PERSONS WITH DISABILITIES AND DEINSTITUTIONALISATION: SOME FUNDAMENTAL CHANGES IN THE ETHICAL FRAMEWORK OF THE CARE MODEL

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Abstract: This paper analyses the fundamental changes in the ethical framework of the care model required for effective deinstitutionalisation in the field of disability. Adopting a doctrinal and conceptual approach grounded primarily in the CRPD, it examines the transition from an assistencialist culture, rooted in institutional forms of care, to a human rights-based approach that recognises persons with disabilities as active rights holders. On this basis, the paper identifies some of the key rights and ethical dimensions that should guide the transformation of care and support systems. It argues that deinstitutionalisation requires not merely a change in the place or manner in which care is provided, but a systemic transformation aimed at enabling persons with disabilities to exercise choice and control over their own lives and to live and participate in the community on an equal basis with others**.**

Keywords: Deinstitutionalisation, Persons with disabilities, Human rights approach, Independent living, Inclusion in the community.

1. INTRODUCTION[2]

The institutional approach has long prevailed in care models in the field of disability, meaning that persons with disabilities who require support have typically been forced to live in segregated residential settings or isolated within the family home or in their own homes, and have not been allowed to make decisions or exercise control over their way of life (Committee on the Rights of Persons with Disabilities, 2017: para. 1).

However, for some years now, the need to transition towards a new community-based care system has been emphasised, with the implementation of deinstitutionalisation processes (European Expert Group on Transition From Institutional To Community-Based Care, 2012)[3]. This need has become more pressing since the social and health crisis caused by the Covid-19 pandemic, which dramatically highlighted the structural shortcomings of the institutional model, having a particular impact on the lives of persons with disabilities.

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[3] Various studies and reports have compared institutional and community-based care in terms of quality and costs, highlighting the clear advantages of the latter model over the former in both respects (Mansell et al., 2007).

Although this transition has been called for by various bodies, and in particular by the European Union[4], in relation to diverse groups and populations, and particularly in relation to long-term care, the framework of the Convention on the Rights of Persons with Disabilities (hereinafter CRPD or the Convention) has been particularly emphatic in establishing obligations for States Parties regarding the requirement for deinstitutionalisation.

This paper aims to explore the meaning, scope and implications of this requirement in the field of disability, and, specifically, to determine the changes in the ethical framework required for the effective deinstitutionalisation of the care system for persons with disabilities, and to identify, based on this framework, certain key rights essential to the success of the process.

The paper adopts a doctrinal and conceptual approach, taking the CRPD as its main normative framework and analysing it in the light of the interpretative work of the Committee on the Rights of Persons with Disabilities, other United Nations human rights mechanisms and bodies, relevant policy documents, and specialised academic literature[5]. Against this background, the specific contribution of the paper is to identify and systematise the fundamental ethical and conceptual changes involved in moving from a care model rooted in institutional culture to a community-based support model grounded in human rights, and to show how these changes point to the recognition and effective guarantee of certain key rights as essential components of deinstitutionalisation.

2. Institutional Culture, Deinstitutionalisation and Disability

At present, there appears to be a broad consensus that institutionalisation should not be identified simply with the number of people living together in a particular building or with its size, but rather with a framework for understanding care relationships that could be termed institutional culture.

This culture is essentially characterised by the following features: isolation and segregation from the community; a one-size-fits-all approach, block treatment and rigid routines regardless of the individual's wishes and preferences; prioritisation of the organisation's interests over individual needs; a lack of control over one's own life and the decisions that affect them; and a systematic asymmetry, a power imbalance, between

[4] Among the first instruments to address the 'transition' from institutional care to local or community-based care, it is also worth mentioning the European Disability Strategy 2010–2020 and the Opinion of the European Economic and Social Committee adopted in 2015 on Long-term social care and deinstitutionalisation. More recently, it is worth mentioning 1) the European Pillar of Social Rights, adopted by the European institutions in 2017, in particular its principles 17 and 18 relating, respectively, to persons with disabilities and to long-term care; 2) the 2018 Opinion of the European Committee of the Regions on 'Deinstitutionalisation of care systems at local and regional level', specifically referring to persons with disabilities; 3) the new European Disability Strategy 2021–2030. Furthermore, at a more global level, the European Care Strategy adopted by the European Parliament in 2022 also reiterates the obligations and commitments of the European Union and the Member States regarding the transition from segregated institutional settings to community and family-based care, and the regulation of European Funds has played a central role in promoting the shift towards a community-based support model.

[5] These sources perform different functions and have different legal status: while the provisions of the CRPD establish binding obligations for States Parties, the Committee's General Comments, Guidelines, Concluding Observations and Views adopted in individual communications are used as interpretative materials, whereas reports and policy documents provide additional analytical and policy guidance.

carers and care recipients, which manifests itself, among other dimensions, in the normalisation of the use of restraints (European Expert Group on Transition from Institutional to Community-Based Care, 2012: 10–12 and Gregorio Peces-Barba Institute of Human Rights, 2024: 9–11).

In the specific field of disability, too, these cultural dimensions have been cited as defining features of institutionalised settings, with the further observation that institutional culture may be present not only in large care homes, but also in small group homes, and even in services provided in individual homes and in the care provided to persons with disabilities by their families (Committee on the Rights of Persons with Disabilities, 2017: para. 16, WHO Europe, 2010: 12; Council of Europe Commissioner for Human Rights, 2012). It has thus been noted that "it follows that an institution is not necessarily where you live or with whom you live, but also under what conditions. Moreover, if someone is 'forced' to live under specific conditions that limit their personal choices and they lack control over their life, they can be institutionalised in their own home. If a family does not take into account the needs and wishes of the disabled family member, they can act as an institution" (European Network on Independent Living, 2023: 15). This does not, of course, imply an equivalence between residential institutions and family-based care. Rather, it highlights that institutionalisation is defined not only by the setting in which support is provided, but also by the nature of the support relationship and, in particular, by the degree of choice and control exercised by the person receiving support.

Institutional culture, as various studies have shown, has a negative impact on the quality of life of persons living in institutional settings (McCarron et al., 2019), but also on families and workers in the sector, and leads to serious violations of rights, as has been particularly emphasised, once again, by the Committee on the Rights of Persons with Disabilities (2022a: para. 6)[6].

For this reason, as explained in the introduction and, in particular, following the experience of the pandemic (Knapp et al., 2021: 3 and 4), the call to deinstitutionalise the care system has gained momentum.

In line with the preceding reflections, deinstitutionalisation, including in the field of disability, should not be equated simply with the closure of residential centres where a certain number of persons with disabilities are concentrated, rather it should be understood as a process of change involving the dismantling and eradication of all the defining aspects of institutional culture, as mentioned above, across all care settings and all care relationships.

With regard to the subject matter of this paper, it is also essential to emphasise that, according to the CRPD model, deinstitutionalisation as a process is linked to independent

[6] According to the Committee, "Institutionalisation is a discriminatory practice against persons with disabilities, contrary to Article 5 of the Convention. It involves a de facto denial of the legal capacity of persons with disabilities, in breach of Article 12. It constitutes detention and deprivation of liberty based on disability, contrary to Article 14. States parties should recognise institutionalisation as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention involving psychotropic medications, such as sedatives, mood stabilisers, electroconvulsive therapy and conversion therapy, infringing Articles 15, 16 and 17. It exposes persons with disabilities to the administration of drugs and other interventions without their free, prior and informed consent, in violation of Articles 15 and 25".

living and inclusion in the community as objectives—dimensions recognised as principles and rights in Articles 3 and 19 of the CRPD[7] (Lewis and Richardson, 2020: 26).

Although the CRPD does not expressly refer in its text to the requirement for deinstitutionalisation, from its very first Concluding Observations, the Committee on the Rights of Persons with Disabilities has categorically stated that the implementation of Article 19 of the CRPD at the national level requires the implementation of effective deinstitutionalisation strategies (for example, Committee on the Rights of Persons with Disabilities, 2011: paras. 35 and 36).

Both in General Comment No. 5, adopted in 2017 with the aim of clarifying the meaning and obligations arising from Article 19 of the CRPD, and in the Guidelines on Deinstitutionalisation, including in Emergencies**,** adopted in 2022 with the aim of guiding and supporting States Parties in planning deinstitutionalisation processes and preventing institutionalisation, the Committee affirms the fundamental incompatibility between institutional culture and independent living and inclusion in the community. Thus, the Committee states, for example, that "both independent living and being included in the community refer to life settings outside residential institutions of all kinds", noting that regardless of their size, purpose or characteristics, or the duration of confinement or deprivation of liberty, an institution can never be considered to be in line with the Convention (2017: para. 16c), that "all forms of institutionalisation" must be eradicated and that "institutionalisation must never be considered a form of protection for persons with disabilities, or a 'choice'" (2022a: para. 8). The Committee thus appears to adopt an abolitionist stance, on the understanding that deinstitutionalisation requires the immediate closure of all institutions, which, in the Committee's view, would encompass all residential centres and all collective living environments.

In response to this approach, it could be argued that some of these residential settings might be transformed and that some persons with disabilities might freely choose to live in them, provided that genuine alternatives are available. However, this qualification does not alter the fundamental requirement that deinstitutionalisation demands the closure of all facilities and services, and the departure of persons with disabilities from all environments that retain elements of institutional culture; and that this requirement is not met by the mere redesign or improvement of institutional care if these features continue to be reproduced, even on a small scale. From this perspective, the decisive criterion is not the formal designation, size or collective nature of a particular living arrangement, but whether persons with disabilities effectively enjoy choice and control over where, with whom and how they live, exercise control over the supports they receive, and are able to participate in the community on an equal basis with others. A residential setting that reproduces segregation, rigid routines, lack of individual choice or

[7] It should nevertheless be noted that deinstitutionalisation has not historically been grounded exclusively, or necessarily, in a human rights approach. Earlier processes and arguments in favour of moving away from institutional forms of care have also been associated with other rationales, including quality of life, normalisation, the development of community and mainstream services, and changes in models of social and health care. The emergence and consolidation of the human rights model of disability, and particularly the adoption of the CRPD, have reframed deinstitutionalisation in explicitly rights-based terms (Mansell, 2006).

control, or structural power asymmetries cannot therefore be regarded as community-based merely because it is smaller or has been formally redesignated as such.

Furthermore, it is clear from the Committee's statements (2022a: para. 19) that, given its links to the concepts of independent living and inclusion in the community, deinstitutionalisation is understood as a systemic transformation that goes beyond changes to the care system, that is, the manner and location of care provision, whilst also focusing on increasing levels of autonomy, inclusion and equality, and on respecting the preferences and choices of persons with disabilities (Crowther, 2019: 15 et seq.).

Indeed, a fundamental part of this transformation is a profound shift in the ethical framework of the care model, replacing the perspective of assistencialism that underpins the care model rooted in institutional culture with the human rights-based approach inspired by the CRPD, which serves as the foundation for the new care model towards which deinstitutionalisation processes are moving.

3. From an Assistencialist to a Human Rights-Based Approach

In the field of disability, the persistence of a care model based on institutional culture—whose main features were examined in the previous section—is largely explained by an ethical and cultural framework that can be described as assistencialist. The term "assistencialism" is used here to refer to a welfare-based and paternalistic approach that regards persons with disabilities primarily as passive recipients of protection, assistance and care, rather than as active holders of rights. In this sense, successful and meaningful deinstitutionalisation requires challenging the assumptions underpinning this framework from the perspective of a human rights-based approach[8]. This paradigm shift, as will be seen, is reflected both in the CRPD framework and in the work of various international human rights mechanisms that have addressed support systems and services for persons with disabilities.

The assistencialism-based approach involves viewing persons with disabilities as recipients or passive objects of attention and care, such that interventions are justified on the grounds of protecting the person's safety (and, on occasion, even protecting society or third parties). In contrast to this view, the rights-based approach requires that persons with disabilities be regarded and treated as genuine, full and active human rights holders, and that interventions be based on the respect, guarantee and promotion of human rights and aimed at their fulfilment (Quinn and Degener, 2002: 13).

In any case, it is worth bearing in mind that the failure to perceive persons with disabilities as rights-holders, characteristic of the assistencialist paradigm, stems from a standard conception of human rights dating back to the Enlightenment, which regards

[8] In general terms, the human rights-based approach has been defined as a conceptual framework which, from a normative perspective, is grounded in international human rights standards and, from an operational perspective, is geared towards their promotion and protection; it has been developed particularly within the framework of development cooperation, with the reference being the consensus document The Human Rights-Based Approach to Development Cooperation: Towards a Common Understanding Among UN Agencies, adopted by United Nations cooperation agencies as a guide for their programmes and actions in this field. Within this framework, in the present paper the human rights approach is linked to a stronger philosophical and conceptual thesis on the person, dignity, situated freedom, care and community, coinciding with what De Asís (2026: 5 ff.) has termed the Rights-Centred Approach.

capacity, independence, autonomy or self-sufficiency as defining features of moral agency and, consequently, of the attribution of dignity and rights (Cuenca, 2015a: 35).

Thus, falling below the standard level of abilities, the existence of support needs, and/or dependence on others to carry out certain activities or make decisions are interpreted as factors that diminish a person's worth, that imply a loss of dignity, and that prevent persons with disabilities from choosing and pursuing their own life plans.

In light of this perspective, within the discourse on human rights, deinstitutionalisation calls for a re-examination of this standard conception and the development of a new model or theory of human rights, of which the CRPD is an expression (Barranco, 2016: 142), which takes shared humanity as its starting point and adopts an open and inclusive understanding of the human condition and human dignity that regards and treats persons with disabilities, as well as those requiring care and support, as fully dignified individuals and as free moral agents capable of leading their own lives within the community.

The assistencialist approach, and its standard theory of rights, is also linked to the medical model, which regards disability exclusively as a trait or condition of the person arising from the existence of certain 'deficiencies' or 'anomalies' (Oliver, 1996: 31 ff. and Palacios, 2008: 66 ff.). This model "focuses on deviations from a norm (how 'normal' humans function)" and then "on the design of interventions to 'fix' the deviation in the person" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 19).

Thus, from the medical model, the vulnerability that disability represents is conceived solely as an individual condition implying a certain fragility or weakness (Cuenca 2015b: 142, 143) and which, whilst underpinning, from the logic inherent in the welfare-based perspective, the attribution of special protection, also justifies restrictions on rights, limitations on participation and the social exclusion of persons with disabilities who fail to overcome their "deviations". In any case, within the framework of the medical model, these situations are not perceived as instances of discrimination or rights violations, but as a natural and inevitable consequence attributed to the very individual 'impairments' from which persons with disabilities 'suffer' (Lawson, 2007: 584).

This perspective explains why institutionalisation has been accepted as a necessary measure for the protection of persons with disabilities who, due to their condition, cannot live in mainstream settings. Thus, the medical model has contributed to fostering a narrow philosophy of social support that seeks primarily to "compensate" the person with a disability for their "loss" and which focuses attention on "the impairment, not the person" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 19).

For its part, the rights-based approach leads us to consider, in line with the social model, that disability is the result of mental constructs and social circumstances (Palacios, 2008: 103 ff.).

According to this view, the vulnerability that disability represents is not seen exclusively, as in the assistencialist model, as an individual condition, but as a situation generated by the interaction between this condition – viewed in terms of diversity rather

than impairment – and social barriers that place persons with disabilities in a position of subordination (Brogna, 2023).

From this perspective, the limitations on participation and the restrictions on rights suffered by persons with disabilities are no longer viewed as something natural, attributable to impairments, but as a manifestation of structural discrimination and as situations where rights are not being met. Thus, the new framework provided by the social model reveals that institutionalisation, far from being a necessary and justified measure, is linked to the existence of environmental and attitudinal barriers.

The fact is that persons with disabilities are forced to live in segregated, institutionalised settings for reasons linked to the very design of care systems that lack community-based living alternatives and support measures for families (Special Rapporteur on the rights of persons with disabilities, 2016: para. 21) and which make institutionalisation the only route to care, or which invest solely in institutional resources (Committee on the Rights of Persons with Disabilities, 2017: para. 1). Furthermore, medical approaches, charity-based perspectives, and the standard conception of rights are linked to ableism as an ideology— an expression of prejudice and stereotypes—which devalues persons with disabilities and also permeates the assistencialism-based model of care (Office of the United Nations High Commissioner for Human Rights, 2023: para. 6). In contrast to this view, the rights-based approach and the social model outright reject all manifestations of ableism, challenging the privilege of the idea of normality and capacity.

This shift also requires abandoning a homogeneous understanding of disability and incorporating an intersectional perspective. While the assistencialist approach tends to consider disability in isolation, a human rights-based approach must take into account how disability interacts with other personal and social factors, such as age, gender, support requirements, socioeconomic situation, ethnic or migration background, or place of residence, giving rise to different experiences of inequality and discrimination. These intersections are particularly relevant to deinstitutionalisation, since they may affect the risk of institutionalisation, the barriers encountered in leaving institutional settings and the possibilities of accessing adequate community-based support (Committee on the Rights of Persons with Disabilities, 2022a: para. 41).

The assistencialist paradigm also embodies the philosophy of integration, understood in the sense of assimilation (Oliver, 1996: 92), which holds that, in order to lead a life in the community, a person with a disability must conform to the previously existing social norms, ways and values of the dominant society, thereby justifying the isolation, separation or segregation of those who fail to conform to the standard of normality defined in accordance with the physical and mental parameters of the culturally dominant model (Courtis, 2004: 7). Following this approach, individuals must adapt to the organisation of services. This circumstance, and the fact that the model focuses on ‘impairment’ and its management, explains why the interventions consist of uniform and standardised treatment that leads to the objectification of persons with disabilities.

Once again, the social model and the rights-based approach challenge this view by advocating for inclusion and demanding that society accommodate human diversity and allow persons with disabilities to be active participants in it. From this perspective, the services must adapt to people’s needs, and not the other way round.

In connection with all of the above, assistencialism adopts an individualistic stance that fails to take into account interdependent relationships or the importance of the community in people's lives. Indeed, this care model does not aim to "forge inclusive pathways into communal life" and "left out altogether was the connection between the advancement of disability rights and community development" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 19).

However, the rights-based approach signals a shift in focus that emphasises the community-based approach, recognising that "social inclusion is vital to the evolution of our sense of self" and that new services "should stitch together social capital to ensure an equal right to belong, to grow and to be connected with others" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 24). In this sense, living in the community is not merely one dimension of social inclusion, but also a condition for the effective exercise of other rights, having been described as a "precursor" or gateway through which other rights can be realised (Kanter, 2014).

In accordance with its basic premises, the assistencialist care model is not oriented towards the moral self-determination of persons with disabilities whom, as noted above, it regards as persons without moral agency and, therefore, without the capacity to make their own decisions about their lives or to control and direct the support and care they receive (Office of the United Nations High Commissioner for Human Rights, 2023: para. 6). This leads to a form of hyper-paternalism that involves substituting decision-making by relying on a third party's judgement regarding the objective well-being of persons with disabilities. This justifies the imposition, in the best interests of persons with disabilities, of ways of life and living arrangements without taking into account, or by disregarding, their will, wishes and preferences—which is, once again, an inherent characteristic of institutionalisation, intrinsic to 'institutional culture'. Although this imposition is certainly justified by the paternalistic argument of protecting the objective best interests of the person concerned—which is considered to take precedence over their subjective preferences in such cases—the truth is that it is, rather, a form of cultural imperialism[9] where the interests and needs of the institution take precedence over the needs of the individuals.

In contrast to the hyper-paternalism that prevails within the assistencialist cultural framework and the tendency to make decisions on their behalf, the rights-based approach demands that persons with disabilities take the lead in all matters relating to their own lives. It is therefore necessary to stop focusing on people's individual circumstances and to raise awareness of the importance of respecting the choices made by persons with disabilities regarding their own way of life. In this regard, it has been noted that the services of the future should enable people to "self-actualise in the world"; consequently, alongside social inclusion, moral self-determination takes on greater importance—that is, having a voice of one's own, being able to choose, and exercising control (Special Rapporteur on the rights of persons with disabilities, 2023: paras. 21 and 24).

[9] In the sense of Young, 1990.

The cultural framework within which the assistencialist care model is situated is also characterised by fostering and promoting power and domination relationships between carers – particularly, though not exclusively, when referring to professionals working in support services– and those receiving care. These power relationships underpin the justification for the use of restrictive measures, like physical, chemical, or environmental restraints, that are normalised as routine safety solutions and create a significant risk of violence, exploitation and abuse. Based on these cultural assumptions, it is understood that the concept of care carries, for persons with disabilities, a heavy historical connotation of oppression and subjugation (Special Rapporteur on the rights of persons with disabilities, 2016: para. 23).

The rights-based approach requires, at this point, the eradication of power relations in care which, as has been noted, underpin the use of restraints as a naturalised basic element of care. This approach conceives of care as a symmetrical relationship and takes into account the rights of all those involved, both those receiving care and carers (Office of the United Nations High Commissioner for Human Rights, 2023: para. 9). Likewise, it is necessary to prevent situations of violence, abuse and exploitation in care relationships and to ensure that their organisation ceases to focus on 'deficits', shifting the focus to the person.

In any case, the assistencialist paradigm of services for persons with disabilities reflects the general devaluation of care in our society and the view that it is a private matter. People in need of care are regarded as a burden that imposes negative consequences on society, the weight of which must be borne by families, who are entrusted exclusively with the provision of care. Moreover, it is a burden which, in accordance with the prevailing patriarchal culture, must fall primarily on women, the feminisation of care being another of the key aspects of the model[10].

On the other hand, the cultural framework within which assistencialism is embedded holds that the rights of persons with disabilities—particularly when it comes to demands involving State provision, as is the case with care—are not genuine human rights, but merely matters of social welfare (De Asís, 2013: 90). Thus, the coverage and fulfilment of these demands depend on the goodwill of States and the availability of economic resources. When these demands are considered matters of rights, they are exclusively subsumed under economic, social and cultural rights, which are regarded as second-class rights (Ansuátegui, 2010: 50).

Another aspect that helps explain the characteristics of this model and its institutional nature relates to the view of housing not as a right, but as an economic good subject to market forces (Special Rapporteur on the rights of persons with disabilities, 2023: para. 54).

For its part, the rights-based approach calls for a revaluation of care in our societies and advocates for its equitable distribution. Care must be understood not as a burden, but as a "necessity for the existence and reproduction of societies, which needs to be valued and, as a consequence, collectively shared through a system that redistributes

[10] This aspect of the model is emphasised, for example, by the Office of the United Nations High Commissioner for Human Rights, 2023, cited above.

care work through co-responsibility among all persons, particularly men and women, and among families, communities and the State" (Office of the United Nations High Commissioner for Human Rights, 2023: para. 7 following International Labour Organization, 2018). Thus, the demands of persons with disabilities regarding the provision of care and support services should not be viewed as welfare issues, but as rights-based issues that impose obligations on States.

Likewise, the progressive realisation of economic, social and cultural rights cannot ignore the interconnection and interdependence between all human rights, an aspect also emphasised by the CRPD in overcoming divisions between categories of rights, bearing in mind that a lack of support can impede the exercise and enjoyment of all rights. In this vein, the rights-based approach also requires moving beyond the conception of housing as a market commodity.

Finally, the contrast between the assistencialist and the human rights-based approaches also extends to the political and public spheres. The assistencialist model has traditionally relegated persons with disabilities to a passive position, excluding them not only from decisions concerning their own lives, but also from decision-making processes concerning the laws, policies and services that affect them. By contrast, the human rights-based approach requires their recognition as active participants in the collective processes through which these norms, policies and services are designed, implemented and evaluated (Committee on the Rights of Persons with Disabilities, 2018: paras. 2, 6–9, 15 and 21–28). This requirement is particularly relevant to deinstitutionalisation, which cannot be conceived as a transformation designed merely for persons with disabilities, but must be developed with their active and meaningful participation, including through their representative organisations. Accordingly, persons with disabilities, including those living in institutions and survivors of institutionalisation, must be involved in the planning, implementation and monitoring of deinstitutionalisation strategies and in the development of community-based support services (Committee on the Rights of Persons with Disabilities, 2017: para. 56; 2018: para. 82; 2022a: paras. 34–36 and 67–68).

4. Key Rights in Deinstitutionalisation Processes

The ethical framework of the rights-based approach applied to deinstitutionalisation, whose differences from the approach of assistencialism were analysed in the previous section, points to a series of key rights, largely recognised in the CRPD, which also highlight some basic ethical dimensions that must be taken into account in the process of change.

4.1. The right to choose a way of life and to make decisions that affect one's own life

A first set of rights that is particularly relevant to deinstitutionalisation concerns the right of persons with disabilities to choose their way of life and to make decisions concerning their own lives.

These dimensions are closely connected to Articles 19 and 12 of the CRPD. Article 19 expressly recognises the equal right of persons with disabilities to live in the

community, with choices equal to others, while Article 12 recognises their right to enjoy legal capacity on an equal basis with others in all aspects of life. Taken together, these provisions reinforce the recognition of persons with disabilities as moral agents entitled to determine how they wish to live their lives and to make their own decisions.

In its General Comment No. 5, when analysing the dimensions of the right to independent living recognised in Article 19 of the CRPD, the Committee states that independent living "does not necessarily mean living alone" and "should not be interpreted solely as the ability to carry out daily activities by oneself", and links this concept to personal autonomy, self-determination, and control "over their lives and make all decisions concerning their lives".

Thus, the Committee affirms that the right to independent living "refers to an individual dimension, as a right to emancipate oneself without being denied access and opportunities" (2017: para. 19), and that personal decisions – which certainly encompass not only the place of residence but all aspects of a person's life: their schedules, routines and way of life – "are linked to the development of a person's identity and personality" insofar as "where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be indoors or outdoors, have a tablecloth and candles on the table, have pets or listen to music" … "constitute who we are". Therefore, from a rights-based perspective, "independence as a form of personal autonomy means that the person with a disability is not deprived of the opportunity for choice and control regarding personal lifestyle and daily activities" (2017: para. 16a).

Thus, the concept of choice and control must feature as a fundamental component of the exercise of autonomy in support and care systems (see also Office of the United Nations High Commissioner for Human Rights, 2023: para. 4).

For its part, Article 12 of the CRPD, which under the heading 'Equal recognition before the law' recognises the right to equal legal capacity for persons with disabilities, aims to grant persons with disabilities "the ability to shape their own lives and thus change the way in which the world interacts with them … is an antidote to the tendency of traditional service systems to bypass the wishes of the person and to entrap them in a world not of their own making. It points strongly towards the personalisation of services" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 22). The recognition and effective exercise of legal capacity is therefore a fundamental condition for deinstitutionalisation. The transition from institutional to community-based settings cannot, in itself, be considered sufficient if persons with disabilities continue to be deprived of the possibility of making legally effective decisions concerning their place of residence, their living arrangements, the support they receive or other fundamental aspects of their lives. In this sense, the replacement of substitute decision-making by appropriate support for the exercise of legal capacity is closely connected to the transition from institutional culture to a rights-based support model.

In any case, in accordance with Article 12 of the CRPD, persons with disabilities have the right to support in making their own decisions regarding the world in which they wish to live. The emphasis on the elements of choice and control must not lead us to forget that there are barriers that will always affect the capacity for self-determination (Vicente, 2026: 250), without this being a reason for not receiving support services —

which, as will be emphasised later, are for everyone — and that choice and control over services can be exercised with the assistance of others who help to ensure that the will and preferences of persons with disabilities are respected[11].

Indeed, as the Committee on the Rights of Persons with Disabilities has pointed out, Article 12 requires that "the person's rights, will and preferences be respected" and that, where "after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the 'best interpretation of will and preferences' — a standard which implies that the support person must make the decision by seeking to determine what the person concerned would have wished, taking into account their life history, life course, beliefs and values — "must replace the 'best interests' determinations" (Committee on the Rights of Persons with Disabilities, 2014: paras. 20 and 21). Thus, Article 12 "does not mean fixating on the myth of the completely atomistic individual, but taking human interdependence seriously" (Special Rapporteur on the rights of persons with disabilities, 2023: para. 22)[12].

4.2. The right to inclusion in the community and the right to accessibility

A further right that is central to deinstitutionalisation is the right of persons with disabilities to be included in the community, expressly recognised in Article 19 of the CRPD and closely connected to the exercise of other rights throughout the Convention. From a rights-based perspective, inclusion in the community requires more than the physical presence of persons with disabilities in community settings: it entails the possibility of participating in, contributing to and being valued as part of the community. Indeed, from a rights-based perspective, and as previously noted, "community is fundamental to our sense of who we are" and "communities are stronger when we are all included and when everyone can participate, contribute and be valued" (Inclusion International, 2012: 3). Thus, as the Committee has again pointed out, "the right to be included in the community entails a social dimension, i.e., the positive right to develop inclusive environments" (Committee on the Rights of Persons with Disabilities, 2017: para. 19).

The success of deinstitutionalisation therefore depends, in an essential sense, on the creation of inclusive communities as spaces which, amongst other aspects, respect the

[11] This issue arose precisely in the case of *S.K. v. Finland*, in which an individual communication was submitted to the Committee concerning the denial of personal assistance to a person with physical and intellectual disabilities on the grounds that he lacked the capacity to determine the content of the assistance and the manner in which it should be provided. In its Views, the Committee recalled that the right to live independently and be included in the community "entails having freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society", considered the argument relied upon by the State to deny personal assistance to be discriminatory, profoundly ableist and contrary to the human rights model of disability, and affirmed that the right recognised in Article 19 also protects persons who require support in decision-making (Committee on the Rights of Persons with Disabilities, 2022b).

[12] Thus, it has been noted that Article 12 values mechanisms of (inter)dependent agency by guaranteeing the right to support in the exercise of legal capacity, recognising that every individual has the right to exercise their autonomy, but that this may be exercised with the help and assistance of others (Arstein-Kerslake, 2017: 62) and by considering that the aim of the support process is not to impose an external decision regarding what others believe to be the person's objective best interests, but rather to reach a decision, as informed as possible, based on the person's own will and preferences (De Bhailis and Flynn, 2017: 17).

rights and promote the participation of persons with disabilities in all spheres of social life and, in particular, in education, employment, culture, leisure and sport, areas in which the CRPD also emphasises inclusion. Inclusive communities value diversity and mobilise all available resources to enable persons with disabilities to realise their life plans.

This certainly implies the need to prepare communities for inclusion. As indicated by the Committee on the Rights of Persons with Disabilities (2022a: para. 100), deinstitutionalisation requires that "States parties should support awareness-raising activities on the inclusion of persons with disabilities, building the capacities of families, neighbourhoods and communities on the values and practices of inclusion".

The right to inclusion in the community is therefore closely connected to the right to accessibility. Inclusive communities must necessarily be accessible communities, since accessibility is a precondition for persons with disabilities to live independently and participate fully in all aspects of life, as recognised in Article 9 of the CRPD. In any case, it is important to clarify that deinstitutionalisation, particularly if understood as in this paper as a systemic transformation, requires the adoption of a broad concept of accessibility. From this perspective, accessibility is considered not only a principle but also a right, and it applies not only to specific areas, goods and services but also to all rights as an essential condition for guaranteeing their exercise on an equal basis, thus also forming part of the right to equality (De Asís, 2023: 3). Therefore, deinstitutionalisation must be accompanied by general and structural reforms aimed at guaranteeing full accessibility to the community, as is also expressly called for in the final clause of Article 19 of the CRPD.

4.3. The right to support and personal assistance

The rights to choose one's way of life and to be included in the community are closely connected to the right to receive the support required to exercise these and other rights. Support occupies a central and cross-cutting position in the CRPD and is expressly addressed in relation to several rights, with Articles 12 and 19 being particularly relevant to deinstitutionalisation (Special Rapporteur on the rights of persons with disabilities, 2016: para. 37).

Article 12, as already noted, refers to support in decision-making; support which, in any case, as previously stated, must respect the will and preferences of persons with disabilities and, where these cannot be determined, must be guided in its actions by the best interpretation of that will and those preferences, rather than by the criterion of the best interests inherent in the welfare model.

For its part, Article 19 refers to support to promote independent living and prevent people from being separated from the community.

Indeed, deinstitutionalisation requires the existence of support systems – understood as a network of people, products and services, both formal and informal, including family-based support, and both human and technological– that provide assistance to persons with disabilities so that they can lead a life of their own choosing within the community (Office of the United Nations High Commissioner for Human Rights, 2023: para. 4).

PERSONS WITH DISABILITIES AND DEINSTITUTIONALISATION: SOME FUNDAMENTAL CHANGES IN THE ETHICAL FRAMEWORK OF THE CARE MODEL

As the Committee on the Rights of Persons with Disabilities has noted, persons with disabilities have the right to rely on natural support systems and networks that are essential for leading an independent life. These include "relationships that an individual develops with family members, friends, neighbours or other trusted persons who provide the support that a person requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community" (Committee on the Rights of Persons with Disabilities, 2022a: para. 69). Deinstitutionalisation, from a rights-based perspective, requires recognition of the existence of these forms of informal support, the funding of community support, and the protection and promotion of these relationships; but also, as the Committee has emphasised, that the individuals, circles and support networks are chosen by persons with disabilities (Ibid., paras. 72 and 74).

Certainly, "support is a normal part of community life, with families serving as the first source of support for everyone" and "for many persons with disabilities, family support serves as a bridge to access other assistance needed to fully enjoy their human rights" (Special Rapporteur on the rights of persons with disabilities, 2016, para. 20). However, as has also been noted, on occasions, families, forced to meet care needs without assistance, may end up adopting practices typical of institutional culture; consequently, they have sometimes been a source of conflict, trauma or loss of autonomy for persons with disabilities[13] (Special Rapporteur on the rights of persons with disabilities, 2023: para. 36). Furthermore, in these situations, the rights of families and carers, particularly women, may also be affected. Moreover, it must be remembered that the admission of a person with a disability to an institution has long been, and still largely remains, the only support available to families to gain access to basic services.

Taking these dimensions into account, the rights-based approach requires that family support be based, as is generally the case with informal support, on the free choice of persons with disabilities. This implies that other alternatives must be available and requires that, if persons with disabilities decide to receive support from their families, these families are provided with adequate resources and services to enable them to support their family members in living independently in the community (Committee on the Rights of Persons with Disabilities, 2022a: para. 74). This is an aspect which, although not expressly mentioned in Article 23 CRPD, has been considered by the Committee in its views in individual communications as part of the right of persons with disabilities to respect for home and family[14]. In general, States "should recognise the existence of informal support and ensure that communities and families are trained and supported in

[13] Indeed, "when no other options are available and families are the sole source of support, the autonomy of persons with disabilities and their family members is reduced. Those being supported have no choice or control over the assistance they require to pursue their life plans, and questions of overprotection and conflict of interest commonly arise", Special Rapporteur on the rights of persons with disabilities, 2016, para. 20.

[14] In its Views in Bellini v. Italy (CRPD/C/27/D/51/2018), the Committee considered that the lack of support for family carers constituted a violation of Article 23 and identified as appropriate support services: respite care or temporary replacement of the primary carer, psychological and social support measures, financial support, and other support options.

providing support that is respectful of the choices, will and preferences of persons with disabilities" (Ibid., para. 71).

In any case, deinstitutionalisation cannot be built on the assumption, present in the assistencialist model based on institutional culture, that families will absorb or re-absorb all the support needs of persons with disabilities. This would, in effect, have a disproportionate impact on women who typically took time out of the labour market to care for a family member with a disability, in turn potentially affecting their life goals and pension rights and, consequently, also the quality of care they might need in the future. A new rights-based support model must not perpetuate gender inequalities (Special Rapporteur on the rights of persons with disabilities, 2023: paras. 44–46).

In this regard, one of the central dilemmas posed by the transformation of the service model linked to deinstitutionalisation is, precisely, the balance between formal and informal care policies and family support. From a rights-based perspective, the final decision on how to achieve this balance must take into account that, in many societies, the family is the primary source of support and that this reflects, in part, prevailing cultural norms, but also the absence or inadequacy of formal support systems; it must recognise and address the gender impact and must give a voice to persons with disabilities (Ibid: paras. 60, 70, 88 and 89).

Alongside informal support, the success of the deinstitutionalisation process critically depends on the State developing a wide range of formal independent living support services which, according to the Committee, must meet the following features: be designed to facilitate community living and full inclusion and participation and to prevent isolation and separation from others, and be suitable for that purpose; be individualised and personalised and based on the choice of persons who have the right to choose services and their providers according to their individual needs and personal preferences; be flexible to adapt to the needs of service users and not the other way round; be accessible, affordable, acceptable and adaptable for all persons with disabilities; take into account different living conditions, considering situations where disability interacts with other factors; and be based on a rights-based approach (Committee on the Rights of Persons with Disabilities, 2017: para. 60).

This rights-based approach also requires a non-restrictive support model, which eliminates practices such as involuntary institutionalisation on the grounds of disability—considered by the Committee (2016) to be contrary to the CRPD—and moves beyond the notion of restraints and restrictions as an element of care or assistance, viewing them instead as a violation of rights.

It is also important to emphasise that supports for independent living include both human and technological support.

Human support includes support persons, support staff, direct support professionals, etc. (Committee on the Rights of Persons with Disabilities, 2022a: para. 84), highlighting, in particular, the role of personal assistance, expressly mentioned in Article 19 CRPD and considered a key tool for the development of an independent life and, therefore, a central element in deinstitutionalisation processes. From a rights-based perspective, personal assistance must be regarded as a right of all persons with disabilities,

regardless of their age and the extent of their support needs (De Asís, 2019). The Committee defines personal assistance as 'person-directed/"user"-led human support available to a person with a disability and is a tool for independent living' and highlights the following defining features: control, decision-making power and self-management by the person with a disability, with decision-making support where needed, adaptation to each person's individual needs and life circumstances, and the non-linkage of this service to a specific living arrangement (Committee on the Rights of Persons with Disabilities, 2017: para. 16).

Technological support includes a variety of devices such as traditional technical aids, assistive products and other related technologies, for example, those involving artificial intelligence. Artificial intelligence, if used appropriately and responsibly, can contribute to the transformation of services for persons with disabilities and promote independent living by contributing to the personalisation and comprehensiveness of support and to the continued presence of persons with disabilities in family and community settings, which can be facilitated through the remote use of AI systems (Special Rapporteur on the rights of persons with disabilities, 2022). Once again, a rights-based approach calls for striking a balance between the opportunities and risks of using new technologies that may affect privacy and intimacy, be based on discriminatory biases, and lead to exclusion due to the digital divide—which may particularly affect women with disabilities—as well as the associated costs and the potential for dehumanisation in care (Ibid.). It has also been warned that reliance on artificial intelligence technologies may be used by service providers as an argument "to reduce or eliminate the need for human caregivers". This may entail "serious risks to the mental health of persons with disabilities and exacerbate segregation and isolation" (Ibid.), potentially giving rise to a form of technological institutionalisation. In any case, States, based on this balance, must expand and guarantee, once again as a right, access for persons with disabilities to affordable assistive technologies (Committee on the Rights of Persons with Disabilities, 2022a: para. 85).

With regard to the right to support, and from the perspective of shared responsibility, the role of the social economy—that is, of non-profit organisations, but also of businesses—must be taken into account; consequently, the challenge of the commodification of care must be addressed. From a rights-based perspective, the market – which, in fact, plays a central role in many societies today in the provision of support services for persons with disabilities – must be a means and not an end that leads to inequality in care and the commodification of the individual. To avoid this outcome, the State must always retain its role as the provider of last resort; it must carry out significant oversight and regulatory work by creating – for example, through public procurement legislation – regulatory frameworks and incentives to reorient for-profit and non-profit services[15] towards social support objectives, ensure their alignment with the rights-based

[15] Certainly, "through public procurement law, States can reshape markets (if markets are relied upon) to ensure better outcomes for persons with disabilities. Clear standards can be developed, linking social support goals with procurement policies, gathering data to ensure compliance and imposing clear penalties for lack of compliance. Public procurement laws should reflect a vision of the type of services and support needed in the future and should give preference to smaller service organisations. Standards should include

approach, and guarantee decent working conditions for professionals (Special Rapporteur on the rights of persons with disabilities, 2023: para. 87 and Office of the United Nations High Commissioner for Human Rights, 2023: paras. 29 and 30).

4.4. The right to housing and social protection

The right to housing and the right to social protection are also essential to the success of deinstitutionalisation processes. The possibility of leaving an institution and living independently in the community depends not only on the availability of adequate support, but also on access to safe, accessible and affordable housing and to sufficient economic resources.

In this sense, Article 19 of the CRPD is directed at enabling the free development of one's personality in a home of one's own and with free interaction in the community (Special Rapporteur on the rights of persons with disabilities, 2023: para. 23), while Article 28 recognises the right of persons with disabilities to an adequate standard of living and social protection, including housing.

From a rights-based perspective, therefore, access to housing cannot be left exclusively to market forces, since the effective exercise of the right to live independently in the community requires that adequate housing options are actually available to persons with disabilities. In this regard, it has been stated that States must ensure the availability of safe, accessible and affordable accommodation in the community, either by providing public housing or by offering rent subsidies to persons with disabilities, and it has been noted that for housing to be considered adequate, it must meet minimum criteria relating to legal security of tenure, the availability of services, materials, facilities and infrastructure, affordability, habitability, accessibility, location and cultural suitability (Committee on the Rights of Persons with Disabilities, 2022a: paras. 32 and 33). This also requires much closer coordination between housing and support policies, since the availability of community-based support cannot ensure effective deinstitutionalisation where persons with disabilities lack access to adequate housing in which such support can be provided.

Taking into account the general content of Article 28 CRPD, deinstitutionalisation also requires addressing poverty and social exclusion among persons with disabilities. Insufficient economic resources may increase the risk of institutionalisation and, at the same time, constitute a barrier to leaving institutional settings and establishing a life in the community. States must therefore ensure, among other measures, adequate income support to cover disability-related expenses (Ibid.: para. 86) and avoid financial arrangements for support services that undermine the effective exercise of the right to live independently in the community.

person-centred principles, decision support, choice and control, administrative practices such as seeking participant feedback, the inclusion of persons with disabilities as advisors, and workforce training. Standards should also be based on support approaches that have proven to be effective. Another approach that States may wish to consider is to designate a non-governmental entity to accredit disability service providers based on best practice standards", Special Rapporteur on the rights of persons with disabilities, 2023: paras. 72 and 73.

4.5. The rights of carers and care workers

Reflection on support and care, from a rights-based perspective, must take into account its relational nature and must consider not only the rights of persons with disabilities who receive care, but also the rights of carers, which are, moreover, considered to be "inextricably linked"[16], overcoming the tension "between carers and care recipients" that characterises the care relationships typical of institutional culture. A rights-based approach to support and care is therefore needed to harmonise multiple perspectives, ensure the structuring of co-responsibilities that respects the rights of all those involved, and guarantees that those who receive and provide support and care, and self-care, do so under conditions of equality (Office of the United Nations High Commissioner for Human Rights, 2023: para. 9)[17].

It is therefore essential to transform the conditions in which support and care relationships take place. In relation to informal care, this requires adequate support for families and other persons providing unpaid care, as already emphasised. In relation to professional care and support, it requires greater investment in the sector and appropriate regulation and oversight to ensure fair, safe and dignified working conditions (Office of the United Nations High Commissioner for Human Rights, 2023: para. 55). Improving these conditions may also contribute to challenging the feminisation of workcare and to increasing the participation of men in the sector.

In any case, improving the conditions in which support and care are provided, caring for those who care, is therefore not external to the objectives of deinstitutionalisation. Rather, it is an important condition for building sustainable support systems capable of respecting the rights of persons with disabilities and enabling them to pursue their own life plans and to be fully included in the community.

5. Final Reflections

The analysis developed in this paper shows that effective deinstitutionalisation in the field of disability cannot be reduced to the closure of institutions or the relocation of persons with disabilities to smaller or formally community-based settings. It requires a broader transformation of the institutional culture underpinning traditional care systems and, in particular, a shift from an assistencialist framework to a human rights-based approach centred on the recognition of persons with disabilities as rights-holders with choice and control over their own lives.

[16] In this regard, the Office of the United Nations High Commissioner for Human Rights (2023: para. 9) notes that "overburdening unpaid or underpaid carers necessarily affects the quality of care they can provide, whilst a carer-centred system risks obscuring the agency and autonomy of care recipients".

[17] As the Office of the United Nations High Commissioner for Human Rights notes, these considerations relate to the Triple R (3R**)** framework, referred to in the International Labour Organization's report Care Work and Care Jobs for the Future of Decent Work (2018), which states that care work must be Recognised and Redistributed, and that Unpaid care work must be Reduced. For its part, UN Women (2022) adds 'Reward' and 'Representation' to the 3R framework for paid care workers, promoting decent work – including for migrant workers – by ensuring their representation, social dialogue and collective bargaining. The *European Care Strategy*, mentioned above, is also worth highlighting in relation to the rights of carers.

This transformation entails fundamental changes in the ethical and conceptual framework of support and care and requires particular attention to the interrelated rights to choose one's way of life and exercise legal capacity, to inclusion in the community and accessibility, to support and personal assistance, and to housing and social protection. It also requires attention to the rights and conditions of carers and care workers, without displacing the rights, agency, will and preferences of persons with disabilities as the central normative reference point of deinstitutionalisation.

For these changes to result in effective deinstitutionalisation, however, they must be translated into legal frameworks, policies and support and care practices.

Admittedly, whilst legal changes are not in themselves sufficient to ensure the success of the deinstitutionalisation process, it is essential to have a robust legal framework in line with the rights-based approach that supports and guides the process (European Expert Group on Transition from Institutional to Community-Based Care: Chapter 4).

The reform of national legal frameworks must therefore include the abolition of provisions that facilitate or permit institutionalisation on the grounds of disability and ensure the legal recognition, enforceability and effective protection of the rights identified above. It must also ensure that persons with disabilities have access to effective legal remedies against institutionalisation and discrimination on the grounds of disability. Furthermore, from the perspective of deinstitutionalisation outlined in this paper, legal reform must be comprehensive and holistic, extending beyond disability legislation and regulations on social services and care to other areas of law, including civil law, housing law, health law (including mental health), social protection, education and employment, among others (Committee on the Rights of Persons with Disabilities, 2022a: paras. 53–59). Consistently with a human rights-based approach, persons with disabilities, including those living in institutions and survivors of institutionalisation, and their representative organisations must be actively and meaningfully involved in the design, implementation, monitoring and evaluation of these legal and policy reforms and of deinstitutionalisation strategies more broadly.

Beyond regulatory changes, progress towards support systems based on a rights-based approach requires that this culture of rights truly permeates the care model and transforms it, which logically requires a paradigm shift in support and care practices.

With regard specifically to professional support and care, this demands new strategies, new skills and new professional roles aimed, in accordance with the human rights approach, at supporting the free choice of life plans and the full inclusion of persons with disabilities in the community.

In any case, to ensure, both during the transition period and after the implementation of the rights-based support model, that the new services do not reproduce the characteristics of the institutional culture, a substantial change in the service evaluation system is essential (European Expert Group on Transition from Institutional to Community-based Care: Chapter 9). In contrast to the quality evaluation model typical of the institutional approach – which focuses on the service and revolves around compliance with

requirements or technical aspects – a new model is needed that centres the measurement of quality on the person and their rights (rather than solely on their needs)[18].

Finally, a critical element is to bring about a profound and widespread cultural change, which involves extending human rights education to various contexts; ensuring the training of professionals from diverse fields, not just those directly involved in care; educating families; empowering persons with disabilities; and raising awareness throughout the community about the rights of persons with disabilities and the importance of respecting their choices.

Ultimately, deinstitutionalisation should therefore be understood as a systemic transformation of the relationships, services, legal frameworks, social attitudes and conditions that shape the lives of persons with disabilities. Its success must be assessed not by the number or size of institutions that have been closed or transformed, but by the extent to which persons with disabilities effectively exercise choice and control over their own lives, receive the support they require, and participate in the community on an equal basis with others.

REFERENCES

ANSUÁTEGUI ROIG, Francisco Javier (2010). "Argumentos para una teoría de los derechos sociales", *Revista Derecho del Estado*, 24, 2010, pp. 45-64. https://dialnet.unirioja.es/servlet/articulo?codigo=3335660&utm

ARSTEIN-KERSLAKE, Anna (2017). *Restoring Voice to People with Cognitive Disabilities*: *Realizing the Right to Equal Recognition before the Law,* Cambridge, Cambridge University Press.

BARRANCO AVILÉS, María del Carmen (2016). *Condición humana y derechos humanos. Algunas claves filosóficas para un modelo contemporáneo de derechos*, Dykinson, Madrid.

BROGNA, Patricia (2023). "Una noción triádica: condición, situación y posición de discapacidad", *Revista Andamio*, pp. 333-362. https://doi.org/10.29092/uacm.v20i52.1019

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2011). *Concluding observations of the Committee on the Rights of Persons with Disabilities on Spain's initial Report*, CRPD/C/ESP/CO/1.

[18] On this point, I find the quality of life model referred to by the European Expert Group on Transition from Institutional to Community-based Care, 2012: 142, to be insufficient. In my view, Robert L. Schalock's Quality of Life Framework, which has been developed in Spain by Miguel Ángel Verdugo, whilst placing the focus of the assessment on the individual, incorporates the components of choice and control and, in general, is consistent with the values of the CRPD, presents some weaknesses from a human rights perspective in that it posits that the dimensions of quality of life are defined, essentially, in terms of needs rather than rights (see Wang; Schalock; Verdugo and Jenaro, 2010).

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2014). *General Comment Nº1 Article 12: Equal recognition before the law,* CRPD/C/GC/1.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2016). *Guidelines on the right to liberty and security of persons with disabilities* included as Annex Report of the Committee on the Rights of Persons with Disabilities, A/72/55.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2017). *General Comment Nº5 on living independently and being included in the community*, CRPD/C/GC/5.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2018), *General Comment Nº7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*, CRPD/C/GC/7.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2022a). *Guidelines on deinstitutionalization, including in emergencies*, CRPD/C/5.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2022b), *Views adopted by the Committee in S.K. v. Finland*, CRPD/C/26/D/46/2018.

COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES (2023) Views adopted in Bellini v. Italy, CRPD/C/27/D/51/2018.

COUNCIL OF EUROPE COMMISSIONER FOR HUMAN RIGHTS (2012). *The right of persons with disabilities to live independently and to be included in the community*, https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-beinc/16806da8a9 (10/06/2026).

COURTIS, Christian (2004). "Discapacidad e inclusión social: retos teóricos y desafíos prácticos", *Jueces para la democracia*, 51, 2004, pp. 7-14. https://www.juecesdemocracia.es/wp-content/uploads/2004/11/revista-51-noviembre-2004.pdf?utm

CROWTHER, Neil (2019), *The right to live independently and to be included in the community in European States*, ANED synthesis report.

CUENCA GÓMEZ, Patricia (2015a) "Disability and Human Rights: A Theoretical Analysis", *The Age of Human Rights Journal*, 4, pp. 34-59. https://doi.org/10.17561/tahrj.v0i4

CUENCA GÓMEZ, Patricia (2015b). "Disability, normality and Human Rights", *Essays on human rights*, Aranzadi Thomson Reuters, Pamplona, pp. 141-158.

DE ASÍS ROIG, Rafael (2013). *Sobre discapacidad y derechos*, Dykinson, Madrid.

DE ASÍS ROIG, Rafael (2026), "Sobre el enfoque centrado en derechos (ECD) reflexiones para su construcción y su concreción en el análisis de las intervenciones sociales", *Papeles el tiempo de los derechos*, nº1.

DE ASÍS ROIG, Rafael (2023). "The Right to Universal Accessibility", *The Age of Human Rights Journal*, 21, pp. 1-13. https://doi.org/10.17561/tahrj.v21.7788.

DE ASÍS ROIG, Rafael (2019). "Apoyo y asistencia personal", *Ius fugit. Revista de Cultura Jurídica*, nº22, pp. 15-28. https://researchportal.uc3m.es/display/act521929?utm

DE BHAILÍS, Clíona and FLYNN, Eilionóir (2017). "Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD", *International Journal of Law in Context*, 13(1): 6-21. https://doi.org/10.1017/S174455231600046X

EUROPEAN EXPERT GROUP ON TRANSITION FROM INSTITUTIONAL TO COMMUNITY-BASED CARE (2012). *Common European Guidelines on transition from institutional to community-based care*, 2012, https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-finalenglish.pdf (10/06/2026).

EUROPEAN NETWORK ON INDEPENDENT LIVING (ENIL) (2023). *Proposal of the European Network on Independent Living for the European Commission Guidance on Independent Living and being included in the community*.

GREGORIO PECES-BARBA INSTITUTE OF HUMAN RIGHTS (2024). *Study on deinstitutionalisation processes and transition to personalized and community support models,* Executive Summary, https://estudiodesinstitucionalizacion.gob.es/wp-content/uploads/2024/01/Resumen-ejecutivo-estudio-transversal-en-ingles.pdf (10/06/2026).

INCLUSION INTERNATIONAL (2012). *Inclusive Communities = Stronger Communities: A Global Report on Article 19*. https://inclusion-international.org/resource/inclusive-communities-stronger-communities-a-global-report-on-Article-19/ (10/06/2026).

INTERNATIONAL LABOUR ORGANIZATION (2018). *Care Work and Care Jobs for the Future of Decent* Work, Geneva.

KANTER, Arlene S., *The Development of Disability Rights Under International Law: From Charity to Human Rights,* Routledge, London, 2014.

KNAPP, Martin; CYHLAROVA, Eva; COMAS-HERRERA, Adelina and LORENZ-DANT, Klara (2021). *Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities*, Care Policy and Evaluation Center, London School of Economics and Political Science.

LAWSON, Anna (2007). "The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?", *Syracuse Journal of International Law and Commerce*, 34, 2007, pp. 563- 619. https://openurl.ebsco.com/EPDB%3Agcd%3A15%3A14015/detailv2?id=ebsco%3Agcd%3A32507817&jrnl=00930709&sid=ebsco%3Aplink%3Acrawler&link_origin

LEWIS, Oliver and RICHARDSON, Genevra, "The right to live independently and be included in the community", *Int J Law Psychiatry*, 69, 2020, pp. 1-27. https://doi.org/10.1016/j.ijlp.2019.101499

MANSELL, Jim; KNAPP, Martin; BEADLE-BROWN, Julie y BEECHAM, Jennifer (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report.* Canterbury, Tizard Centre, University of Kent.

MANSELL, Jim (2006), "Deinstitutionalisation and community living: progress, problems and priorities", *Journal of Intellectual & Developmental Disability*, 31(2), pp. 65–76. https://doi.org/10.1080/13668250600686726

MCCARRON, Mary; LOMBARD-VANCE, Richard; MURPHY, Esther; MAY, Peter; WEBB, Naoise; SHEAF, Greg; MCCALLION, Philip; STANCLIFFE, Roger; NORMAND, Charles; SMITH, Valerie and O'DONOVAN, Mary Ann (2019). "Effect of deinstitutionalisation on quality of life for adults with intellectual disabilities: A systematic review", *BMJ Open*, 9(4). https://doi.org/10.1136/bmjopen-2018-025735

OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER (2023). *Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic,* A/HRC/52/52.

OLIVER, Mike (1996). *Understanding Disability, From theory to practice*, Palgrave, Malaysia.

PALACIOS, Agustina (2008). *El modelo social de discapacidad: orígenes, caracterización y plasmación en la Convención Internacional sobre los Derechos de las Personas con discapacidad*, Ediciones Cinca, Madrid.

QUINN, Gerard and DEGENER, Theresia (2002). *Disability and Human Rights*, United Nations, HR/PUB/02/1, New York and Geneva.

SPECIAL RAPPORTEUR ON THE RIGHTS OF PERSONS WITH DISABILITIES (2023). *Thematic study Transformation of services for persons with disabilities*, A/HRC/52/32.

SPECIAL RAPPORTEUR ON THE RIGHTS OF PERSONS WITH DISABILITIES (2022). *Thematic study on artificial intelligence and the rights of persons with disabilities*, A/HRC/49/52.

SPECIAL RAPPORTEUR ON THE RIGHTS OF PERSONS WITH DISABILITIES (2016). *Thematic study on access to support by persons with disabilities*, A/HRC/34/58.

UNSDG, Human Rights Working Group (2023). *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies*.

UN-WOMEN (2022). *A toolkit on paid and unpaid care work: from 3Rs to 5Rs*.

VICENTE ECHEVARRÍA, Irene (2026). *Cuidados y derechos. Los feminismos y los estudios de la discapacidad en diálogo,* Dykinson, Madrid.

WHO EUROPE (2010). *The Case for Change. Background paper for the conference Better health, better lives: Children and young people with intellectual disabilities and their families,* World Health Organization.

YOUNG, Iris Marion (1990). *Justice and the politics of difference,* Princeton University Press.

WANG, Mian; SCHALOCK, Robert L.; VERDUGO, Miguel Ángel and JENARO, Cristina, "Examining the factor structure and hierarchical nature of the quality of life construct", *American Journal on Intellectual and Developmental Disabilities*, nº115, 2010, pp. 218-233. https://doi.org/10.1352/1944-7558-115.3.218

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