodations when accessing public services, and ensuring supported decision-making for all persons who need it.
* Community services should include all kinds of emergencies, not just the medical one
* Universal design and universal accessibility must be implemented for all types of disabilities, including psychosocial and autism-related disabilities, in particular through "passive" or "active" (human) adaptations to be provided by the socio-administrative system and by any public or private entity.

**Information (art.21)**

 *Recommendation*

* It is important to provide information, which is accessible to persons with disabilities.

**Control and right to privacy (article 19-23)**

*Concerns*

* Within institutional care, people must waive their privacy and personal freedom as they are required to follow organizational routines

**Support to families (arts 19 and 23)**

*Recommendations*

* Investing in prevention of family separation is key.
* Family reunification and changes of placement must be well-resourced, prepared and managed.

**Education (article 24)**

*Concerns*

* A very high share of young persons with intellectual disabilities is enrolled in special schools. The number of pupils directed towards special education continues to increase because of a lack of efforts by public authorities
* The Minister of education announces to strengthen special education rather than promoting inclusion
* During the pandemic, it took a long time to provide for the right to education of children and adolescents with disabilities and for their inclusion in the classroom, leaving the support teacher to organize sporadic initiatives and only on some subjects.

*Recommendations*

* Orientation to self-determination should be a part of school curriculum, and programs based on similar principles should be offered country-wide rather in very few locations.

**Health (arts, 11, 19, and 25)**

*Concerns*

* The Covid-19 pandemic has seen a dramatic contraction of health services provided in terms of personnel, facilities and services: Persons with autism who usually have greater difficulty in accessing care services, had to stop in their personal health care pathways and treatments.
* Persons with disabilities waited until the last round of registration to vaccinate against COVID-19, unless they were in age cohort eligible to be vaccinate earlier

**Housing (art.19 and 28)**

*Concerns*

* There is a shortage of accessible affordable housing for persons with a disabilities who want to live outside residential care.
* Municipalities have no policies aimed at young people with a disability who want to leave their parental home and live on their own.
* Disability policies do not provide for individual supports, accessible and affordable housing or mainstream community services.
* Alternative housing options in the community often maintain an institutional organization, denying to residents choice and control over their own lives.
* Housing benefit levels only meet about 40% of the cost of the rent.
* Individual social housing, together with accompanying measures in access to employment, education, social and health care etc., is not considered as the main option for independent living.
* Most people with intellectual disabilities are still offered to rent an apartment from the municipality, but the offer usually only includes rental apartments in housing where all the residents have an intellectual disability
* Persons who buy a home in the ordinary housing market experience to be denied necessary services in their homes
* The ministry of local government has the general responsibility for social housing, while the ministry for health and care services has the responsibility for housing for persons with disabilities. For this group of people housing is considered to be a health or care service.
* Housing solutions have been activated in an emergency manner during the time of pandemic. This was done based on minimal economic resources in many local social services. Often people are placed in residential structures at risk of being segregated. This is happening because in the Welfare system there is a very limited economic support for individualized projects compared to the financing for the activation of large residential structures.
* Eligibility criteria for public housing are very limited and rent subsidies do not cover even the lowest rent
* Universal design in housing has not been regulated in law, but some projects have shown the possibility to cooperate between civil society and the commercial building sector.
* Lack of universally designed and affordable housing, and services that allow persons with disabilities to live independently in the community.
* Few options that persons who receive intensive neuro rehabilitation in our Foundation have available upon being discharged. Unfortunately, in most cases, those persons end in residential facilities.

*Recommendations*

* Make sure that municipalities are obliged to make agreements with social housing corporations for Persons with Disabilities
* The responsibility for housing must remain in the same ministry for all groups of disadvantaged people in the housing market.
* Budget should not go to the provider but to follow the person according to their choice, and funding community living should depend on personal needs (including housing) and not on type of living arrangement.
* Provide genuine choices which promote dignity and independence, and shift investments into expanding the availability of accessible housing.
* Prioritise improving public housing when making investment decisions, instead of allocating funding to congregate care settings
* Social housing and personal assistance should be made available to all persons with disabilities without exception.
* Establishing a public authority to provide for access to housing, economic and social support in order to facilitate deinstitutionalization and the right to live independently and be included in the community. Such assistance programmes should not be centred on the provision of mental health services or treatment, but affordable community-based services, including alternatives that are free from medical diagnosis and interventions
* People who do not wish to live in collective housing should not be forced to do so.
* Develop new and publicly funded social services to ensure and maximise the options to stay at home: adapted, accessible, affordable and inclusive housing arrangements are essential.
* Guarantee real access to public social housing for persons with disabilities to rent and purchase, anticipating emergency situations due to disability
* Guarantee universal access to subsidies to adapt your home.

**Work (art.27)**

*Concerns*

* As someone with Multiple Sclerosis, I lost my own job when I disclosed my disability, because of the need for my constant, physical presence in the workplace during working hours; home working was not permitted.
* Persons with disabilities do not always have the same opportunities due to the lack of resources and conditions that allows them to be chosen for the job they are applying for. In society, people with disabilities are put aside and are not permitted to participate actively in their community.
* The deficit in vocational training severely limit access to the labor market; wages and social benefits are very low

*Recommendations*

* Persons with disabilities need a fair income, preferably through employment in the open labor market. Appropriate financial support must be available for them.
* Possibilities of working time, which should be compatible with the choice of disabled person, while respecting the right of the employee;
* The right to work is vital for IL. New skills are needed, in order to enable IL.

**Poverty (art.19 –art.28)**

*Concerns*

* Another barrier to independent living is increasing poverty among people with disabilities. In 2010 the percentage of people with disabilities (younger than 65) at risk of poverty and social exclusion was 12 %. In 2018 the percentage increased to 18 %
* Social benefits are very low, many people with disabilities below the poverty line; the Support Products Assignment System suffers from permanent underfunding.

**Data (art.31)**

*Concerns*

* Authorities fail to collect disability-disaggregated data.
* A key challenge in monitoring deinstitutionalisation remains a lack of harmonized and disaggregated data of persons living in institutions across Europe.

*Recommendations*

* Provide data on existing personalized in-home services especially for people who need extensive support. Data on financial aspects and sustainability would be highly helpful

**International cooperation (art.19-art.32)**

*Concerns*

* Cases have been reported of countries using the funds to renovate existing institutions or to build entirely new care settings which, while sometimes small in scale, remain segregated from the community and do not give persons with disabilities any agency over how they live their lives.
* The ability of the European Commission to monitor the quality of investments and their adherence to the CRPD appears limited
* The recovery and Resilience Facility, which is a fund of 560 billion euros to help Member States make reforms and recover from the COVID-19 pandemic is not governed by the same rules as other EU funds, and therefore regrettably does not prohibit investment in institutions.
* EU funds are improperly used by the local authorities, to build sheltered houses most of them in remote area in the wilderness, near some poor villages, without public transportation or services nearby and in the same courtyard as the residential institution.
* In 2019, separate complaints against national authorities managing EU funds, for using European Structural and Investment Funds (ESI Funds) to build new institutions for persons with disabilities were filled. The European Commission rejected the complaints.
* The European Commission wrongly interpreted General Comment No 5 of the CRPD Committee in the following way: “Based on all the above [provisions of the General Comment No 5], it is clear that there is no general and absolute prohibition for the ESI Funds to support long-stay residential institutions”.

*Recommendations*

* European Commission’s flagship initiative in its new Disability Rights Strategy 2021-2030, to present guidelines on de-institutionalisation and independent living to the Member States, should be compliant with art.19.
* Address the support and funding the EU gives to local and national NGOs to enable them to monitor whether EU funds are used in line with the CRPD.
* The E.U. money should not go towards building or renovating institutions or rather should go towards transition and the family, community-based care.
* The use of ESI Funds should be strictly limited to projects that fully comply with the UN Convention on the Rights of Persons with Disabilities. -
* The Commission should withdraw, as a matter of priority, the internal Legal Opinion of June 2018, which allows for investments in institutions
* Member States should use React-EU and the Recovery and Resilience Facility to support “emergency deinstitutionalisation”, by supporting the development of community-based services.
* The Commission should closely monitor implementation of ESI Funds.

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