

## COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES

# GUIDELINES ON DEINSTITUTIONALIZATION, INCLUDING IN EMERGENCIES

### ANALYSIS AND COMMENT by ANFFAS NAZIONALE

#### **Warning**

The textual analysis of the "[GUIDELINES ON DEINSTITUTIONALIZATION, INCLUDING IN EMERGENCIES](#)" was conducted based on an un-official translation by the "Centre for Legal and Social Studies" of Anffas Nazionale.

#### **Foreword**

The *Guidelines on Deinstitutionalization* (henceforth Guidelines) drafted by the Committee on the Rights of Persons with Disabilities (henceforth Committee) and published last October 2022 deserve an analysis and commentary. It'll be based on crucial value that Article 14 and Article 19 of the CRPD take on in the complex, articulated and not short-lived process of implementing the international standard.

The Committee (in the paragraph defining the purpose and process of the Guidelines) makes it clear that the document should be read in conjunction with Committee's General Comment No. 5 (2017) on Independent Living and Community Inclusion - Article 19 CRPD- and its Guidelines (2016) on the right to liberty and security of persons with disabilities -Article 14 CRPD- and, therefore, Anffas' analysis has certainly looked at these important acts as well.

However, Anffas believes that, for obvious reasons of transparency and fairness, this document will be focused on the Guidelines and will express the Association's opinion on a series of passages considered problematic. This is the reason why, with this initiative, Anffas hopes to initiate a broad and participatory discussion at every level: people with disabilities and their families, Third Sector organizations (TSO), research centres and institutions.

## Analysis

As a preliminary step, Anffas reiterates its full adherence to the contents of the CRPD. **All the contents, none excluded**, represent and prefigure goals of peaceful, civil, equitable, sustainable and inclusive progress valid for all Humanity. Anffas has taken as a reference these contents, even within the limits of our actions, for the start of a refunding process of its being a “Third Sector Subject” committed to the promotion and protection of the rights of people with disabilities and their families. A commitment that we, as Anffas, have declined and will continue to decline at every level: political, technical-scientific research, associative, experiential, communicative, etc. This commitment, especially at the level of concrete planning, has seen us for many years engaged in some strategic areas for the implementation of the CRPD: the primacy of the individual personalized and participatory life project for the definition and delivery of the rights supports; the concrete implementation of person with disabilities’ self-representation and self-determination as result of the supreme principle of respect for individual and social dignity; the adoption of strategies, approaches and tools to combat discrimination; the study and experimentation of services, related to the person, as something that will help also the people’s inclusion.

To adhere wholeheartedly and without any delay to the dictate of the CRPD, Anffas thinks that the action of the Committee has to be considered central, strategic and vital in order to properly set up the complex processes of implementation of the Convention.

In this spirit, and on the strength of the measurable and concrete initiatives that characterize our actions, we express unease, perplexity and concern, and on some passages, even dissent, at the language and generalizations we find in some passages of the Guidelines.

## Independent living = antidote to segregation

The General Comment No. 5, the 2016 Guidelines referring to Article 14 and, now, the Guidelines that are the subject of these notes clearly express the unequivocal and non-reducible human right to be able to decide where, how and with whom to live (Article 19) in a condition of full legal capacity in making choices, reiterating that States Parties should:

- Recognize that "*institutionalization contradicts the right of persons with disabilities to live independently and to be included in the community.*" (para.7)
- "[...] *abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions.*" (par.8)

- Consider that "*Institutionalization can never be considered as a form of protection of children with disabilities. All forms of institutionalization of children with disabilities – that is, placement in any non-family setting – constitute a form of segregation, are harmful and violate the Convention.*" (Para.12)
- "[...] *immediately provide individuals with opportunities to leave institutions, revoke any detention authorized by legislative provisions that are not in compliance with article 14 of the Convention, whether under mental health acts or otherwise, and prohibit involuntary detention based on disability. States parties should immediately halt new placements in institutions, adopt moratoriums on new admissions and on the construction of new institutions and wards, and should refrain from refurbishing or renovating existing institutions.*" (Para. 13)

### **The identifying elements of institutionalization**

The Guidelines provide, consistent with General Comment No. 5, some guidance for "recognizing" institutionalizing practices and places, often coupled with the concept of detention (deprivation of liberty, production of damages that should be compensated to "survivors of institutionalizations"- an expression used 25 times in the text of the Guidelines). The Guidelines consider a place of institutionalization and detention everything that is not intended and organized as a community service; **in essence, according to this apodictic reading, the entire system of personal services active in our country is to be considered extraneous to the concept of "support" based on the CRPD.** In fact, the Guidelines describe institutionalization as follows:

- "*There are certain defining elements of an institution, such as obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment*" (par.14)
- "*Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as "care" or "treatment". Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic*

*psychiatric settings, transit homes, albinism hostels, leprosy CRPD/C/5 3 colonies and other congregated settings. Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.” (par.15)*

- *"[...] Aggregating persons leaving institutions into communal housing arrangements or in assigned neighbourhoods, or bundling housing with medical or support packages, are incompatible with articles 19 and 18 (1) of the Convention." (Para.32)*
- *Finally, it is pointed out that "The absence, reform or removal of one or more institutional elements cannot be used to characterize a setting as community-based. Such is the case, for example, in settings where adults with disabilities continue to be subjected to substituted decision-making or to compulsory treatment, or where they have shared assistants; settings located “in the community” where service providers set a routine and deny autonomy; or “homes” where the same service provider packages housing and support together." (Para.16)*
- *In such a view, which we reiterate is, in our opinion, to be better substantiated and deepened, also "Day-care centres or sheltered employment do not comply with the Convention." (par.77)*

### **Full legal capacity**

The Guidelines, as mentioned in the introduction, should be read in conjunction with the General Comment No. 5 and the Guidelines (2016) of the Committee on the Right to Liberty and Security of Persons with Disabilities. The issue of legal capacity is addressed in relation to the contents of Article 14 CRPD: *"In its general comment No. 1 (2014) on equal recognition before the law, the Committee has clarified that States parties should refrain from the denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without the free and informed consent of the persons concerned or with the consent of a substitute decision maker, as that practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention." (Para. 8)*

Article 14 CRPD is directly related to what is provided in Article 19 CRPD: *"Enjoyment of the right to liberty and security of the person is central to the implementation of article 19 on the right to live independently and be included in the community." (Para. 9)*

## Deinstitutionalization processes, use of resources, and involvement of people with disabilities and their organizations

In contrast, and thus as an alternative to the current institutionalization-based system, States parties should initiate deinstitutionalization processes designed as follows:

- *"Deinstitutionalization comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live." (Para.19)*
- *"Processes of deinstitutionalization should be led by persons with disabilities, including those affected by institutionalization, and not by those involved in managing or perpetuating institutions. Practices that violate article 19 of the Convention should be avoided, such as renovating settings, adding more beds, replacing large institutions with smaller ones, renaming institutions, or applying standards such as the principle of the least restrictive alternative in mental health legislation." (Para.20)*
- *"States parties should prioritize the development of a range of high-quality, individualized support and inclusive mainstream services in the community, without delay." (par.22)*
- *"A core element of living independently and being included in the community is that all persons with disabilities have the support, based on their own choices, that they may require to carry out daily activities and participate in society. Support should be individualized, personalized and offered through a variety of options. Support encompasses a wide range of formal assistance, as well as informal community-based networks." (Para.23)*
- *"Persons with disabilities should be enabled to exercise their legal capacity in choosing, managing and terminating the provision of community-based support. Support in exercising legal capacity can be provided as a service funded by the State or through the individual's informal networks." (Para.24)*
- *"Definitions of community-based support services, including in-home and other support services, and personal assistance should prevent the emergence of new segregated services, such as group housing – including small group homes – sheltered workshops, institutions for the provision of respite care, transit homes, day-care centres, or coercive measures such as community treatment orders, which are not community-based services."(para.28)*
- *"Investments in institutions, including renovation, should be prohibited. Investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently. States parties should refrain from suggesting that persons with disabilities "choose" to*

*live in institutions or using similar arguments to justify the maintenance of institutions." (Para.29)*

The involvement of persons with disabilities in the design and implementation of de-institutionalization processes is central:

*"States parties should closely involve persons with disabilities, and their representative organizations – and give priority to the views of persons leaving institutions and survivors of institutionalization, and their representative organizations – in all stages of deinstitutionalization processes, in accordance with articles 4 (3) and 33 of the Convention. Service providers, charities, professional and religious groups, trade unions and those with financial or other interests in keeping institutions open should be prevented from influencing decision-making processes related to deinstitutionalization." (Para.34)*

### **Commentary on the Guidelines**

In Anffas' history, style and vocation, we always took clear positions, including for the full respect of the principle of transparency that must distinguish a "Third Sector Subject" that works for the protection and enhancement of common goods and for the growth of levels of active participation, cohesion and social protection.

An attitude that we consider vital and indispensable for the productive, broad and participatory process of change initiated with the advent of the CRPD, **otherwise the risk that this fundamental normative reference will be considered unworkable and demagogic. This is a risk that must always be kept in mind when it comes to addressing, in political, cultural and professional terms, the human rights of persons with disabilities, often branded as an ideological approach, synonymous with the useless flaunting of concepts and principles that are not applicable to persons with disabilities, especially in the presence of interpretations and orientations based on positions that risk appearing excessively and unnecessarily rigid and with little respect for the concrete reality and undisputed variability, peculiarities and specificities, present in the different welfare systems with which the States parties have endowed themselves over time.**

The Guidelines, briefly analysed here, represent in our view this risk, together with a deep sense of unease and astonishment in some passages.

### **Language and content**

*Detention, survivors of institutionalization, victims of torture...* these are the words used in the Guidelines to describe the living conditions of people using services not placed in the community.

The risk that people with disabilities in the world may suffer mistreatment, violence, abuse, degrading treatment and torture is not theoretical. It represents the dramatic and unacceptable profile that still connotes the lives of so many people with disabilities. Concrete risks because they are linked to real and contemporary facts, not only to dark and terrible pages of History, including recent ones, and which even the Italian chronicles sometimes bring out.

This means that vigilance, the guarantee of ethical rigors, even before the professional specializations, actions to protect the victims and condemn of the perpetrators must characterize the actions of institutional, social, professional and scientific communities, including the fight against silence and the complicity useful to induce tolerance toward unacceptable practices.

Strident and disconcerting, however, is the way the Committee addresses these issues, aligning all services aimed at people with disabilities not placed in the community with the concept of institutionalization/detention and, therefore, equating these services with places of detention and mistreatment.

An absolute equation, in the words of the Committee, that does not allow modulations or specifications to be placed in relation to the concrete care and support needs of either people with disabilities or their families. Modulations that cannot be mistaken for complicity or disguised detentions, but that respond to certain specific conditions of life of both the person with disabilities and their family members. Modulations that must be activated in a regime of total transparency and in supervised, controlled and monitored contexts, in a system that provides for sanctions and interruptions in the presence of even the slightest suspicion of a detrimental behaviour to personal and social dignity. A system of supervision and control over the services that actually have an agreement with the public organizations or in a phase of accreditation that today appears more focused on administrative and formal aspects rather than on outcomes in terms of quality of life of the people who use them.

### **Modulations in the definition and delivery of supports: why?**

Because it is necessary to start from the observation that the population of persons with intellectual disabilities and neurodevelopmental disorders, unlike, for example, most people with physical or sensory disabilities, includes situations of extreme complexity, especially regarding the concrete possibility of carrying out one's life on tracks of awareness and ability to make choices. It includes situations where the person manifests inadequate and at times dangerous behaviour, where the

inadequacy is not related to social customs or etiquette, but to one's physical, psychological and existential integrity.

Neurodevelopmental disorders encompass broad groups of difficulties: intellectual disabilities, attention deficit disorders, autism spectrum disorders, attention-deficit/hyper-activity disorder, specific learning disabilities, movement disorders and disorders without specification.

Each of these situations is expressed in an extremely differentiated way, generating very different levels and intensities of support and ways to respond to. For obvious reasons, these responses must be differentiated and modulated, precisely by taking into account these undisputed peculiarities. In this sense, Anffas is completely - for a long time now - and rigorously arrayed against the predictive value of diagnoses and claims the centrality of multidimensional assessment and the personalization of supports, which translates into the political action carried out at every level (national, regional and local) to promote, initiate and defend the process of change in the system of personal services to reverse the equation that is mostly active today: person with disabilities = services, followed by the predominance of supply over the actual support needs of the person. At the same time, Anffas argues, just as forcefully, that we need to overcome a logic in which people are adapted to pre-constituted and pre-packaged services with rigid standards rather than modulating the services themselves with respect to the actual support needs of individuals with disabilities, as detected through evidence-based systems. From here, however, to deeming any form of service (residential or day care) deleterious and contrary to the CRPD in favour of the only possible forms, according to the Committee, of support (personal care and community-based services) we believe is a plan that does not consider the multiplicity and complexity of such situations and, therefore, not at all shared or agreeable to Anffas.

There are personal and family situations whose complexity, as in the cases of Rare and Complex Diseases, which can arise as early in life as in adulthood, which present very different clinical and functional pictures, and which often pose quite particular problems since they are chronic and disabling diseases, most often genetic diseases that pose diagnostic difficulties and often lack treatment.

There are personal and family situations that often register conditions generated by neurodevelopmental disorders associated with a condition of comorbidity, for example the incidence of psychiatric diagnoses in intellectual disability which present complex psychopathological pictures to assess and deal with (including exposure to high risk factors, bio-psycho-social vulnerability, frequent association with severe behavioural disorders).



## The family with disabilities

There is also another very strong element to take into account: the condition of the family. Let us omit any mention of the noble (allow us the term) history of our association, which even before being a history of advocacy and/or service management reality is the existential history of families of people with intellectual disabilities and neurodevelopmental disorders.

The Committee does portray well the advocacy scenarios that States Parties should and must set up:

*- "Where a person chooses to receive support from family members, States parties should ensure that the latter have access to adequate financial, social and other assistance to fulfil their support role. State support for family members should be provided only with full respect for the right of persons with disabilities to have choice and control over the kind of support received and the way in which it is used. Support for family members should never include any form of short- or long-term placement of persons with disabilities in an institution, and should enable persons with disabilities to realize their right to live independently and to be included in the community."*  
(Para.38)

The reality of yesterday, today, and, as we see things, tomorrow (excluded the achievements in terms of concretely demanded rights that need to be recorded compared to past eras) is quite different: supports for families are currently concentrated in a few normative and programmatic provisions on leaves of absence, in a system that provides some tax breaks, in timid supports for corporate welfare initiatives, in equally timid supports to accompany the departure of the relative with disabilities from the family unit, in a few opportunities to use the so-called relief services or to cope with emergency situations (both forms, moreover, classified by the Committee as institutionalizing - par. 17). An organic policy and planning of supports for the welfare of the family with disabilities that comprehensively addresses their material and existential living conditions is totally absent. The absence of services to the person properly placed in a planning framework in terms of essential levels of services concerning civil and social rights still represents a goal of progress and social equity that Anffas will never give up.

In this sense, Anffas, will continue to support families also through the provision of relief and/or emergency services and will maintain the necessary pressure on public decision-makers at every level to ensure that such services increase the responsiveness to families' requests, in the name of the principle that disability is not a private matter, but of the "State" and, therefore, of the community. Anffas will continue until the situation changes in concrete and homogeneous terms in the

territories (it is no coincidence that our country has been urged by the Committee to define and implement integrated policies to support family caregivers).

There's one thing that needs to be said, in short: action needs to be taken for the conversion of the personal services system from the current catalogue of health, social and socio-health care units of supply toward a decisive expansion of support opportunities. A change where residential services must increasingly become part of housing policies for the generality of citizens, and where day services must become services for inclusion, with extensive collaborations and synergies with territorial realities and with repertoires of activities based and calibrated on individual, personalized and participatory life projects.

It is quite another thing to establish, without any modularity and attention to some specific conditions of personal and family life, the need to proceed with definitive and total dismantling, overnight, of the current service-based system.

Such processes must take note of specific *starting conditions* of persons with disabilities who present, (we repeat) not in relation to diagnosis but to the outcomes of a well conducted multidimensional assessment, the need for supports not otherwise deliverable except in dedicated services. We mean, by "well-conducted" multidimensional assessment, a transparent process based on validated approaches and tools, really multi-professional and with appropriately trained teams, genuinely participatory and oriented toward the definition of the personal life project that takes into account the person's expectations and wishes, even if expressed in infinitesimal form.

And this applies and will apply to the types of services (residential, day care, outpatient) that, in relation to the concrete needs of the territories, must be guaranteed by the institutions, in full compliance with safety regulations and the protection of the dignity of the person.

Finally, we note that the same Committee, in its concluding remarks to Italy's first report, while expressing concern about the "[...] *trend to re-institutionalize persons with disabilities and that funds are not being reallocated from institutions to promoting and ensuring independent living for all persons with disabilities within their community*" (par.47 concluding obs.), in the introduction it "[...] *commends the State party, which for the last three decades has been striving to implement an inclusive education system free of segregation*" (par.4 concluding obs.). The Italian Law No. 112/2016 on Assistance for People with Serious Disabilities Lacking Family Support, the Guidelines for the development of projects for Independent Living, the delegation of powers to the government in the field of disability, the concrete development of

more and more experiences in the territories experimenting with inclusive forms both in living and in the approach to the labour market, project investments aimed at defining approaches inclusive tools and practices put in place by so many third-sector actors and the objective expansion of opportunities in many areas of community contexts in favour of the civic protagonism of persons with disabilities are all elements that make us think we are on the right track, albeit with the delays, shortcomings, and inefficiencies of a system that is still far from the inclusive philosophy.

On the contrary, we strongly fear that the enemies of such a way of understanding community development, as mentioned in this commentary note, will see the Guidelines as an auspicious opportunity to demonstrate the infeasibility and unreality of the goals set in CRPD. In this sense, we believe that the Committee, in carrying out its valuable and irreplaceable activity, otherwise of not doing a good service to the task to which it is entrusted, must include aspects of modularity and progressiveness in the actions of the States Parties, enhancing, if anything, the activity of monitoring and denunciation with respect to dilatory behaviour.

In any case, Anffas believes that in the Committee's activities, evaluations and guidelines, greater consideration must be given, from now on, to the views of the organizations of persons and family members with disabilities, especially intellectual and neurodevelopmental disabilities, not only for constant adaptation of their activities to the contents of the CRPD, but to define policies, plans and programs, starting from the national level, consistent with CRPD and the Committee's activity, which also take due account of their specificities and peculiarities.

The norms and some programming documents currently operating in the field of de-institutionalization (the Italian Law No. 112/2016, two-year programs) represent an undoubted and epoch-making step forward for our welfare system, but they are weak about the possibility of having a real impact in the territories, perhaps starting from the realities that still show those "institution-like" characteristics denounced by the Committee.

This is why, as mentioned in the introduction, Anffas hopes for a less rigid review by the Committee of its Guidelines that takes into account the considerations expressed above and that Anffas' solicitation in this perspective will be taken up by the entire movement of persons with disabilities and by Italian institutions starting with the Ministry of Disabilities, opening with the Committee itself, for this purpose, a comparison and a constructive dialogue.