



A/HRC/37/56

# Universal legal capacity

to ensure the equal recognition of  
persons with disabilities before the law

*Figure 1 Photo by Christian Tasso. text: Universal legal capacity to ensure the equal recognition of persons with disabilities before the law.*

## About this document

The Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, presented this report at the 37<sup>th</sup> session of the Human Rights Council (2018).

This version of the report has been adapted for wider distribution. Changes have been made to presentation, and in some cases, to content. The original is available [here](#).

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## I. Introduction

Around the world, experiences of peer support, advanced directives, advocacy and other support networks are showing the way to fulfil the right of persons with disabilities to full legal capacity and equality before the law. The notion of universal legal capacity advanced in this report calls for societies in which every person—with or without disabilities—has the same rights, and is therefore equal before the law.

Throughout history, many persons with disabilities have been deprived of the exercise of their rights by denying their legal capacity. While the practice has been widely accepted and viewed as necessary to protect both the individuals concerned and society, it has proved to be wrong.

Denial of legal capacity takes away people's control over their lives, from critical decisions like getting married, forming a family, choosing where to live or with whom, to all aspects of their daily routines, drastically reducing their opportunities to participate in society. It has also allowed the proliferation of harmful practices, such as coercion, institutionalization and sterilization, which resulted in the ultimate objectification of persons with disabilities.

The recognition by States of the full legal capacity of all persons with disabilities, and the availability of supported decision-making are necessary steps for making their rights a reality, providing the freedom and opportunity to lead meaningful lives, in accordance with their values and preferences.

In this report, the Special Rapporteur establishes a path towards universal legal capacity on the basis of the UN Convention on the rights of persons with disabilities (CRPD) and other international human rights treaties, illustrated by experiences from a growing number of countries, including Costa Rica, Ireland, Kenya and Sweden.

In its conclusion, the document reminds States of their obligations as signatories of the CRPD, and provides a series of recommendations to ensure the equal recognition of persons with disabilities before the law. These include:

- Recognition of the right to legal capacity of persons with disabilities in domestic legislation, abolishing all laws and regulations that restrict this fundamental right.
- To suspend all new applications of substitute decision making, and create a path for persons with disabilities under such regimes to have their legal capacity restored.
- To promote and guarantee the access of persons with disabilities to mechanisms of supported decision making, by providing adequate funding, policy frameworks produced in consultation with persons with disabilities, and by adequately training judges, service providers and all other relevant State authorities.

The Special Rapporteur also calls the UN system and all international cooperation actors to play their part towards the implementation of universal legal capacity frameworks globally, providing funding, technical capacity and general support to States, as they embark in universal legal capacity implementations.

## II. The right of persons with disabilities to equal recognition before the law

### A. A paradigm shift towards universal legal capacity

Equal recognition before the law is central to human rights. Often described as the “right to have rights”, it articulates the right of every person to be a holder of rights and obligations under the law, which is a necessary precondition for the exercise of all other human rights and fundamental freedoms. At the international level, it is recognized in the Universal Declaration of Human Rights (art. 6), the International Covenant on Civil and Political Rights (art. 16), the Convention on the Elimination of All Forms of Discrimination against Women (art. 15), the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (art. 24) and the Convention on the Rights of Persons with Disabilities (art. 12). At the regional level, it is recognized in the American Convention on Human Rights (art. 3) and the African Charter on Human and Peoples’ Rights (art. 5).

Recognition as a person before the law and legal capacity are closely interlinked concepts. Equal recognition as a person before the law guarantees the right of every human being to have his or her existence recognized in the legal order, that is, being recognized as possessing legal personality and coming within the purview and protection of the law. Legal capacity entails holding rights and duties (legal standing) and exercising those rights and duties (legal agency). The evolving interpretation of the right to equal recognition as a person before the law implies that legal capacity is a universal attribute inherent to all persons by virtue of their humanity. Therefore, if a person’s legal agency is denied, his or her status as a person before the law is also affected.

Throughout history, many groups have been denied their legal capacity as both legal standing and legal agency, including women, minority groups, indigenous persons, migrants, refugees and asylum seekers. Among them, persons with disabilities face a wide range of violations to their right to legal capacity in all jurisdictions worldwide. Challenges are particularly acute for persons with psychosocial disabilities, persons with intellectual disabilities, autistic persons and persons with dementia. Their legal capacity is usually restricted on the basis of having a medical condition or impairment (status approach), having made a decision perceived as poor (outcome approach), or having deficient decision-making skills (functional approach). Once their legal capacity is restricted in one or more areas of life, they are put under a substitute decision-making regime such as guardianship or curatorship, where a legal representative is appointed to make decisions on their behalf, or where decisions will be made by designated medical personnel or by a court.

Persons with disabilities under guardianship have no control over decisions related to their lives, from entering into contracts to choosing where or with whom to live.

The denial of and restrictions to the legal capacity of persons with disabilities are grave and pervade all aspects of life. Persons with disabilities under

guardianship, for example, lose their capacity to exercise all or almost all of their rights and have no control over decisions related to their lives, from entering into contracts to choosing where and with whom to live. Restrictions may also apply on a case-by-case basis. For example, legislation based on a functional approach may limit a person’s rights and freedoms in specific areas of life such as marriage, voting, parenting or free and informed consent to health care. Furthermore, in many jurisdictions, those who have not been formally placed under any form of substituted decision-making may also face restrictions in exercising their rights, as it is commonly assumed that they have no legal capacity or that they need a third person to validate their acts. All those practices perpetuate discrimination and exclusion against persons with disabilities, and pave the way to different forms of abuse, corruption, exploitation, coercion and institutionalization.

Women with disabilities experience aggravated forms of discrimination and specific violations against their right to legal capacity. Owing to gender stereotypes and gender-based violence, they are at particularly high risk of being placed under substitute decision-making regimes. For instance, women with leprosy-related disabilities are often deprived of rights, such as the right to property. Furthermore, in most countries, women with disabilities cannot take autonomous decisions with regard to their reproductive and sexual health and rights, resulting in highly discriminatory and harmful practices (A/72/133).

Similarly, older persons with disabilities are at heightened risk of being denied or restricted in their legal capacity, formally or informally, owing to prejudices and assumptions based on both age and disability. Many of them are placed in institutions, confined at home or are not allowed to exercise their legal capacity without the consent of family members, even if there is no substitute decision-making regime in place. These practices lead to the loss of control of their lives and expose older persons with disabilities to high levels of violence, abuse and neglect.

For too long, the international human rights system did not pay attention to those multiple violations of the right to legal capacity of persons with disabilities. In fact, there has been a significant underuse of the international legal framework to advance this and other human rights for persons with disabilities (see A/70/297, para. 18).

In that context, the Convention on the Rights of Persons with Disabilities introduces a paradigm shift in relation to the legal capacity of persons with disabilities. The Convention moves away from medical and paternalistic approaches to disability towards a human rights-based approach and considers persons with disabilities as rights holders, rather than as mere receivers of protection, rehabilitation or welfare. In the Convention the universality, indivisibility, interdependence and interrelatedness of human rights are recalled by stressing that persons with disabilities should fully enjoy all their rights without any kind of discrimination. While in the text of the Convention the subsistence of structures and practices that are contrary to the human rights of persons with disabilities is questioned, the importance of positive measures to ensure the effective implementation of the Convention is also stressed.

## The paradigm of the CRPD enshrines the universal recognition of legal capacity and the support needed to exercise it.

In the Convention a universalist understanding of the right to legal capacity is upheld and it states that all persons with disabilities enjoy legal capacity on an equal basis with others. Moreover, the role of support in the actual implementation of the right to legal

capacity is emphasized, underlining the diversity and interdependence of human experiences. Accordingly, persons with disabilities should have access to appropriate support to exercise their legal capacity and not be restricted in its enjoyment. The paradigm of the Convention enshrines the universal recognition of legal capacity and the provision of the support needed to exercise it. In doing so, it challenges traditional discriminatory approaches and acknowledges the structural barriers to exercising legal capacity experienced by persons with disabilities. Furthermore, the Convention has expanded the understanding of the right to equal recognition before the law in the international human rights system for persons with disabilities and other groups. On that account, the obligations arising from other international human rights treaties should be complemented by the provisions of the Convention and interpreted in the light of it.

The paradigm shift of the Convention in relation to legal capacity has already had an important impact on the work of the United Nations and of regional organizations. Different United Nations treaty bodies, special procedures and agencies are progressively adjusting their standards to the Convention. In the inter-American human rights system, the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities adopted a general comment calling for the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities to be interpreted in line with article 12 of the Convention on the Rights of Persons with Disabilities. The draft protocol to the African Charter on Human and Peoples' Rights on the rights of persons with

disabilities in Africa, adopted in 2016, also recognizes the right to legal capacity of all persons with disabilities.

## **B. The normative content of article 12 of the Convention on the Rights of Persons with Disabilities**

Article 12 of the Convention articulates the content of the right to equality before the law as it applies to persons with disabilities. Article 12 (1) reaffirms the right of persons with disabilities to be recognized as persons before the law. Article 12 (2) recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. Article 12 (3) sets out the State obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. Article 12 (4) outlines the safeguards that must be present in a system of support for the exercise of legal capacity. Finally, article 12 (5) requires States to ensure the rights of persons with disabilities with respect to financial and economic affairs, on an equal basis with others.

There are four primary State obligations arising from article 12. First, States must recognise universal legal capacity for all persons with disabilities, including for those requiring more intensive support. That entails adopting legislation that explicitly recognizes the capacity of persons with disabilities to create, modify or end legal relationships, as well as providing effective legal protection against any interference with such capacity. That recognition must include the exercise of the right to property, access to all forms of financial credit and the right to control one's own financial affairs, as recognized in article 12 (5) of the Convention. States cannot restrict the legal capacity of persons with disabilities and must rather protect it against any interference in all aspects of life, including decisions related to medical treatment, living independently or financial matters.

The recognition of universal legal capacity for all persons with disabilities strongly influences the exercise of all other human rights and fundamental freedoms. Those rights include access to justice (art. 13 of the Convention), liberty and security of the person (art. 14), freedom from torture or cruel, inhuman or degrading treatment or punishment (art. 15), freedom from exploitation, violence and abuse (art. 16), integrity (art. 17), nationality and liberty of movement (art. 18), living independently and being included in the community (art. 19), freedom of expression and opinion, access to information (art. 21), privacy (art. 22), marriage, family, parenthood and relationships (art. 23), health, including the right to free and informed consent (art. 25), work and employment (art. 27), adequate standard of living and social protection (art. 28), and participation in political and public life (art. 29). States must eliminate, in law and practice, all denials or restrictions of legal capacity of persons with disabilities in the exercise of these rights.

### **All forms of substitute decision-making are prohibited under the CRPD, including those based on the assessment of mental capacity skills.**

by a third party takes decisions based on what he or she considers is in the best interests of the person concerned, even if that goes against the will of the latter. They include plenary and partial guardianship, judicial interdiction, curatorship, conservatorship and mental health laws that allow involuntary treatment and commitment. All forms of substitute decision-making are prohibited under the Convention, including those based on the assessment of mental capacity skills.

Third, States must develop supported decision-making arrangements of varying types and intensity, including informal and formal support arrangements. Such arrangements include, for example, support networks, support agreements, peer and self-support groups, support for self-advocacy, independent advocacy and advance directives. Contrary to substitute

Second, States must abolish and prohibit all regimes of substituted decision-making. According to the Committee on the Rights of Persons with Disabilities, these regimes can be defined as systems where legal capacity is removed from a person (even if limited to a single decision) and a substitute decision maker appointed

decision-making regimes, under a supported decision-making arrangement, legal capacity is never removed or restricted; a supporter cannot be appointed by a third party against the will of the person concerned; and support must be provided based on the will and preferences of the individual. The right to legal capacity is not contingent on the acceptance of any form of support or accommodation, as persons with disabilities have the right to refuse them.

## Support arrangements should be designed to enable direct choice and control by persons with disabilities, so that they can plan and direct their own support.

All forms of support must incorporate a human rights based-approach that is respectful of the general principles of the Convention (art. 3). States must take all appropriate measures to ensure that support programmes respect the inherent dignity, individual autonomy (including the freedom to make one's own choices), and independence of persons; are

provided on a voluntary basis; and respect the principles of non-discrimination and equality. Support arrangements should be designed to enable direct choice and control by persons with disabilities, so that they can plan and direct their own support (see A/HRC/34/58, para. 55). Furthermore, States must adopt a community-based approach to the provision of support. That allows the provision of culturally sensitive support arrangements in the communities where persons with disabilities live, builds on existing social networks and community resources, and enables stakeholders (family, friends, neighbours, peers and others) to play a significant role in supporting persons with disabilities (see A/HRC/34/58, para. 61).

Support arrangements must be available, accessible, adequate and affordable (see A/HRC/34/58, paras. 48–56). States should ensure the availability of an adequate number of functioning programmes and services to provide the fullest possible range of support to the diverse population of persons with disabilities. Support arrangements should also be accessible to all persons with disabilities, particularly the most disadvantaged ones, without discrimination of any kind. States must ensure that support is available within the safe physical and geographical reach of everyone, including those in institutions. Support must be affordable for all persons with disabilities, and States must ensure that support is available at nominal or no cost to the maximum extent of their available resources and take into account gender disparities in income and access to financial resources. States are also required to provide accessibility measures and reasonable accommodation to ensure that persons with disabilities can exercise legal capacity. The State obligation to ensure access to support goes beyond the right to legal capacity, as some persons with disabilities may need support for decisions that have no legal impact (see A/HRC/34/58, paras. 29–41).

Fourth, States must establish safeguards to ensure the respect for the rights, will and preferences of the individual who is availing themselves of that support. Safeguards on the provision of support must: (a) be based on the person's rights, will and preferences; (b) offer protection against abuse and undue influence; and (c) be proportional and tailored to the individual. Safeguards should include accountability mechanisms to ensure that the person's will and preferences are respected in the provision of support, as well as mechanisms to challenge the action of a support person if there is a belief that the support person is not acting in accordance with the will and preferences of the person concerned. Ensuring that persons with disabilities have access to different forms of support, including independent advice, also contributes to reducing the risk of undue influence. It is important to emphasize that safeguards are meant to protect individuals in the provision of support, not prevent them from making decisions, or from the possibility of taking risks and making mistakes. Support should never amount to substitute decision-making and the primary purpose of the safeguards outlined in article 12 of the Convention is to ensure the respect of the rights, will and preferences of the person concerned.

The Special Rapporteur acknowledges that in certain situations the will of the person concerned might be difficult to determine. In situations where this cannot be established even after significant efforts, including through the provision of support and

accommodations, a “best interpretation of the will and preference” standard should be applied as a last resort. That standard implies ascertaining what the person would have wanted instead of deciding on the basis of her/his best interest. The process should include consideration of the previously manifested preferences, values, attitudes, narratives and actions, inclusive of verbal or non-verbal communication, of the person concerned.

Similarly, the provision of support to persons experiencing an emotional crisis and severe distress poses certain difficulties. The default response in most jurisdictions today is to override the legal capacity of the person concerned and to authorize forced psychiatric interventions. However, such an approach does not respect the inherent dignity and autonomy of the individual. The support paradigm offers a rights-based approach to deal with such cases. For instance, advance plans allow persons with disabilities to give instructions on how to deal with future emotional crises and/or to appoint a person to support them in those particular circumstances. In addition, there is growing evidence as to the effectiveness of non-coercive support practices within and outside the health sector (see A/HRC/35/21, para. 29). Those practices need to be further researched, developed and implemented, and must be based on the principles set out above regarding supported decision-making. In addition, there is an urgent need to address the structural aspects that make it impossible for persons with disabilities to access support during an emotional crisis (for example, because of prejudice, low expectations, lack of flexibility, lack of resources or stringent liability).

Article 12 of the Convention was one of the most discussed articles and the one that demanded the greatest consensus during the negotiations. The issues of universal legal capacity and substituted decision-making were discussed extensively during the drafting process. The text adopted reflects the common understanding that all persons with disabilities should enjoy the right to legal capacity on an equal basis with others, as well as the right to access support if requested. In fact, proposals to limit the scope of the right to legal capacity and to incorporate a substituted decision-making paradigm, including the proposal to include a footnote conditioning the understanding of the term legal capacity in several languages, were rejected prior to the adoption of the Convention.

### III. Legal capacity law reform

Under international human rights law, States have an obligation to respect, protect and fulfil the right of all persons with disabilities to legal capacity. The obligation to respect means that States should refrain from interfering with or curtailing, by any means, the enjoyment of persons with disabilities of the right to legal capacity. The obligation to protect requires States to prevent third parties, including private actors, from interfering with persons with disabilities to realize and enjoy the right to legal capacity. The obligation to fulfil requires States to take positive actions to facilitate the exercise of their legal capacity, including by facilitating access to support and training.

International human rights law also imposes on States an obligation to ensure that their domestic legislation is consistent with international standards. Article 4 (1) (a) and (b) of the Convention requires States to adopt all the appropriate legislative measures to implement the human rights and fundamental freedoms recognized therein and to repeal any inconsistent legislation that constitutes discrimination against persons with disabilities. States must therefore review the adequacy of their existing legislation in view of their obligations under article 12 and other related articles of the Convention.

Accordingly, States should identify all legislation to be abolished, amended or adopted to render their normative framework compliant with article 12 of the Convention. The legal review should be comprehensive and take into account the interdependence and indivisibility of all human rights. It should also be all-encompassing and exhaustive, going beyond the traditional areas of law related to legal capacity (civil, family and mental health law), to include legislation on political participation, privacy, health, employment, social protection, immigration, criminal law and access to justice, among other things.

Thirteen States parties to the Convention have issued reservations and declarations upon ratification or accession, with the intention of limiting the implementation of article 12 and other related articles. According to article 19 of the Vienna Convention on the Law of Treaties and article 46 of the Convention itself, reservations and declarations incompatible with the object and purpose of the Convention are not permitted. Given the centrality of article 12 to the enjoyment and exercise of all rights set out in the Convention, such restrictions clearly contradict the object and purpose of the Convention, as they hinder and/or deny the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. In that regard, the Special Rapporteur urges the States parties concerned to withdraw all their reservations and declarations.

## A. Law reform trends on legal capacity and supported decision-making

Since the adoption of the Convention, several States have started or completed legal reforms in relation to the right to legal capacity of persons with disabilities as part of their obligations under the Convention, or in order to harmonize their legislation prior to ratification or accession. While most of these laws and bills are not in full compliance with article 12 of the Convention, they show that a growing number of States acknowledge that

Since the adoption of the CRPD, several states have started legal reforms in relation to the right to legal capacity.

their legal systems, and particularly their substitute decision-making regimes, fail to guarantee the rights of persons with disabilities.

In 2016, Costa Rica adopted Law No. 9379, which abolished all forms of guardianship and created the legal figure of “guarantor

for the equality before the law of persons with disabilities”, whose role is to ensure the full enjoyment of legal capacity by all persons with disabilities. The Special Rapporteur welcomes this significant development and encourages Costa Rica to promptly adopt the necessary regulations to effectively implement the reform in line with the principles and rights of the Convention.

Some countries have adopted provisions declaring universal legal capacity for persons with disabilities. Those declarations reaffirm that persons with disabilities have the right to equal recognition before the law and legal capacity, as enshrined in article 12 of the Convention. While those declarations often contradict other provisions in the same legal framework, they open the space for further law reforms and court interventions. For example, in the general law on persons with disabilities of Peru a universal recognition of legal capacity was introduced and at the same time a parliamentary committee was created to review the Civil Code in line with the declaration in the general law.

Several countries have also introduced recognition of supported decision-making regimes into their legislation. The scope and formality of those regimes vary from country to country, but generally they allow individuals to appoint one or more persons to assist them to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision. In some jurisdictions, however, the role of supporters includes representation as a general rule, which renders the support as a de facto mechanism of substitute decision-making.

In a number of countries, persons with disabilities must access the courts in order to have supported decision-making arrangements recognized. The courts are mandated either to determine the scope of such arrangements, or to ensure that the proposed scope is suitable. While in most cases such measures have no impact on a person’s legal capacity, requiring the intervention of a court creates a series of challenges for persons with disabilities: (a) in most jurisdictions they encounter barriers in access to justice owing to the lack of accessibility and procedural accommodations; (b) it is a more costly system, which makes access to support less affordable; (c) court delays can compromise access to support;

and (d) intense training is required to ensure a paradigm shift in the way judges address the legal capacity of persons with disabilities.

### Supported decision-making through private agreements:

In some countries, persons with disabilities can create supported decision-making arrangements through private agreements. Such regimes are voluntary and can be terminated at any time. While those agreements do not require judicial intervention, in many jurisdictions they are usually subject to very rigorous validity requirements and must be notarized and/or registered in order to have legal effect and be monitored. As the procedure can compromise the confidentiality of personal information and could be wrongly perceived as a condition for exercising legal capacity, it requires appropriate regulation to ensure adequate safeguards to avoid compromising the full exercise of legal capacity.

### Advance directives that express will and preferences beforehand:

Many legal systems also provide for advance directives, which allow individuals to express their will and preferences beforehand, so they can be followed at a time when they may not be in a position to communicate them. The scope of the potential advance decisions is usually specified in each jurisdiction. Advanced health-care directives are among the most common, but some countries allow advanced directives with a broader scope, including personal, patrimonial or finance matters (enduring power of attorney). The person concerned should decide the moment in which an advance directive enters into force and ceases to have effect. However, in most jurisdictions advance directives only enter into force when the person is declared legally incapacitated. Moreover, in many countries they are not binding or can be overruled in certain situations.

### Regimes of co-decision making:

Some countries have implemented regimes of co-decision-making. Under those regimes, an individual appoints a co-decision maker who will make decisions jointly with the appointer in order for those decisions to have legal effect. Such arrangements are usually implemented through private agreements, although some legal frameworks require court intervention. In most jurisdictions, however, the co-decision maker has the power, in certain circumstances, to veto a person's decision, thus restricting the exercise of their legal capacity. As long as such arrangements are involuntary and the person concerned does not have the right to terminate or change the relationship at any time, the directives cannot be considered as a form of supported decision-making.

### Independent advocates, or "personal ombudsmen":

States have also introduced independent advocates to support persons with disabilities to exercise their legal capacity. In Sweden, for example, independent advocates, called "personal ombudsmen", conduct outreach and establish relationships of trust with persons with psychosocial disabilities, providing them support in different areas of life, including decision-making. Research has shown that this nationwide scheme provides significant benefits not only to its clients but also to society in general, by reducing the use and the costs of specialized services. In some jurisdictions, however, independent advocates work within the framework of substituted decision-making regimes, assisting individuals who have been deprived of their legal capacity to express their will and preferences and/or to communicate with the guardian or curator.

All supported decision-making regimes include a broad range of safeguards. Many jurisdictions require supporters to respect the will and preferences of the individuals, while regretfully others still refer to the "best interest" standard. Several countries have incorporated provisions in their laws to prevent abuses and undue influence, such as time limits, periodic review, requirements for being a supporter, liability, complaint and redress mechanisms, and monitoring. For example, in Ireland the Assisted Decision-Making (Capacity) Act 2015, provides that anyone can lodge an administrative complaint against a decision-making assistant.

Many of the efforts towards supported decision-making regimes maintain elements of substitute decision-making and/or coexist with regimes of substitute decision-making. In

some jurisdictions, courts can impose a supported decision-making arrangement or a co-decision-making arrangement, or decide who should act as a supporter and what acts she or he may perform. Many countries have established thresholds to access support, usually based on an assessment of a person's mental capacity, where those who cannot reach such thresholds are "doomed" to substitution decision-making regimes. The use of the "best interest" standard in some supported decision-making regimes is also worrisome, as it contradicts respect for the will and preference of individuals. Furthermore, in certain jurisdictions, accessing certain forms of supported decision-making compromises the legal capacity of the person and can translate into a loss of rights, including parental and political rights.

Despite such limitations, the growing number of countries adopting supported decision-making schemes is encouraging and shows that substitute decision-making regimes are increasingly being challenged. Colombia and Peru, for example, are in the process of undertaking major legal reforms in this area, which include the recognition of the capacity to act of all persons with disabilities, the elimination of guardianship regimes, and the introduction of a set of supported decision-making arrangements. In both countries, draft bills prepared by multi-stakeholder commissions received the endorsement of different political parties and civil society. The Special Rapporteur welcomes those processes and strongly encourages the States to promptly adopt these important reforms.

**As long as mental health laws allow for involuntary deprivation of liberty, forced treatment or medication, those laws are contrary to the CRPD.**

The Special Rapporteur has also identified countries that have undertaken reforms to ensure more procedural safeguards in the implementation of substitute decision-making regimes. Changes introduced include the possibility to choose the person who would act as guardian, the

periodic review of guardianship orders and the right to appeal decisions that remove or restrict one's legal capacity. Some countries have also limited guardianship to being a measure of last resort, when no other less restrictive measure can be applied. All such reforms fall short in respecting the rights of persons with disabilities, as the existence of substitute decision-making regimes is contrary to article 12 of the Convention.

In a similar effort, a number of countries have removed plenary guardianship entirely from their legal systems, only permitting substitute decision-making in certain circumstances and for a limited period of time. In the majority of cases, States transition from plenary guardianship to partial guardianship or curatorship, limiting restrictions to legal capacity to health and/or financial matters. While the abolition of plenary guardianship is an important step, maintaining or creating regimes of partial guardianship and other forms of substitute decision-making are still contrary to the requirements of article 12 of the Convention.

Finally, there are a significant number of countries that have adopted or are considering adopting mental health legislation. As long as mental health laws allow for the involuntary deprivation of liberty, forced treatment and forced medication of persons with disabilities, those laws are contrary to the Convention, including the right of persons with disabilities to legal capacity. Regardless of their rights-based rhetoric and increased procedural safeguards, mental health laws confer on medical professionals the capacity to make decisions on behalf of persons with disabilities, particularly persons with psychosocial disabilities, thus legitimizing coercive practices. Moreover, in the past two decades, there has been a worrisome increase of community treatment orders in mental health legislation, which expands coercive care beyond the confines of mental health facilities. Mental health legislation as it exists today must be repealed, as it creates a separate legal regime for persons with psychosocial disabilities, contrary to the obligations of States under the Convention. Regulation of the practice of mental health services should focus on acceptability and quality, while the rights and freedoms of persons with psychosocial disabilities must be the same as those of others in all areas of law, including legal capacity and liberty and security of the person.

## B. Learning from supported decision-making in practice

Since the adoption of the Convention, there has been an increased interest in exploring how supported decision-making works in practice; pilot projects have been carried out in a number of countries across the world. Some have been carried out or funded by States, whereas others have been directly implemented by civil society organizations, including organizations of persons with disabilities, parent organizations and research centres. These initiatives cover a rich and diverse range of experiences and constitute a valuable source of information for legislators and policymakers.

The different models of supported decision-making include, among others, formal and informal networks, support agreements, independent advocates, peer support, advance directives and personal assistance. Such schemes provide a very broad range of support to individuals, including access to information, support for communication, empowerment,

There is little recognition of peer support in legislation, despite its potential to assist persons with disabilities in exercising their legal capacity.

building self-confidence, relationship building, personal planning, independent living assistance and administrative support. Moreover, while in many jurisdictions supported decision-making involves the appointment of one or more individuals, in practice support is also provided in group settings or using a mixed structure that incorporates both individual and group support. Legislation

needs to acknowledge this diversity in supported decision-making regimes. However, there is little recognition of peer support in legislation, despite its potential to assist persons with disabilities in exercising their legal capacity.

Most supported decision-making schemes reviewed for the present report tend to concentrate on a specific group of persons with disabilities. While some pilot projects have attempted to include a diverse range of participants, the diversity of the disability community requires a response to a very broad range of support needs and specific groups may be in the best position to define those support needs. Furthermore, persons with a high level of support needs, including those with severe cognitive impairments, non-verbal communication and/or complex needs, are usually excluded. In that regard, providing access to a broad range of support arrangements seems better than developing a single model of supported decision-making. A “one size fits all” approach to supported decision-making is ineffective and discriminatory. States should take steps to ensure that all persons with disabilities are provided with the opportunity to access supported decision-making measures.

The nature of the relationship between the individual receiving support and those providing it varies significantly across practices. Some schemes rely on “trusted persons” for the provision of support, frequently family members, friends or peers who have a pre-existing relationship of personal knowledge and trust with the individual concerned. However, in many supported decision-making mechanisms, the supporters do not have a previously existing relationship with the individual receiving support, but are individuals and/or professionals who have been trained to provide support. Some schemes also utilize a mixed approach, operationalized through support networks that are facilitated by a trained individual but populated with trusted persons.

While having a relationship of trust can be conducive to a better understanding of the will and preference of the individual and facilitate the relationship between the individual and supporters, overreliance on persons who have existing relationships can also be problematic. Many people may not have a social network, may have experienced abuse and manipulation by relatives, or just do not want to be supported by relatives, friends or peers. Certain programmes have proved that individuals can build relationships of trust with volunteers and/or paid workers, especially when appropriate training and guidance is available. In that regard, legislation should be flexible enough to respond to this diversity and should not prescribe one form of support over others.

While the majority of supported decision-making mechanisms outlined in legislation include some kind of formality (such as a signed agreement or a court order), there is no clear consensus among pilot projects and programmes on the benefits of operating under a formal arrangement. Some projects have identified many positive outcomes from the inclusion of a written agreement between individuals and their supporters, such as recognizing the autonomy and self-determination of the individual, tailoring and clarifying the scope of the support, making the supporter accountable and challenging community attitudes towards supported decision-making. Procedural safeguards can also be included into formalized support arrangements. However, some programmes intentionally exclude signed agreements, due to concerns about undermining the relationship of trust, as well as the informal nature of support. Legal frameworks should therefore be flexible enough to recognize both informal and formal support arrangements and avoid overregulation.

The majority of supported decision-making practices include a component for training supporters to ensure respect for the will and preferences of individuals and avoid paternalistic attitudes, low expectations and substitute decision-making. Programmes with good practices on training typically involve supporters receiving initial comprehensive training and continuous training, including one-on-one coaching and problem-solving sessions.<sup>1</sup> Topics vary, including basic training on supported decision-making, person-centred approaches, strategies for supported decision-making and human rights. For example, peer support groups in Kenya receive training on human rights, including the

**Community involvement contributes significantly to the success of supported decision-making. Providing support to make decisions is helpful only if others recognize those decisions.**

rights-based approach to disability. It is important to ensure that clear and effective resources and training on supported decision-making are available and easily accessible for anyone providing or receiving support.

Community involvement has been demonstrated to contribute significantly to the success of supported decision-making. Providing support to make

decisions is only helpful as long as others recognize those decisions. Community involvement is necessary to address structural factors that can hinder or violate the exercise of legal capacity of persons with disabilities, such as stigma, discrimination and institutionalization. In that regard, many supported decision-making initiatives have considered training for the authorities and for service providers, including judges, notaries and medical personnel, among others.

Communities also play a role in developing support alternatives, such as support networks or peer and self-support groups, as well as helping people to access existing support networks, particularly persons with a high level of support needs and older persons with disabilities, who may lack other sources of support. Indeed, community-based approaches for the provision of support constitute an effective strategy to ensure that responses consider geographical, social, economic and cultural issues (see A/HRC/34/58, para. 53). According to article 19 of the Convention, legislation must ensure a community-based approach in the provision of supported decision-making and facilitate the flourishing of social networks that ensure the individual autonomy and self-determination of persons with disabilities.

Supported decision-making initiatives use a broad range of safeguards, including adherence to the will and preferences of the individual concerned, express recognition of his or her right to withdraw from any arrangement, the establishment of time limits and periodic reviews of arrangements, coaching sessions and dispute-solving and monitoring mechanisms. In many projects, having multiple supporters was identified as a safeguard, since it ensures that different points of view are present, reducing the risk of undue influence. In relation to monitoring mechanisms, many existing formalized schemes turn to a third party or independent person, who periodically contacts both the persons receiving

and providing support to enquire about how support is provided. That informal type of monitoring is promising, as it avoids bureaucratization. When regulating safeguards, policymakers should strike a delicate balance between ensuring respect for the will and preferences of individuals and protecting them from abuse and undue influence, and ensuring that their lives and choices are not overregulated.

## IV. The way forward

### A. Law reform

States must take immediate measures to reform their legal frameworks in order to ensure or restore the right to legal capacity of all persons with disabilities. It is important that legislation expressly recognize that persons with disabilities have the capacity to both hold and act upon rights and duties. Legislation must also recognize the right to access support for the exercise of legal capacity, if desired, and ensure that support arrangements are available, accessible, adequate and affordable. States must establish an enabling legal framework that facilitates the creation and implementation of various supported decision-making schemes, including the provision of financial and technical assistance to civil society organizations for that purpose. All substitute decision-making regimes must be repealed.

States must ensure an appropriate framework of safeguards to ensure respect for the rights, will and preferences of individuals in the provision of support and protect them from conflicts of interest, undue influence and abuses. When discussing crisis or emergency situations, States must adhere to the principles and rights recognized in the Convention. In particular, States must refrain from establishing exceptions to the full enjoyment of the right to legal capacity of persons with disabilities at all times and from creating new

[Pilot implementations] can provide policymakers and the community valuable information about the functioning, cost and value of supported decision-making, contributing to a better policy design.

apparently disability-neutral responses that will disproportionately and adversely impact on persons with disabilities.

States should initiate a comprehensive law review process and make changes in their legal systems to fully implement the right to legal capacity of persons with disabilities. The review must be comprehensive and encompass different areas of law, including family, criminal,

mental health and tort and contractual law. The concerns of third parties, such as those regarding the duty of care, liability and the security of transactions, must be addressed the light of the Convention. States must be aware that many experts working in the area of legal capacity are not familiar with the standards of the Convention and may thus require prior information and training. The law review process should include persons from different groups and sectors, including persons with disabilities themselves and those providing support in practice.

### B. Policy development

States should consider establishing a comprehensive system to coordinate the effective access to supported decision-making of persons with disabilities. Such a system must adopt a human rights-based approach, take into account equality between men and women and the rights of the most disadvantaged and marginalized groups, and respond to the diversity of support needs of persons with disabilities, including older persons and those with a high level of support needs (see A/HRC/34/58, para. 58).

States must consider the implementation of pilot projects on supported decision-making, as part of their obligation to provide persons with disabilities with access to support for exercising their legal capacity. Demonstrations can provide legislators, policymakers and

the wider community with valuable information about the functioning, cost and value of supported decision-making, thus contributing to a better legal and policy design.

Pilot initiatives should be implemented in collaboration with civil society organizations, particularly organizations of persons with disabilities who represent the full range of potential support users, including persons with intellectual disabilities, persons with psychosocial disabilities, persons with dementia, autistic persons and persons with brain injuries. That is in order to benefit from the outreach capacity of organizations of persons with disabilities, their knowledge of the local context and their mobilization and advocacy capacity (see A/HRC/34/58, para. 64). Supported decision-making experiences can also benefit from involving a broad range of local stakeholders, including authorities and service providers. Evaluation should be considered during programme design, including qualitative data that incorporates the perspectives of participants.

### C. Research

States should undertake or promote research in relation to legal capacity and supported decision-making. Research can offer legislators and policymakers valuable information and possible lines of action to guarantee the right to legal capacity and to implement supported decision-making. There is a need for more quantitative and qualitative data on the current use of different forms of substitute decision-making to understand the extent and impact of that human rights violation, including involuntary commitment to a mental health facility and forced treatment. Similarly, despite the increasing implementation of supported decision-making schemes, there is still a clear need for better quality data to inform subsequent initiatives and policy design. Research on supported decision-making has predominately concentrated on formalized forms of support, with little attention paid to

**States must ensure that all persons under substitute decision-making regimes have access to remedy, and consider a moratorium on new applications.**

other informal forms of support in decision-making, such as natural support networks or the support provided in the framework of peer support groups. There is a need to understand how all those forms of support operate and how they relate and contribute to the exercise of legal capacity of persons with disabilities.

Importantly, research on supported decision-making should respond to the rights of persons with disabilities and include the perspective of the disability community. In line with article 4 (1) (d) of the Convention, States should refrain from funding or engaging in any research project that is inconsistent with the right to legal capacity of persons with disabilities, as enshrined in article 12. Research should, wherever possible, be led by researchers with disabilities, be participatory and include the views of persons with disabilities and their organizations in all phases. Outcomes should be published in accessible formats, including easy-to-read versions.

### D. Access to justice

While the recognition of the right to legal capacity is fundamental to guaranteeing access to justice, it is also essential for the protection and restoration of legal capacity. As required by article 13 of the Convention, States must take appropriate measures to ensure effective access to justice for persons with disabilities on an equal basis with others and promote appropriate training for those working in the field of administration of justice. States should also take all appropriate measures to ensure that persons with disabilities have access to procedural and age-appropriate accommodations, including supported decision-making, in all legal proceedings before, during and after trial.

States must ensure that all persons under substitute decision-making regimes have access to an effective remedy and consider a moratorium on new applications. They must also guarantee that all persons with disabilities who have experienced any form of exploitation,

violence or abuse in the context of substituted or supported decision-making regimes, including arbitrary detention or violations of personal integrity pursuant to mental health legislation, have access to justice and effective remedies. Those remedies should include adequate redress and reparations, including restitution, compensation, satisfaction and guarantees of non-repetition, as appropriate (see A/HRC/34/58, para. 74). National human rights institutions and independent mechanisms for the promotion, protection and monitoring of the implementation of the Convention should be mandated to carry out inquiries and investigations in relation to the enjoyment of the right to legal capacity of persons with disabilities and provide assistance to persons with disabilities in accessing legal remedies.

Litigation can play an important role in the reform of legislation on legal capacity. It can have an impact beyond those directly involved in a particular case, leading to new judicial criteria and changes in the law. In monist countries where treaties are immediately incorporated into domestic law once they have entered into force, litigation has the added value of ensuring the direct application of article 12 of the Convention, thus creating a shift in case law. Indeed, in many countries courts are already applying the standards of the Convention, challenging existing legislation that denies persons with disabilities the full recognition of legal capacity.

## **E. Participation and collaboration**

Article 4 (3) of the Convention explicitly requires States to consult closely with and actively involve persons with disabilities, including children with disabilities, in the development and implementation of legislation and policies concerning issues relating to them. States should closely consult with and actively involve persons with disabilities and their representative organizations in the process of legal harmonization regarding legal capacity. While the legislative process may vary from country to country, legislatures should guarantee the participation of persons with disabilities throughout the entire process, inclusive of deliberative assemblies or chambers that can debate and vote on law proposals. In many countries, citizens have the right to propose legislative initiatives, referendums and petitions without the endorsement of political parties or the State authorities. States must ensure that the procedures of direct democracy are fully accessible for persons with disabilities.

Persons with disabilities and their representative organizations must also participate in all decision-making processes related to the design, implementation, monitoring and evaluation of support services and arrangements. The Special Rapporteur's thematic study on the right of persons with disabilities to participate in decision-making provides specific guidance in that regard (A/HRC/31/62).

## **F. Capacity-building**

States must complement law reform efforts with training for State authorities, public officials, service providers, the private sector, persons with disabilities, families and other key actors. Capacity-building on the Convention is indispensable to ensure the adequate implementation of the right to legal capacity of persons with disabilities. Training should also address the intersecting forms of discrimination with regard to legal capacity that affects persons with disabilities and the forms of prejudice and barriers encountered by specific groups of persons with disabilities, as well as how to promote and deliver supported decision-making.

States must promote appropriate training for those working as notaries, since they play an important role, particularly in civil law countries, in concluding and formalizing legal transactions, such as contracts, wills, and powers of attorney. In doing so, notaries make assessments of the capacity of individuals entering into legal relationships. It is therefore important that notaries understand the recognition of universal legal capacity and the support paradigm brought forward by the Convention, in order to ensure that their work

does not translate into a de facto restriction of legal capacity. They must also receive appropriate training in the provision of accessibility measures and reasonable accommodation.

The role of academia in promoting the right to legal capacity of persons with disabilities is critical, particularly in education, research and innovation. Universities should review their curricula to ensure that the education they offer adequately reflects the innovations of the Convention in relation to the legal capacity of persons with disabilities. They can also support the implementation and evaluation of supported decision-making initiatives. The direct involvement of persons with disabilities with and within academia, and the development and strengthening of critical studies based on the perspectives of persons with disabilities, can strengthen the capacity of universities to identify challenges and propose better solutions.

### G. Awareness-raising

A cultural change in how persons with disabilities are perceived by their communities is essential for ensuring that the decisions of persons with disabilities are respected. States

**A cultural change in how persons with disabilities are perceived by the community is essential for ensuring that their decisions are respected.**

must adopt immediate, effective and appropriate measures to raise awareness throughout society, including at the family level, regarding the abilities and rights of persons with disabilities. States should also take measures to combat stereotypes, negative attitudes and harmful and involuntary practices against persons with disabilities in all areas of life, and promote

the support paradigm in decision-making. Persons with disabilities must not be seen as objects of care, but rather as rights holders in the same way as every member of society (see A/71/314, para. 74).

### H. Resource mobilization

States have an obligation to mobilize resources to their maximum availability to ensure access to the right to legal capacity, including funding supported decision-making initiatives, research, training and awareness-raising campaigns. States must also refrain from funding any act or practice that is inconsistent with the right to legal capacity of persons with disabilities and ensure that the public authorities, service providers and other stakeholders act in conformity with it. Retrogressive measures that affect access to support for persons with disabilities in different areas of life, such as cuts or reductions in subsidies for community support services, in-home services and personal assistance, can also impact the exercise of the right to legal capacity.

The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff in relation to the right to legal capacity of persons with disabilities. International cooperation should also consider increasing funding for the design and development of supported decision-making initiatives, ensuring that those interventions are consistent with the human rights of persons with disabilities.

## V. Conclusions and recommendations

**Throughout history, legal capacity has been denied to many persons with disabilities, who have therefore been deprived of the exercise of their rights. While the practice has been widely accepted and viewed as necessary to protect both the individuals concerned and society, it has proved to be wrong. Denial of legal capacity takes away people's control over their everyday lives and significantly reduces their opportunities to participate in society. Furthermore, it has legitimized and facilitated the continuation of harmful**

practices, such as coercion, institutionalization and sterilization, prompting the ultimate objectification of persons with disabilities. Against that background, the Convention on the Rights of Persons with Disabilities reaffirms the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms, and recalls the role of society in ensuring their full enjoyment. States have an obligation to guarantee the full enjoyment of human rights for all persons with disabilities. The recognition of full legal capacity and supported decision-making are necessary steps for making rights a reality, providing persons with disabilities with the freedom and opportunity to live the lives they value.

States must pay special attention to the right to legal capacity of persons with disabilities and champion law and policy reforms towards its full implementation. As the present report illustrates, the standards introduced by the Convention are being progressively implemented at the international, regional and national levels. The review of substituted decision-making regimes and the implementation of different forms of supported decision-making in many jurisdictions reveal a gradual but steady paradigm shift. There is a broad range of measures that States can implement to respect and ensure the right to legal capacity of persons with disabilities. However, States and their leaders need to systematize those lessons and turn them into systemic, comprehensive and sustainable policy responses.

The Special Rapporteur makes the following recommendations to States with the aim of assisting them in developing and implementing reforms towards the full implementation of the right of legal capacity:

- (a) **Recognize, in domestic legislation, the right of persons with disabilities to legal capacity on an equal basis with others in all aspects of life, and provide them with access to the support they may require in exercising their legal capacity;**
- (b) **Conduct a comprehensive law review process to abolish or revoke all laws and regulations that directly or indirectly restrict the legal capacity of persons with disabilities and/or allow for substituted decision-making;**
- (c) **Adopt an enabling policy framework to ensure the effective access of persons with disabilities to appropriate supported decision-making arrangements, by (a) establishing a comprehensive system to coordinate access to supported decision-making arrangements across the territory, including in rural and remote areas; (b) promoting the establishment and sustained operation of community-based supported decision-making alternatives, including the allocation of resources; (c) implementing or promoting pilot projects and demonstration experiences; and (d) undertaking or promoting research on supported decision-making;**
- (d) **Introduce safeguards in the provision of support related to the exercise of legal capacity to guarantee respect for a person's will and preferences at all times;**
- (e) **Guarantee access to effective remedies to all persons with disabilities currently under substitute decision-making regimes and take immediate action to restore their legal capacity, including the adoption of a moratorium on new applications;**
- (f) **Promote and provide training on the right to legal capacity of persons with disabilities for State authorities, judges, notaries, service providers, persons with disabilities, their families and other relevant actors;**
- (g) **Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the implementation of the right to legal capacity of persons with disabilities, including law reform, policy development and research;**
- (h) **Progressively increase the allocation of funds to ensure access to supported decision-making and refrain from adopting any retrogressive measures that directly or indirectly affect the access of persons with disabilities to support;**
- (i) **Encourage international cooperation actors, including non-profit organizations, to fund and carry out research, provide technical assistance on legal capacity law**

reform and supported decision-making, and refrain from implementing or supporting projects that contravene the Convention on the Rights of Persons with Disabilities.

The Special Rapporteur also recommends that the United Nations system, including all its programmes, funds and specialized agencies, enhance its capacities and adequately consider the right to legal capacity of persons with disabilities in all its work, including when supporting the legislative and policy reforms of States.

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