

RESEARCH PROJECT

Valencian Model of Support for Persons with Disabilities and European Comparative Analysis

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Introduction.

As part of Sustainable Development Goal 16, the United Nations calls on States to promote effective, accountable and inclusive institutions. This principle applies particularly to social services, whose efficiency and accessibility directly determine the protection of the most vulnerable people. Our work focuses more specifically on the issue of disability and the proper application of the principles set out in the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD). Sent by IFFD (International Federation for Family Development) to social services specializing in guardianship in Valencia, we studied how Spain has sought to apply the principles of this charter in the field.

We are a group of philosophy students engaged in ethical reflection on major contemporary issues. Some of us are also pursuing additional training in law, political science, or psychology as part of dual degree programs. This diversity of backgrounds allows us to take an interdisciplinary and critical approach, attentive to principles of justice, legal norms, and human realities. We have analyzed, from a comparative and reflective perspective, the concrete functioning of social services: their legal framework, their administrative application, and their human impact. We have observed professional practices, met with teams, and questioned management methods. This work aims to contribute to a global reflection on the efficiency of social policies for vulnerable people and to formulate recommendations based on our findings.

This report is intended for three partner institutions. IVASS offers an outside perspective, highlighting the strengths and weaknesses of the system observed in light of similar policies in other countries. IFFD offers an ethical and critical analysis to be integrated into a broader reflection on the impact of disability on families. Finally, the UN provides local insight into the effectiveness of its objectives and proposals to further promote disability inclusion in our contemporary societies.

Several issues emerged from our survey. How can general public policies take into account the need for individualized care? How can the fight against discrimination be achieved through the creation of new legal tools? And to what extent are the measures already implemented by some States Parties effective in achieving the objectives set by the CRPD? These questions raise others that are even broader: how can we achieve true social inclusion? How can we respect dignity, understood as respect for autonomy, when that autonomy has been lost? To what extent can States draw inspiration from foreign social systems to better implement UN guidelines (and, in particular, the measures set out in the CRPD)?

This report is divided into three parts. The first part presents the specific observations made within the IVASS, describing the guardianship arrangements in place, the role of professionals, the degree of autonomy allowed, and the particular situations encountered. The second part develops a critical, ethical, and legal analysis of the structural differences compared to other

European systems, namely France, Sweden, Germany, and the Netherlands. Finally, the third part will propose concrete recommendations for partner institutions with a view to strengthening the protection of vulnerable people, their social inclusion, and the active participation of families in the decision-making process.

Part One — The legal and administrative framework of the Valencian model of support for people with disabilities.

1.1. Legislative and institutional framework in Spain.

Introduction.

Since the entry into force of Law 8/2021 of June 2, 2021, Spain has profoundly reformed its system of legal protection for persons with disabilities. This reform marks a major turning point in Spanish civil law, abandoning the old model, in which the guardian or curator substituted their will for that of the protected person (who was deemed “incapacitated”) in favor of a new paradigm centered on respect for the autonomy and preferences of the persons concerned.

This change is part of a broader movement towards the recognition of fundamental rights, initiated at the international level by the United Nations Convention on the Rights of Persons with Disabilities, adopted in New York in 2006. The preamble to the law refers explicitly to this convention¹, and the general spirit of the text is inspired in particular by Article 12 of the convention:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity².

This section sets out the general spirit of this new legislation and the main principles underlying it. It then provides a more technical presentation of the measure of guardianship as now defined in Spanish law. Finally, this section discusses the specific features of the legislative organization in Spain, in particular the relationship between national law and any local adaptations made by the autonomous communities.

1.1.1. Fundamental principles of the new Spanish legal system.

A. The previous legal situation.

The major innovation of the 2021 reform is that it reverses the way in which the law previously regarded persons with disabilities. The previous system provided for two main measures for the

¹ “The present reform of civil and procedural legislation aims to take a decisive step towards bringing our legal system into line with the International Convention on the Rights of Persons with Disabilities, adopted in New York on December 13, 2006.” Law 8/2021, of June 2, reforming civil and procedural legislation to support persons with disabilities in the exercise of their legal capacity, Preamble, I.

² Convention on the Rights of Persons with Disabilities, Art. 12, §1–3.

protection of adults: guardianship and curatorship (*curatela*). Guardianship was the most restrictive measure. The person under guardianship was considered “incapacitated” (), and the role of the guardian was to exercise their own will on behalf of the protected person and defend their interests. The guardian therefore had significant power, similar to parental authority, which left the person under their care with virtually no autonomy. In contrast, the guardianship system was more flexible: the legal capacity of the protected person was not denied, but deemed incomplete. The role of the guardian was therefore to make up for this lack of capacity by intervening to decide or give consent for certain acts, for example in matters of asset management. It is therefore clear that the previous system of guardianship and curatorship was based on the idea that individuals may lose their legal capacity, or lose part of it, and that this justified a guardian or curator substituting (to varying degrees) their will for that of the person concerned. The former Article 200 of the Spanish Civil Code defined this key concept of incapacity as follows:

Causes of incapacity are persistent physical or mental illnesses or deficiencies that prevent a person from governing themselves³.

In this system, the protected person was often excluded from the decision-making process: the guardian acted with general power of representation. This substitute model was based on a logic of protection, but at the cost of a certain infringement of the fundamental rights of the person concerned.

B. Guiding principles of the new regime.

Law 8/2021 is based on a series of fundamental principles that frame the entire support system for persons with disabilities. These principles aim to ensure that protective measures respect fundamental rights, human dignity, and individual autonomy. Several of these key principles are summarized in Article 268 of the Civil Code:

Measures taken by the judicial authority in the context of the assistance procedure must be proportionate to the needs of the person requiring assistance, respect always their maximum autonomy in the exercise of their legal capacity, and take into account, in all cases, their will, wishes, and preferences.

Support measures taken by judicial authorities shall be reviewed periodically within a maximum period of three years. However, the judicial authority may, in exceptional and justified cases, as part of the support procedure or, where applicable, as part of a modification of that procedure, set a longer review period, which may not exceed six years.

Without prejudice to the above, judicial assistance measures shall in any event be reviewed if there is a change in the situation of the person who may require their modification⁴.

Let us summarize the four key principles that reflect the spirit of the reform.

³ ‘Causes of incapacitation are persistent physical or mental illnesses or deficiencies that prevent a person from governing themselves.’.

⁴ Civil Code, Art. 268.

a) Respect for the will, wishes, and preferences of the individual.

The new regime emphasizes respect for the will of the person, which must guide any decision or support measure. The role of the support person (whether guardian or de facto guardian) is not to decide on behalf of the person, but to help them make their own decisions. This principle is radically opposed to the old logic of substitution and reflects the requirement set out in Article 12 of the UN Convention, namely the exercise of legal capacity “on an equal basis with others.” Persons with disabilities must be able to participate actively in any proceedings concerning them. Article 268 §1 specifies that judicial measures must “take into account, in all cases, their will, wishes and preferences⁵ .” Even when the measure is ordered by a judge, it is not, in principle, imposed vertically and unilaterally.

In particular, Article 7 of Law 8/2021 amended Law 15/2015 on “*Jurisdicción Voluntaria*.” This law provides a national framework for non-contentious judicial proceedings in which a judge intervenes to organize or validate certain civil acts without dispute between the parties. The reform notably added an Article 7 bis to Law 15/2015, entitled “Provisions for persons with disabilities.” This provides that persons with disabilities have the right to understand and be understood in all legal proceedings⁶ . In practical terms, this requires the implementation of new adapted measures. Communications, whether oral or written, must be in clear, simple, accessible language, with recourse to easy-to-read formats and sign language interpreters where necessary. In order to facilitate communication, persons with disabilities may also be accompanied by a person of their choice from the first point of contact.

Law 15/2025 has also been expanded with a new Chapter III bis inserted into Title II. This chapter, entitled “Procedure for the implementation of judicial measures to support persons with disabilities,” relates to the non-contentious procedure in which the person to be protected is invited to keep a dialogue with the judge to determine the measures best suited to their particular situation (which may include placement under guardianship). Thus, Article 42 bis b) provides that:

During the hearing, a discussion will take place between the judicial authority and the disabled person. Considering their situation, the disabled person may be informed of the alternatives available to obtain the support they need, either through their social or community environment or through the provision of voluntary support measures⁷ .

⁵ *Ibid.*, §1.

⁶ “Persons with disabilities have the right to understand and be understood in any action that must be carried out.” Law 15/2015, of July 2, on Voluntary Jurisdiction, Art. 7 bis §2.

⁷ “During the hearing, an interview will be held between the judicial authority and the person with a disability, who, in view of their situation, may be informed about the alternatives available to obtain the support they need, either through their social or community environment or through the granting of voluntary support measures.” Law 15/2015, of July 2, on Voluntary Jurisdiction, Art. 42 bis b).

Thus, even though the procedure remains judicial, the measures are not imposed vertically by a judge without knowledge of the actual situation and particularities of the person being supported. On the other hand, when the person refuses all appropriate support measures, the procedure becomes contentious and the judge may order provisional measures pending a decision.

The opposition of the person with a disability to any type of support, or that of the public prosecutor or any other person concerned by the adoption of the support measures requested, will terminate the procedure. However, this does not prevent the judicial authority from provisionally adopting the support measures it deems appropriate for the person or their property⁸.

Ultimately, the judge retains a certain power to order support measures in the interests of persons with disabilities, even when they object. However, the guiding principle of the procedure is that a consensual measure must be sought and discussed, with a view to respecting the wishes of the persons concerned.

b) Principle of necessity and proportionality.

Article 249 §1 of the Civil Code provides that all judicial measures adopted must be “adjusted to the principles of necessity and proportionality⁹.” Any support measure must respond to a real and demonstrated need and may only be implemented if less restrictive alternatives are ineffective. ¹⁰Article 268 §1 adds that “the measures adopted [...] shall be proportionate to the needs of the person concerned.” Support may not exceed what is strictly necessary in the specific situation of the person concerned, in terms of intensity, duration, or scope. The aim behind these provisions is to avoid reducing the autonomy of the protected person more than is necessary. This requirement of proportionality also justifies the evolving nature of the measures, which must be adaptable at any time if the person’s situation changes substantially.

c) Temporality and regular review of measures

A corollary of this criterion of proportionality is that the assistance measures put in place must be monitored regularly to check whether they remain appropriate or whether a change (reduction or reinforcement) is justified.

Support measures adopted by the courts shall be reviewed periodically within a maximum period of three years. However, the judicial authority may, in exceptional and justified cases, set a longer review period, which may not

⁸ “The opposition of the person with a disability to any type of support, the opposition of the Public Prosecutor’s Office, or the opposition of any of the parties interested in the adoption of the requested support measures shall terminate the proceedings, without prejudice to the judicial authority’s ability to provisionally adopt the support measures for the person or their assets that it deems appropriate.” *Ibid.*

⁹ Civil Code, Art. 249 §1.

¹⁰ Civil Code, Art. 268 §1.

exceed six years. [...] In any event, the measures adopted shall be reviewed as soon as the person's situation changes in such a way that a modification is necessary¹¹.

The law ensures that support measures remain as appropriate as possible for individuals and preserve their autonomy as much as possible (if their mental condition allows). This approach is clearly in line with the spirit of the 2006 Convention.

d) Promotion of autonomy and dignity.

The new system aims to enable the protected person to retain "maximum autonomy¹²." Dependence on a support person should not be institutionalized (hence the great importance attached to individual circumstances and regular reviews of measures). In theory, the role of the guardian is not to take over, but to support a process of empowerment, as far as possible. Dignity, respect for free will, and full recognition of the person as a subject of law are the pillars of the new legal framework, in accordance with Spanish constitutional principles (Art. 10), as reiterated in Law 8/2021.

1. The dignity of the person, the inviolable rights inherent to them, the free development of personality, respect for the law and the rights of others are the foundation of political order and social peace.

2. The rules relating to fundamental rights and freedoms recognized by the Constitution shall be interpreted in accordance with the Universal Declaration of Human Rights and the international treaties and agreements on the same matters ratified by Spain¹³.

1.1.2. The system of support measures provided for by Law 8/2021.

Law 8/2021 establishes a comprehensive system of support for the exercise of legal capacity by persons with disabilities. This system provides for three main categories of measures: informal measures, voluntary measures, and judicial measures. The system is based on the principle of subsidiarity: as much responsibility as possible should be left to those most directly affected by the situation. It is primarily the responsibility of the family and close relatives of the person with a disability to assist, without the need for a court decision (de facto guardianship system). The judge must intervene as little as possible to order measures such as guardianship or placement in centres such as those run by IVASS (in the example of the Autonomous Community of Valencia). This approach aims to ensure a response tailored to the specific needs of each person, favouring the least restrictive forms of intervention. The support measures are presented here from the most informal to the most restrictive.

¹¹ Civil Code, Art. 268 §2-3.

¹² Civil Code, Art. 268 §1.

¹³ Spanish Constitution, Article 10.

A. Informal measures: guarda de hecho.

Guarda de hecho (or de facto guardianship) is a form of support provided spontaneously by a relative (often a family member) without prior intervention by a notary or judge. It is based on a relationship of trust and allows simple daily needs to be met, in accordance with the person's wishes. However, judicial authorization is still required for certain particularly important acts (those with significant legal or financial implications), as provided for in Article 264 of the Civil Code. Although informal, this measure is legally recognized. The judge, acting on the request of the public prosecutor or a third party, may at any time ask the de facto guardian to provide an account of their activities (Article 265 of the Civil Code). There are therefore certain safeguards in place to protect persons with disabilities from potential abuse of power by their de facto guardian.

B. Voluntary and notarized measures.

The Spanish legal framework values people's power of anticipation and self-determination, always intending to preserve "maximum autonomy" (Article 268 of the Civil Code). Individuals can organize their support arrangements in advance, for example, by appointing or rejecting a future guardian (*autocuratela*):

Any adult or emancipated minor, in anticipation of circumstances that may make it difficult to exercise their legal capacity [...], may propose, by notarized deed, the appointment or rejection of one or more specific persons to act as guardian. They may also lay down provisions relating to the functioning and content of the guardianship, in particular concerning their care, the rules for the administration and disposal of their property, the remuneration of the guardian [...], as well as measures of supervision and control, and propose the persons responsible for implementing them¹⁴.

These arrangements are established before a notary and have legal effect, provided that they remain appropriate to the situation. Unforeseen changes in circumstances may justify the judge departing from them (for example, if the appointed guardian himself needs guardianship measures). These voluntary measures are taken into account when assessing the necessity criterion mentioned above: if a de facto guardian and appropriate guardianship arrangements have already been validly chosen, the judge must, in principle, accept them. Subsidiarity requires that the judge not take a unilateral decision when a consensual and appropriate solution has already been found.

¹⁴ "Any person of legal age or emancipated minor, in anticipation of circumstances that may hinder them from exercising their legal capacity on an equal footing with others, may propose in a public deed the appointment or exclusion of one or more specific persons to exercise the function of guardian. They may also establish provisions on the functioning and content of the guardianship and, in particular, on the care of their person, rules for the administration and disposal of their property, the remuneration of the guardian, the obligation to make an inventory or its waiver, and measures of supervision and control, as well as propose the persons who are to carry them out." Civil Code, Art. 271.

C. Judicial measures: guardianship and legal representation.

Where informal measures (de facto guardianship) or voluntary measures (self-guardianship) are non-existent, insufficient, or inappropriate, the judge may introduce a judicial support measure: guardianship. The following section of the report provides a detailed explanation of this system. This measure may only be adopted by a reasoned decision of the judicial authority, which must take into account the personal situation of the person concerned, their will, wishes and preferences (in accordance with Article 249), as well as any available medical or social reports and the opinion of the public prosecutor (Article 42 bis b of Law 15/2015 on voluntary jurisdiction). Any representation measure must be limited, targeted, and proportionate to the actual needs of the person.

Where the guardian is in a situation of conflict of interest, temporary incapacity, or failure to act, the judge may appoint a legal defender whose task is to ensure the protection of the rights and interests of the person concerned on an ad hoc basis. This exceptional appointment is provided for in Article 295 of the Civil Code and ensures continuity of support while guaranteeing the impartiality of the measure.

Law 8/2021 establishes a scale of support, allowing the intensity and formalization of measures to be adjusted according to the specific needs of the person concerned. Although central to practice, judicial guardianship is only used as a last resort, within a framework strictly governed by the principles of necessity, proportionality, and respect for the will of the person concerned.

1.1.3. Focus on guardianship: framework and functioning.

The IVASS administers social services for people with mental disabilities in the Autonomous Community of Valencia. As such, one of its tasks is to provide guardianship for people who require advanced support measures but whose families are unable or unwilling to provide guardianship. Guardianship is therefore removed from the private and family sphere and provided by a public actor, at the request of a judge. Before examining how this branch of the IVASS operates and assessing its effectiveness and compliance with the objectives set by the legislator, it is therefore necessary to have a clear understanding of how the guardianship system works. Guardianship is a measure of last resort, ordered by a judge based on criteria of necessity and proportionality. In some cases, it is imposed on the protected person: care must therefore be taken to respect the rights, wishes, and preferences of the person throughout the placement procedure.

With Law 8/2021, Spain has undergone a profound legal paradigm shift: legal capacity is now presumed to be inalienable and inherent to every human being, regardless of their level of disability:

Title XI of Book One of the Civil Code is reworded and renamed 'On support measures for persons with disabilities in the exercise of their legal capacity,' so that the pivotal element of the new regulation will not be the incapacitation of someone who is not considered sufficiently capable, nor the modification of a capacity that is **inherent** to the condition of a human person and, therefore, cannot be modified¹⁵.

As a result, the very concept of legal incapacity is abandoned. The legislature intended to create a less general system of assistance that respects individual autonomy and will. There is no longer any question of "guardianship" for persons with disabilities, and this regime now refers exclusively to the guardianship exercised by parents over their children. The remaining regime is that of curatorship.

A. Definition and purpose of guardianship.

Curatorship is a judicial measure to support the exercise of legal capacity, defined by the Spanish Civil Code in Article 250:

Measures to support the exercise of legal capacity by persons who need it include, in addition to voluntary measures, de facto guardianship, curatorship, and the appointment of a legal guardian.

Guardianship is a formal support measure that applies to people who need ongoing assistance. Its scope is defined by the corresponding court decision, in line with the situation, circumstances, and support needs of the person concerned¹⁶.

It does not in any way entail a general removal or restriction of the person's rights, but aims to provide them with appropriate assistance in areas where they encounter difficulties. Guardianship is therefore designed as a personalized, proportionate, and evolving measure that promotes autonomy (in accordance with Article 268).

It can take two forms:

- *assistance* guardianship, which consists of supporting the person in their decisions without taking their place;
- *representation* guardianship, which is exceptional and allows the guardian to act on behalf of the person for certain specific acts, under the strict conditions set out in Article 268 of the Civil Code.

In both cases, the judge must base their decision on an individual assessment of the person's situation, considering their will, wishes, and preferences (Articles 249 and 268 of the Civil Code,

¹⁵ " Title XI of Book One of the Civil Code is rewritten and renumbered "On measures to support persons with disabilities in the exercise of their legal capacity," so that the focus of the new regulation will not be the incapacitation of those who are not considered sufficiently capable, nor the modification of a capacity that is inherent to the human condition and therefore cannot be modified. " Law 8/2021, Preamble, III.

¹⁶ "Support measures for the exercise of legal capacity by persons who require it are, in addition to those of a voluntary nature, de facto guardianship, curatorship, and legal representation [...] Curatorship is a formal support measure that shall be applied to those who require continuous support. Its scope shall be determined in the corresponding court decision in accordance with the situation and circumstances of the person with a disability and their support needs." Civil Code, Art. 250 §1, 5.

Article 42 bis b) of Law 15/2015), as well as the principle of maximum autonomy affirmed by Law 8/2021.

B. Conditions for recourse to guardianship.

Guardianship may be established for any adult or emancipated minor whose disability prevents them from exercising their legal capacity independently, in accordance with Article 250 of the Civil Code. The aim is not to protect an abstract category of persons, but to respond to a specific situation of vulnerability, assessed on an individual basis.

One of the fundamental principles governing the use of guardianship is that of subsidiarity: this measure may only be ordered in the absence or inadequacy of informal support mechanisms (such as *de facto* guardianship, Articles 263 to 267) or voluntary mechanisms (such as self-guardianship, Articles 271 to 274). The judge may only intervene if these mechanisms, although available, do not guarantee the rights or interests of the person concerned.

Any decision must also comply with the principles of necessity and proportionality, which are explicitly set out in Article 269 of the Civil Code and explained above.

The application for guardianship may be made in several ways: at the request of the person concerned, a relative (family member or trusted person), or the public prosecutor, particularly in the absence of identified relatives or in cases of emergency (see Article 42 bis b of Law 15/2015).

Finally, the procedure must fully respect the procedural rights of the person concerned, including the right to be informed in accessible language, the right to appropriate legal assistance, and the right to be heard directly by the judge (see *above*, I. B. a). These guaranteed in ensure that the person remains at the centre of the decision-making process, in accordance with the requirements of the 2006 Convention.

C. Appointment of the guardian.

The appointment of a guardian by the judge follows an order of priority that respects the wishes of the person concerned. The first option considered is self-guardianship, i.e., the advance appointment of a guardian by the person, before a notary, in a voluntary and preventive manner. This right is recognized in Articles 271 to 274 of the Civil Code, provided that the mandate remains compatible with the person's actual situation. The judge may only deviate from this in serious and duly justified circumstances (Article 272).

In the absence of such a designation or if it is manifestly unsuitable, the judge will give priority to the appointment of a family member or close relative who has the required capacity and offers sufficient guarantees of respect for the rights of the person (Article 275). This priority given to the inner circle aims to preserve a relationship of trust and continuity.

However, where no close relative is able or willing to act as guardian (or if the judge considers this to be contrary to the interests of the person concerned), guardianship may be entrusted to a specialized public or non-profit organization, such as IVASS in the Valencian Community.

This recourse to an institution is expressly provided for in Article 276 of the Civil Code, subject to compliance with the condition laid down in Article 275 § 1:

Foundations and other non-profit legal entities, whether public or private, whose purpose is to promote the autonomy and assistance of persons with disabilities may also act as guardians¹⁷.

It is also possible to appoint several guardians, a right recognized in Article 277. In this case, the judge shall specify the organizational arrangements, the respective areas of responsibility, and the rules for coordination between the guardians, ensuring the effectiveness of the measure and the protection of the person's interests.

D. Duties and obligations of the guardian.

The guardian, whether a relative or a public body such as IVASS, is responsible for actively supporting the protected person in exercising their rights, without replacing them. The guardian must facilitate personal decision-making without substituting for the protected person, in accordance with Article 249 of the Civil Code. The guardian must facilitate personal decision-making and not impose choices.

The guardian's obligations are governed by several articles of the Civil Code, in particular Articles 287 to 290. The guardian must report annually on their management, both in terms of assets and personal matters, by providing the judge with a report on the situation of the protected person. This accountability ensures regular monitoring and, if necessary, adaptation of the content of the measure.

The law also provides for the optional possibility of drawing up a guardianship plan (Article 280), in consultation with the person concerned. This document specifies the objectives of the support, the terms of the guardian's intervention, the acts for which assistance is required, and the limits of his or her action.

For certain important property-related acts (such as the sale of real estate, the acceptance or renunciation of an inheritance, or the taking out of a loan), prior judicial authorization is mandatory. The exhaustive list of these acts can be found in Article 287 of the Civil Code. This requirement aims to ensure enhanced protection in situations with a significant economic or legal impact, where a mistake made by the protected person could have harmful consequences.

Finally, the guardian is bound by a set of strict ethical duties: confidentiality, disinterest, and absence of conflict of interest.

No person exercising a support measure may:

1. Receive gifts from the person requiring support or their beneficiaries;
2. Provide support measures when acting in the same capacity in their own name or on behalf of a third party, in the event of a conflict of interest;
3. Acquire, for consideration, property belonging to the person receiving support, or transfer property to them for consideration¹⁸.

¹⁷ Civil Code, Art. 275 §1.

¹⁸ Civil Code, Art. 251.

In the event of a conflict or inability to act, the judge may appoint a legal guardian (Article 295) to protect the rights of the person concerned.

This mechanism aims to ensure respectful support for the person being supported, based on trust and responsibility but within clear limits. It provides a framework for the guardian's actions in a personalized support approach, ensuring judicial supervision tailored to the evolving needs of each protected person.

1.1.4. Competence of the Autonomous Communities.

Law 8/2021 is a national law applicable throughout Spain. It reforms the main texts of common civil law (Civil Code, civil procedure, notarial law) and establishes a uniform legal framework for supporting persons with disabilities. However, to fully understand how guardianship works in Spain, it is essential to consider the country's decentralized territorial organization.

The autonomous communities have significant powers in the areas of social affairs, health, and personal services. They can:

- Organize public support services (guardianship associations, support mechanisms, monitoring of guardians).
- Implement local protocols (e.g., intervention by social services, coordination with the courts).
- Offer support resources for the protected person and their family and friends.

Thus, although the legal framework is uniform, the practice of guardianship may vary from one region to another depending on the resources available, political guidelines, and local mechanisms. In our case, IVASS is a public body under the jurisdiction of the Autonomous Community of Valencia, whose operations are governed by local regulations.

1.2. Legislative and institutional framework in Spain.

In the autonomous community of Valencia (*Generalitat Valenciana*), social services for people with disabilities are provided by the IVASS (*Instituto Valenciano de Servicios Sociales*). Its mission is to provide adults with mental disabilities with the assistance they need for their full development in society, according to their specific needs. Management is therefore decentralized, although it fits perfectly within the national framework presented above.

1.2.1. Regulatory framework.

The administrative functioning of the IVASS is governed by Decree 7/2013 of January 4, approved by the *Consell* (government of the Valencian Community), and subsequently amended by Decree 180/2017. These texts constitute the Regulations on the Organization and Functioning of the IVASS (*Reglamento de organización y funcionamiento del Instituto Valenciano de*

Atención Social y Sanitaria). Its status is that of a public entity responsible for implementing the social and medico-social policies of the *Generalitat*.

A. Origin and legal status of the IVASS.

The IVASS was formed from the merger of two previous entities (the IVADIS and the AVAPSA) as part of a public sector rationalization plan (Decree 7/2012). It is a public law entity with its legal personality, its assets, and full capacity to act in the exercise of its functions (Art. 1 of the Regulations). It is attached to the *Conselleria de Serveis Socials, Igualdad y Vivienda* (Department of Social Services, Equality, and Housing).

The IVASS acts as a “*medio propio instrumental*” (own instrument) of the *Generalitat* (art. 22), which means that it can be directly entrusted with public management tasks without competitive tendering.

B. Main tasks.

The regulatory framework defines the tasks of the IVASS:

- direct management of specialized centres and services for people with disabilities or in situations of dependency;
- implementation of social and professional integration programs, including support for employment;
- the exercise of guardianship and trusteeship functions upon judicial appointment (amendment made by Decree 180/2017, Art. 2.1.f);
- personalized support focused on the individual, with a view to quality of life and respect for rights;
- and participation in research, innovation, and development (R&D&I) projects in the social field.

C. Governance of IVASS.

a) Board of Directors.

This is the collegial body responsible for steering and supervising IVASS. It is composed of representatives of the various directorates-general involved in social, economic, and public management policies, in particular:

- the autonomous secretary responsible for social services (vice-chair),
- the directors-general responsible for disability, social action, and public management,
- representatives of regional finance (5.2.c).

It approves:

- the annual activity plan (6.b),
- the provisional budget (6.c),
- recruitment and job structure (6.e–g),
- and validates proposals for public–private partnerships (6.i).

The Board meets at least every three months (7.1)

b) Executive Management (Art. 8).

The Executive Management is the executive body of IVASS. It is proposed by the Presidency and appointed by the Board of Directors (8.1). It is responsible for day-to-day management and implements the decisions of the Board:

- personnel management, drafting job descriptions (8.2.f),
- budget execution, preparation of accounts (8.2.c),
- monitoring of centres, services, and projects.

The current Director General, Maria José Rico, also serves as Secretary of the Management Board (5.2.d).

D. Internal organization.

IVASS is organized into functional sub-departments, which may be sector-based (e.g., legal, economic, human resources) or territorial. Each new sub-department must be proposed by the general management and approved by the Management Board.

The administrative structure also includes:

- an independent internal auditor, attached to the *Corporación Pública Empresarial Valenciana*, responsible for internal control (Art. 11),
- an Advisory Committee (Art. 9.A), composed of representatives of families, the administration, and trade unions, responsible for issuing opinions on the budget, reports, and guidelines,
- centre councils (Art. 9.B), present in each establishment, to involve families and professionals in local decisions.

E. Financing and economic control.

a) Sources of funding (Art. 17).

The IVASS is financed by:

- annual allocations from the budget of the Generalitat (17.1),
- income from its activities (17.2),

- income from its assets (17.3),
- loans or credits authorized in accordance with regulations (17.4),
- donations, subsidies, bequests (17.5),
- and any other income provided for by law (17.6–7).

b) Budget and control (Articles 18–20)

The IVASS budget is integrated into that of the Generalitat, following financial stability rules. It is controlled:

- by the *Conselleria* of Finance and the *Corporación Pública Empresarial Valenciana*,
- and subject to internal accountability requirements, via the Management Board (6.d).

The IVASS administrative model is based on a balance between the autonomy of the centres in contact with the people receiving assistance and regional strategic management. The structure is designed to meet operational efficiency requirements (through direct management of the centres) while ensuring close political and economic control by the Generalitat authorities.

1.2.2. Functional organization of IVASS.

IVASS is responsible for various tasks listed in the decree mentioned above. These various tasks are divided into several departments, the main ones being as follows.

A. Guardianship management: SAPEMA.

IVASS is the body designated by Law 13/2016 of December 29 as the competent entity of the Generalitat to exercise guardianship measures for adults with disabilities, upon judicial decision. In order to fulfil this mission, Decree 180/2017 of November 17 established a specialized administrative unit within the IVASS: the *Servicio de Apoyo y Protección a las Personas Mayores o con Discapacidad* (SAPEMA), responsible for coordinating the institute's guardianship activities. SAPEMA is structured around three areas of expertise (social, legal, and economic) that work together to provide comprehensive support to protected persons in all aspects of their lives. The IVASS Directorate-General has legal responsibility for all acts relating to guardianship. It is the only body authorized to validate major decisions, whether personal, financial, or legal. In practical terms, decisions are prepared in advance by professional teams in the field (social workers, educators, care staff), in consultation with the person concerned and, where appropriate, their family and friends. When an important decision must be made, such as a change of residence, medical intervention, banking transaction, or inheritance issue, a standardized form is sent to SAPEMA, accompanied by a report justifying the request in the best interests of the person concerned. This file is then analysed by a multidisciplinary team of three professionals,

each examining the case from a specific angle: social, legal, and economic. Based on this assessment, the General Management makes its final decision: approval, adjustment, or refusal. However, the Civil Code stipulates that certain transactions (such as the sale of real estate) cannot be authorized by the guardian alone, but only after review by the judicial authority. IVASS emphasizes on its official website that this organization aims to implement a person-centered support model, in accordance with the principles of the United Nations Convention on the Rights of Persons with Disabilities (2006), which recognizes universal legal capacity and promotes decision-making autonomy, dignity, and full and effective participation in society. This new model of care involves working closely with people under guardianship and guaranteeing them a system of support for decision-making.

SAPEMA's work is based on three pillars:

- **Ecological approach**¹⁹ : moving from a system focused on the limitations of the individual to a system focused on context and interaction.
- **Quality of life approach**: moving from a system focused on the efficiency of services, programs, and activities to a system focused on improvements in quality of life and changes and improvements that should be reflected in each person.
- **Personal and family environment approach**: moving from a system focused on professionals to a system that considers the individual and their family members.

B. Occupational centres.

IVASS also supports people with disabilities, without necessarily exercising guardianship over them. As such, it runs several occupational day centres, which are open to users throughout the week. Some centres are specialized, for example in caring for dependent elderly people, people with brain damage (following a stroke, head trauma, etc.), or people with a birth disability. These facilities offer a range of tailored activities—manual work, sports, gardening, educational games—aimed at maintaining people's functional abilities and preserving their social ties. They thus enable those concerned to remain active and connected to a community environment, rather than remaining isolated at home or within their family circle.

C. Housing for people with disabilities.

IVASS also provides housing solutions for people with disabilities whose families are unable or unwilling to care for them at home. Following Spanish legislation, which prioritizes autonomy and

¹⁹ This approach takes into account the systems in which the person is integrated (micro-system, meso-system, etc.) and emphasizes that living conditions, social relationships, and the institutional context influence well-being as much as, if not more than, personal limitations.

independent living as much as possible, several types of accommodation are available depending on the needs of the individuals concerned.

The first option is supervised apartments (*Viviendas tuteladas*). These are shared accommodations where several people live together and receive daily support from an IVASS caregiver. This model allows residents to maintain a certain degree of independence: they are free to organize their own schedules and can work. This solution is suitable for people who need regular support but do not require intensive institutional care.

The IVASS network consists of five homes of this type, located in the province of Valencia, offering technical and personal support tailored to the needs of residents. The total capacity of the scheme is currently 29 people, but IVASS plans to develop this solution further.

The other solution offered is residential accommodation (*Residencias*). This is a stable, temporary, or permanent accommodation service for adults with intellectual disabilities who have extensive and/or generalized support needs in their personal and social functioning. This facility is particularly aimed at those who do not have an adequate environment or support to enable them to live at home or with their families. These residences are suitable for people with more severe disabilities. They provide more intensive support, tailored to the reduced level of autonomy of the individuals concerned.

D. Professional intermediation.

IVASS has two employment agencies, located in the provinces of Valencia and Alicante. Their main mission is to facilitate access to employment for people with disabilities and those at risk of social exclusion, once they are registered as job seekers. These agencies also act as intermediaries between candidates and companies in the Valencian economic fabric, linking them directly with available job offers. In coordination with the Public Employment Service, they implement professional intermediation actions aimed at offering each person a job that matches their skills, profile, and specific needs, while supporting employers in their search for personnel suited to their requirements. Thanks to this system, many people facing serious difficulties in accessing the labour market are now finding a concrete path to professional integration.

In parallel with this activity, since 1998 IVASS has been developing various training and integration initiatives, co-financed by the Valencian Employment and Training Service and the European Social Fund (ESF). These initiatives are mainly aimed at unemployed people with disabilities.

In this context, IVASS offers its users practical workshops designed to enable them to strengthen their professional skills and better prepare for integration into the labour market.

1.2.3. IVASS resources.

A. Human resources.

IVASS employs approximately 1,400 staff members with a variety of profiles. Its staff includes caregivers, specialised educators, social workers, psychologists, workshop instructors, activity leaders, administrative and general service staff, among others.

In recent years, increasing the workforce has been a priority, with the aim of bringing staff-to-user ratios into line with the standards set by Valencian Law 3/2019 on Inclusive Social Services. For example, 502 new positions were created in 2021 to meet the needs of the nearly 6,000 users supported throughout the Valencian Community.

IVASS staff also benefit from a wide range of continuing training opportunities, aimed at ensuring that skills are regularly updated in all centres and services. This training policy contributes directly to improving the quality of support provided to users and their families.

B. Financial resources.

IVASS is funded by €71 million in annual subsidies from the *Generalitat Valenciana*, whose consolidated budget for 2025 amounts to €32.29 billion, with just under 0.22% allocated to IVASS. In 2021, the institute's budget saw an exceptional increase of 35.4% compared to the previous year. This increase was intended to support the integration of new centres, particularly those taken over as part of the Plan Convivint (social services expansion plan), and to increase staffing levels in order to bring support ratios into line with the standards set by Valencian Law 3/2019 on inclusive social services.

IVASS's annual expenditure now stands at around €60 million, broken down as follows: €43 million for salaries, €14.8 million for operating costs, €2.8 million for depreciation, and €500,000 for rent. In addition, there is €4.5 million in investments, mainly dedicated to renovating equipment and improving reception facilities. The institute also has a positive cash flow of €6 million, which gives it a management margin and a certain degree of self-financing capacity.

IVASS also receives targeted co-financing for its training and integration activities, notably from the European Social Fund (ESF), SERVEF (the Valencian employment service) and the ERDF (European Regional Development Fund). Its accounts are subject to rigorous internal and external budgetary control mechanisms, ensuring transparency and regularity in its management.

C. Material resources.

IVASS has a network of around 36 establishments spread across the three provinces of the Valencian Community (Valencia, Alicante, Castellón), covering all the support needs of people with disabilities. This network includes around ten day centres and occupational centres, which

offer educational, social, and pre-vocational activities to adults who need support to live independently.

The institute also manages around ten specialized residences, offering permanent accommodation with comprehensive care (health care, supervision, daily living assistance) for the most dependent individuals.

In addition, IVASS coordinates a group of five supervised housing units (*viviendas tuteladas*) located in the province of Valencia. These units accommodate a total of 29 people, living in shared accommodation, with daily support provided by care assistants and technical professionals. This model aims to promote independent living while maintaining appropriate supervision.

These structures are complemented by several additional facilities: an early intervention centre in Valencia (for children with developmental disorders), a centre for people with severe mental disorders (*Centro específic d'Enfermedat mental, CEEM*), and a centre for social and professional integration (*Centro de Recursos Marítimos*).

Part Two — European comparative analysis.

Preamble: Methodological choices.

Selection of criteria.

The countries relevant for comparison were selected on the basis of nine main criteria.

The aim was to select social systems operating in socio-economic contexts similar to that of Spain, but with sufficiently different approaches to allow for comparative analysis.

The criteria focused on both quantitative elements (level of human development, budgetary efficiency, extent of assistance provided) and qualitative elements (diversity of practices, capacity for innovation and transnational cooperation), and targeted the needs identified by IVASS (deinstitutionalization, respect for autonomy, and the role of the family).

Quantitative criteria:

1) Human development level.

The countries selected have an HDI equivalent to or higher than that of Spain. This first criterion avoids comparisons that would be distorted by excessive differences in resources, infrastructure, or social priorities. The aim is to ensure that the differences observed are the result of political, legal, or cultural choices, rather than unequal structural conditions.

2) Availability and quality of data.

As the study was conducted remotely, it was essential to have access to data: public reports, institutional evaluations, official databases, as well as academic articles and testimonials from actors in the field. Priority was therefore given to countries whose systems are based on rigorous evaluation and transparency, with clear indicators and active participation by users or their representatives. This criterion presupposes the existence of a self-evaluation process within these social services.

Qualitative criteria:

1) Diversity of practices.

To enrich the perspectives of the IVASS, it seemed essential to compare its model with significantly different practices. The study therefore excludes countries that replicate the Valencian model too closely, in order to provide a comprehensive overview of the areas for improvement in the Valencian system. In addition, we paid particular attention to ensuring that the countries compared had models that were diverse from one another.

2) Originality, uniqueness.

This criterion of diversity is also reflected in the unique perspective it brings to the European Union. The aim was not to identify perfect models, but rather original experiences that could give rise to alternatives or levers for improvement. This uniqueness could take the form of a philosophy of care, an atypical institutional structure, or a more participatory culture of social policy.

3) Capacity for innovation.

Preference was given to countries capable of renewing their approaches, whether through technological innovations (digital tools, collaborative platforms), organizational innovations (forms of governance, integrated services), or methodological innovations (personalized pathways, beneficiary participation). Innovation is understood here as a means of better meeting users' needs, not as an end in itself.

4) Capacity for innovation and transnational cooperation.

Furthermore, the capacity for innovation can be achieved through openness to European cooperation. The countries selected are distinguished by their active participation in applied research projects and their involvement in European partnerships. This transnational dynamic reflects a capacity to adapt to new social challenges.

5) Commitment to international resolutions

Finally, the last criterion focused on the countries' openness to European and international resolutions on disability. Adherence to the principles of the United Nations Convention on the Rights of Persons with Disabilities, as well as the consideration of the observations made by the CRPD Committee, were considered concrete indicators of ethical commitment. The selection process favoured countries committed to progressive compliance with these principles and actively participating in international exchanges on ethical practices.

Criteria relating to issues specific to IVASS:

1) Deinstitutionalization strategy.

This criterion addresses a key issue for IVASS: deinstitutionalization. The Valencian model still relies heavily on residential facilities, which in some cases can restrict the autonomy of those receiving care. Countries that are developing care models that promote community living, social inclusion, and professionalization were therefore selected.

2) Recognition of the role of the family.

The place given to families and caregivers was also considered a benchmark, as it was identified as a limitation by IVASS users. Countries that promote a systemic approach to personal support, integrating all the relational resources available in the individual's environment, were selected.

Key indicators compared between IVASS and foreign systems:

Based on these criteria, three countries were selected for comparison with the IVASS model: Germany, Sweden, and France. Each country sheds light on the IVASS's work from a specific angle, according to the eight key indicators:

1) Legal framework.

The first dimension of analysis is the legal framework. This is the structure that determines the care provided, setting out the fundamental rights of the people concerned and defining the obligations of public institutions. The law determines the general logic of public action: protection, compensation, inclusion, or empowerment. The upstream legal framework is therefore decisive in justifying the organization of care.

2) Governance model.

The governance model derives from the legal framework. Here, we examine the distribution of powers between the central government, local authorities, and private or voluntary organizations. This is reflected in particular in the degree of decentralization, the share of the public sector and the non-profit sector, and in the decision-making and implementation processes. The contrast with the highly regionalized Valencian model provides valuable insight into decision-making processes.

3) Culture of care.

The legal framework and governance model, together with the culture of care, help to structure the care of people with disabilities at the national level. It is important to analyse how vulnerability is viewed as a cultural factor to understand how societies conceive of care for dependent persons, interpersonal solidarity, and social justice. It is this social project that then has an impact on economic and human investment in care.

4) Control of public spending.

Controlling public spending is also an important indicator. This involves assessing the efficiency of social policies: some countries manage to achieve good results in disability care

with controlled budgets by focusing on service coordination, prevention, or empowering local actors.

5) Types of care systems.

A major area for exploration is the typology of services offered by each country. This involves mapping all existing responses: institutional care, home services, day centres, supported housing, mainstream services, etc. This analysis highlights the diversity of solutions available and how they work together to ensure optimal adaptation to people's preferences and changing needs.

6) Degree of individualization of care.

Another area of comparison concerns the degree of specialization and personalization of support. Faced with complex situations, such as multiple disabilities or severe intellectual disabilities, some countries have set up highly individualized systems that seek to respond in a targeted manner to the specific needs of each person. This includes assessing functional abilities, developing individualized life plans, and using multidisciplinary teams.

7) Role of families.

The place of families and support for caregivers is also a key dimension. The analysis focuses on policies that aim to actively involve relatives in support, recognize their role, and offer them appropriate support conditions. This can mean avoiding or delaying state guardianship as much as possible, or offering assistance to enable people to remain in their own homes. In cases where guardianship is provided by the state, some countries involve relatives in the design, implementation, and evaluation of the arrangements, offering them recognition (with institutional status), financial compensation, specific leave, the right to training, and even the right to respite.

8) Self-assessment of the system.

Finally, the comparison includes the ability of systems to evaluate themselves. This refers to the existence of monitoring mechanisms, performance indicators, regular audits, or user participation in the evaluation of services. A system that evaluates itself is a system capable of progressing, correcting its limitations, and adapting its actions to social or legal changes.

Methodological limitations:

The selection of countries is necessarily subject to methodological biases.

First, this selection was conditioned by the availability of reliable data, as the study was conducted remotely. Thus, the accessible data sources were mainly extracted from the countries'

self-assessment. This limited the scope of countries that could be consulted. In addition, the study relies on the authenticity of these data, which is a prerequisite. Thirdly, we do not have access to criticism from users themselves, or only through the state, organizations, or associations. Therefore, in order for the approach to be rigorous and the comparison more relevant, it would have been ideal to be able to compare based on a field analysis carried out by another research team affiliated with IFFD, as was done in Treviso, Italy.

Furthermore, the selection criteria require a focus on social systems operating in socio-economic contexts similar to that of Spain. This means that the richness of care in other countries is overlooked. For example, at the international level, adults with intellectual disabilities are mainly cared for by their families, particularly in low- and middle-income countries (LMICs) (McKenzie & McConkey, 2015²⁰). It might have been interesting to draw inspiration from family care models.

2.1. Sweden.

Introduction: general principles.

Since the 1990s, Sweden has implemented an innovative legal framework focused on self-determination, inclusion, and the right to equality. This framework is based in particular on the LSS (*Lagen om stöd och service till vissa funktionshindrade*, 1993:387), a specific law on support and services for certain persons with disabilities, as well as on the principles of the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Sweden in 2008.

2.1.1. Swedish legal framework.

A. The LSS Act: pillars of support for persons with disabilities.

The cornerstone of the Swedish legal framework for support for persons with disabilities is the LSS Act (*Lagen om stöd och service till vissa funktionshindrade*), which entered into force on January 1, 1994. This text introduces a change comparable to that introduced by the Spanish reform of 2021: it is not based on a logic of protection or guardianship, but recognizes the right of the persons concerned to individualized assistance, with a view to enabling them to live “in conditions as similar as possible to those of other members of society” (LSS Act, Chapter 5, § 1).

²⁰ McKenzie, J., & McConkey, R. (2015). Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 531–541. <https://doi.org/10.1111/jar.12209>.

“The activities shall promote equality in living conditions and full participation in society for the persons referred to in Section 1. The aim shall be to enable the individual to live like others.”

Rather than assessing legal capacity or restricting civil rights, the LSS adopts a compensation approach based on the recognition of disability-related needs. Benefits are granted upon express request (Chapter 8, Section 1)²¹, without triggering a regime of incapacity or substitution of will. Thus, the law organizes a concrete response to functional limitations while respecting autonomy, with the goal of equal opportunities, dignity, and full social participation.

The LSS law is aimed at three clearly defined groups of beneficiaries²²:

- 1) People with intellectual disabilities, autism spectrum disorders or similar developmental disorders;
- 2) People with brain damage (head injury, stroke, etc.) that occurred in adulthood and has resulted in a permanent disability;
- 3) People with a severe and long-term physical or mental disability who do not fall into the first two categories but require comprehensive and structured support in their daily lives.

Beneficiaries have a legal right to be offered 22 specific types of benefits, which are listed exhaustively by law²³. The granting of these benefits does not depend on the applicant’s economic resources or the financial capacity of the municipality. However, the central eligibility criterion is the need for appropriate support, which is assessed on a case-by-case basis²⁴. The LSS thus guarantees a high level of protection, while seeking to promote self-determination, avoid institutionalization, and strengthen the personal and social capacities of the individuals concerned.

The explicit objective of the legislature is to enable persons with disabilities to live “in conditions as similar as possible to those of other members of society” (LSS, Chapter 5, §1²⁵). This wording illustrates the inclusive aim of the law, which is not limited to providing material assistance but seeks to ensure full citizenship based on dignity, freedom of choice, and active participation in social life.

²¹ “Insatser enligt denna lag ges efter ansökan av den enskilde eller av dennes ställföreträdare.”

²² Article 1 of the LSS.

²³ The LSS (Act 1993:387) provides for 10 specific benefits in Chapter 9 § 1, while other benefits are guaranteed by other documents such as the So Act (but are not defined as subjective rights).

²⁴ “Persons referred to in Section 1 are entitled to assistance [...] if they need such assistance in their daily lives and if their needs are not met in any other way.” LSS Section 7(1).

²⁵ “Activities under this Act shall promote equality in living conditions and full participation in society for the persons referred to in Section 1. The aim shall be to enable the individual to live like others.” trad *“The action provided for in this Act shall promote equality of living conditions and full participation in social life for the persons referred to in Article 1. The aim is to give each individual the opportunity to live like others.”*

B. Other related laws.

Although the LSS forms the basis for support for persons with disabilities in Sweden, it can only be understood in conjunction with several complementary texts that structure the entire social and legal protection system. Together, these laws form a comprehensive framework in which support measures are not limited to the social dimension, but also encompass aspects of health, legal representation, and institutional organization.

The Social Services Act (Socialtjänstlagen, SoL) is the general law applicable to the entire population in terms of social needs. Unlike the LSS, the SoL does not confer subjective rights, but establishes a framework for intervention based on the assessment of needs by municipal services²⁶. People who do not meet the criteria of the LSS may nevertheless receive personalized support (often more limited) for housing, home help, or social relations through the SoL. In practice, the LSS and SoL are therefore complementary²⁷, with the former taking precedence and the latter filling any gaps.

From a legal perspective, the Parental Code (Föräldrabalken) and the Guardians and Administrators Act (Lag om god man och förvaltare, Chapter 11 of the Parental Code) govern the mechanisms for representing people whose ability to exercise their rights is impaired. The figure of *the god man* (supporting guardian) provides assistance in the management of personal or property affairs without removing legal capacity. On the other hand, the use of a *förvaltare* (administrator) entails a partial or total substitution of will, by court decision²⁸, which raises important questions of compliance with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Finally, Swedish law provides for several texts in the field of health, in particular the Health Services Act (Hälsa- och sjukvårdslagen) and the Patient Rights Act (Patientlagen), which guarantee access to quality care on an equal footing. These laws emphasize the need for informed consent²⁹, appropriate information, and the active participation of persons with disabilities in medical decisions that affect them.

²⁶ Those who cannot meet their own needs or have them met in any other way are entitled to assistance from the social welfare board for their livelihood (livelihood support) and for their general living expenses. SoL Chapter 4, Section 1.

²⁷ "LSS shall supplement SoL without replacing or restricting it. Measures under both laws are voluntary and may be granted upon application by the individual." (Stockholm City District Administration, section 8.1) <https://meetingspublic.stockholm.se/welcome-sv/namnder-styrelser/norra-innerstadens-stadsdelsnamnd/mote-2024-04-18/agenda/bilaga-1-riktlinjer-for-handlaggning-av-insatser-enligt-lss-och-bistand-enligt-sol-till-barn-ungdomar-och-vuxna-med-funktionsnedsattningpdf?>

²⁸ "Guardians and administrators: The Parent and Child Code also contains rules on guardians and administrators, among other things. An adult who needs help to protect their rights, manage their property, or take care of themselves may need a guardian. If a person is unable to take care of themselves or their property, a guardian may not always be sufficient. In such cases, it may be necessary to appoint an administrator instead."

²⁹ "Health and medical care may not be provided without the patient's consent, unless otherwise provided by this or another law. Before consent is obtained, the patient shall be provided with information in accordance with Chapter 3." Patient Act, Chapter 4, Section 2.

C. Alignment with the Convention on the Rights of Persons with Disabilities (CRPD).

Sweden signed the Convention on March 30, 2007, and ratified it without reservation on December 15, 2008, along with its Optional Protocol, thereby giving the instrument supra-legislative force in domestic law.

Following ratification, the Swedish legislature proceeded with “diffuse” integration: rather than adopting a single transposition law, it successively adjusted sectoral legislation (LSS, SoL, Hälso- och sjukvårdslagen, Patientlagen, Diskrimineringslagen³⁰) and defined, through the national strategy *Nationellt mål och inriktning för funktionshinderns-politiken 2021–2030*³¹ , a cross-cutting principle of “rights based on self-determination and universal accessibility.”³² In concrete terms, this strategy places self-determination and universal accessibility at the heart of all public policies. This means that all services—whether in housing, health, employment, or education—must be designed to be accessible to all from the outset (*universal design*) and ensure the active participation of persons with disabilities in social life on an equal basis. This approach also requires that support be individualized, proportionate, and geared toward strengthening autonomy.

Despite these advances, the Committee on the Rights of Persons with Disabilities has repeatedly noted inconsistencies between Swedish practice and Article 12 of the CRPD. In its concluding observations of 2014³³ and then in its review of the second and third periodic reports adopted on March 20, 2024, the Committee welcomed the progress made but called on Sweden to definitively abolish substitute measures of legal capacity (*förvaltarskap*), accelerate de-institutionalization, and strengthen effective remedies. In its report, the Committee warns of a return to a medical model³⁴. Sweden has reverted to a disability-focused approach, rather than recognizing interaction with social barriers. The Committee therefore calls for a review of the legal definition³⁵ of disability to enrich it and reflect the human rights-based model.

³⁰ Anti-Discrimination Act SFS 2008:567 adopted in 2008.

³¹ <https://www.regeringen.se/regeringens-politik/funktionshinder/mal-for-funktionshinderns-politiken/>

³² Initiated by the requirements of the ratification of the convention, in 2017, the Swedish parliament defined a new national objective for disability policy. It contains four areas that are found in the strategy *Nationellt mål och inriktning för funktionshinderns-politiken 2021–2030*: universal design; correction of accessibility deficiencies; individual support; and prevention of discrimination. <https://www.mfd.se/utgangspunkter/funktionshinderns-politiken/metodstod-for-strategi/utgangspunkter-for-arbetet/nationellt-mal-inriktning-och-konvention/>.

³³ “Even though declarations of incapacity have been completely abolished, the Committee is concerned that the appointment of an administrator is a form of substituted decision-making.” 2014 report criticizing *förvaltarskap*.

³⁴ “The Committee is concerned that the State party continues to apply a medical model of disability in many areas of the law, focusing on impairments rather than recognizing disability as the result of the interaction between persons with impairments and attitudinal and environmental barriers.” CRPD/C/SWE/CO/2–3, March 20, 2024 § 6 (a).

³⁵ “The Committee recommends that the State party revise its legal definition of disability, in accordance with the Convention, so as to reflect the human-rights model of disability that recognizes disability as resulting from the interaction between persons with impairments and barriers.” CRPD/C/SWE/CO/2–3, March 20, 2024 § 7 (a).

In response, the government has launched several structural reforms: the official inquiry SOU 2021:36 “Gode män och förvaltare – en översyn” proposes a national register of guardians³⁶, mandatory training³⁷ and, above all, a refocusing of mandates on assistance rather than representation, with phased implementation between 2024 and 2027.

2.1.2. Guiding principles of Swedish legislation.

All legal frameworks are based on several guiding principles: these are not technical rules of application, but define the general spirit of the law, how it should be interpreted and applied. In Sweden, disability policies are structured around three fundamental principles that guide both the drafting of legislation and its practical implementation: the right to self-determination, which affirms the primacy of the individual’s will; the rule of necessity, proportionality and subsidiarity, which strictly regulates public intervention; and the principle of inclusion, which requires full social participation. These principles form the ethical and legal framework on which all Swedish support mechanisms are based.

A. Right to self-determination.

The cornerstone of the Swedish guiding principles is the right to self-determination (*självbestämmanderätt*). From the explanatory memorandum to the 1993 reform, the legislator intended to break with any paternalistic logic: everyone, regardless of the severity of their disability, remains a subject of rights and the primary actor in their life choices.

This principle is found in several places in the LSS, including Article 5 § 1³⁸, which requires that public action “promote equal living conditions and full participation in society,” with the explicit goal of enabling “people to live like everyone else.” Similarly, Article 6 § 1 explains that all decisions must respect the right of individuals to self-determination (*självbestämmanderätt*) and their integrity. Finally, Article 8 enshrines *the “prior consent” principle*, meaning that no assistance is granted without the express request of the person concerned. This mechanism transforms assistance from an act of protection into a voluntary entitlement.

The right to self-determination is not purely declaratory; it is embodied in the obligation on the municipality to draw up, at the request of the person concerned, an *individual plan* (*individuell*

³⁶ The entire Chapter 25 of the report is devoted to this issue.

³⁷ Chapter 12.5.

³⁸ “Activities under this Act shall promote equality in living conditions and full participation in society for the persons referred to in Section 1. The aim shall be to enable the individual to live like others.”

plan) detailing the objectives, means and persons responsible^{39,40} The administrative doctrine of the *Socialstyrelsen* (National Board of Health and Welfare) states that this planning must be carried out “på den enskildes villkor” (on the terms set by the person concerned) and reviewed as often as necessary to reflect changes in their preferences.

In concrete terms, the right to self-determination reverses the usual logic of social action: it is not the administration that prescribes, but the individual who decides whether they wish to receive assistance and under what conditions. Municipal services are limited to verifying the legality and feasibility of requests, without being able to impose a course of action against the user’s will, except in cases of obvious danger. All assistance remains reversible at any time: the person may refuse it, interrupt it, or modify its terms and conditions as their choices evolve.

B. Principles of necessity, proportionality, and subsidiarity.

The Swedish legislature combines two complementary requirements: to intervene as little as possible and as close as possible to the individual. This dual logic, explicitly inherited from the “minsta ingripande åtgärd” (least restrictive measure) and the *subsidiaritetsprincipen*, underpins the LSS, the SoL and the judicial guardianship system.

The principle of necessity, triggering action based on a real need, meets the first requirement. Legally, no LSS benefits are granted automatically; they require an express request and proof that the functional limitations cannot be compensated for by other means (LSS 8 & 10 §). As in the SoL, the municipality can only intervene when the individual’s own resources (“individens egna resurser”) are insufficient. The social services must therefore ensure that the family is unable to cope with the difficulty.

A second principle that reconciles these two requirements is that of proportionality. The rule is to always choose the least intrusive measure (“minsta ingripande åtgärd”) to guarantee autonomy. This obligation is reiterated in official reports (SOU 2015:80)⁴¹ and in the case law of the administrative courts. In terms of legal representation, the district court (tingsrätt) can only appoint a förvaltare if a god man is not sufficient⁴².

³⁹ “When a measure under this Act is granted, the individual shall be offered an individual plan with decided and planned measures drawn up in consultation with him or her. A person who has been granted a measure shall at any time be able to request that a plan be drawn up, if this has not already been done. The plan shall also include measures taken by parties other than the municipality or region. The plan shall be reviewed on an ongoing basis and at least once a year.” LSS Article 10 § 1.

⁴⁰ https://www.socialstyrelsen.se/contentassets/fb8ca124b65c48f0b31942a6b412ac24/2001-123-29_200112329.pdf.

⁴¹ “such measures in health care or in the provision of care which, taking into account their nature, scope and other circumstances, appear to be less intrusive or non-intrusive [...] The risks associated with the measure must therefore be taken into account when assessing whether a measure is to be considered less intrusive or not.”

⁴² “However, guardianship may not be arranged if it is sufficient to arrange for a guardian or if the individual can be helped in some other, less intrusive way.” Föräldrabalken, Chapter 11, Section 7.

Finally, the principle of subsidiarity, which responds to the desire for personalized intervention, is the principle of subsidiarity. According to the Riksdag, needs must first be met by natural networks—family, neighbours, associations—before any public intervention. The municipality is the first level of competent authority, responsible for assessing needs, developing individualized assistance plans, and providing most of the services covered by the LSS and SoL laws. The state only intervenes in a complementary role, financing the costliest assistance (such as *assistentersättning*, co-financed by the *Försäkringskassan*), setting national standards, and ensuring oversight through the *Socialstyrelsen* and the *IVO*. This model also recognizes the active role of family members, who can receive specific allowances if they commit to providing daily assistance.

C. Participation and inclusion.

In line with the right to self-determination, Swedish legislation sets full participation in ordinary society as a central objective. This “normalization” clause (*normaliseringsprincipen*⁴³) prohibits the systematic use of separate institutions and requires municipalities to design their services—housing, work, leisure—within the ordinary framework, adapting the environment rather than isolating the individual.

In order to achieve the social inclusion of people with disabilities, the LSS provides for specific benefits to promote their integration into community life. In particular, it provides for day activity centres (*daglig verksamhet*) for unemployed adults, which aim to develop their professional skills and social network. It also includes forms of inclusive housing, such as group housing or adapted apartments (*gruppboende, serviceboende*), deliberately located in ordinary residential neighbourhoods. Finally, the LSS encourages cultural, sporting, and community participation by integrating this support into personalized support plans.

Since the mid-1990s, Sweden has also pursued a policy of gradual deinstitutionalization: closing large psychiatric institutions⁴⁴, developing mobile services, and providing personalized allowances. While several reports still highlight areas of concern like of some large residential care facilities with more than ten places, the trend remains toward reducing group placements⁴⁵.

⁴³ “The normalization principle was introduced by Bengt Nirje, who was ombudsman at FUB in the 1960s. The principle was born as a reaction to institutions and oppression of people with developmental disabilities. Nirje wanted people with developmental disabilities to be recognized as independent individuals. The principle had a major impact in Sweden and abroad. The principle is based on eight points that must be met for good support. They concern the right to a normal life and to decide one’s own daily routine. In short: to live like others in community with others, which was first taken up in the Care Act and then in the LSS. LSS School 2025: Basic Principles (<https://hejaolika.se/artikel/lss-skolan-12-grundlaggande-principer/>).

⁴⁴ “In line with developments in the rest of Western Europe, the ambition in Sweden was to abolish large mental hospitals and replace them with local and open care alternatives.” Report SOU 2012:33 *Make it simpler!*

⁴⁵ <https://www.hemhyra.se/nyheter/utbredd-brist-pa-gruppboetider-vuxna-kan-inte-flytta-hemifran/> “It is remarkable that so many municipalities are running deficits because they are responsible for building these homes.

2.1.3. Support mechanisms: from informal assistance to guardianship.

A. LSS benefits: a range of “tailor-made” support measures.

As already mentioned, the LSS confers a subjective right to ten specific forms of support in Chapter 9 of the LSS, which municipalities are required to offer. This assistance is structured according to a personalized compensation approach.

- *Rådgivning och annat personligt stöd*: Multidisciplinary support (psychologist, occupational therapist, lawyer, etc.) to help develop a life plan, understand one’s rights, and adapt one’s home
- *Personlig assistans*: Individualized human assistance (care, transportation, communication). If ≥ 20 hours/week, the state reimburses most of the cost.
- *Ersättning för personliga assistanskostnader*: Allowance to compensate for costs if the user directly employs their personal assistants (employer model)⁴⁶.
- *Escort service*: Occasional assistance with going out, traveling, participating in leisure activities, or completing administrative tasks.
- *Kontaktperson*: Volunteer or employee responsible for providing regular social contact (emotional support, friendship, mentoring) to prevent isolation.
- *Avlösarservice i hemmet*: Temporary home care to relieve family caregivers, from a few hours to a few days.
- *Korttidsvistelse utanför det egna hemmet*: Temporary stays away from home (respite centers, camps, etc.) to provide experiences and a break for families.
- *Korttidstillsyn för skolungdom över 12 år*: After-school or holiday care for teenagers with disabilities.
- *Boende i familjehem eller bostad med särskild service för barn och unga*: Foster care or small residential units for children/young people whose homes are not suitable.
- *Bostad med särskild service för vuxna / annan särskilt anpassad bostad*: Protected or highly adapted housing with staff available 24 hours a day if necessary.

There is an 11th, more restrictive right that is added to the LSS catalog:

- *Daglig verksamhet*: Daytime activities for adults who are not in employment or education: workshops, pre-vocational training, social and community life.

They depend on several factors, but it is clear that it is primarily a question of money. Unfortunately, I think the delay in construction is deliberate, as it means young people can stay with their parents for a few more years, which is more economical for the municipality.” Eva Borgström, interest policy coordinator at the Swedish Disability Federation (FUB). Quoted in the article.

⁴⁶ Funded by Försäkringskassan.

The aim is to achieve a high level of support, and with regard to these services, the person can use several services at the same time (personal assistance, ledsagarservice, daytime activities) if their individual plan justifies it. These services are provided in such a way that the service user does not have to pay any financial contribution except for ordinary expenses (rent, meals). As for how they are implemented, Sweden emphasizes the choice of personal assistance provider. Users can hire their assistant directly, go through the municipality, or use an approved cooperative/company (this freedom of choice embodies self-determination).

B. Informal and family support.

In accordance with the principle of subsidiarity, relatives are the primary caregivers, which allows the municipality to play its role without exhausting itself and provides more emotional support for individuals. Despite this, in the case of extra-familial support, relatives remain at the heart of the support system.

Since 2009, the SoL has required municipal social councils to “offer support and respite to those who care for a relative who is chronically ill, elderly, or disabled”; this *anhörigstöd* can take the form of counselling, support groups, training, or respite care at home⁴⁷. The Socialstyrelsen circular specifies that support must be proactive: the municipality must inform families of their rights and tailor assistance to their specific needs.⁴⁸

Of course, the LSS services mentioned above provide support for the family (without necessarily replacing them entirely). Home respite care (*avlösarservice i hemmet*) allows a qualified caregiver to temporarily take over from the disabled person, giving the family a break. Or the support service (*ledsagarservice*) allows a third party to accompany the person in their outside activities, so that the family member is not always needed.

The philosophy of self-determination allows users to recruit their own personal assistants; many beneficiaries hire a relative (often a spouse or parent of a disabled child) thanks to the assistance allowance provided for in Chapter 51 of the *Socialförsäkringsbalk*. In addition, some municipalities offer *anhöriganställning*⁴⁹: the close relative becomes an employee of the municipality to provide daily assistance, with remuneration in line with that of home care staff. The criteria (duration, hourly limit, training) vary locally.

⁴⁷ “The social services committee shall offer support to facilitate the lives of people who care for a relative who is chronically ill or elderly, or who support a relative with a disability.” SoL 5 chap. 10.

⁴⁸ “It is important that the municipality’s information about the right to support ... reaches the target groups and that the support is tailored to the unique needs of relatives.” *The circular Stöd till anhöriga Vägledning till kommunerna för tillämpning av 5 kap. 10 § socialtjänstlagen*.

⁴⁹ “It is common for relatives to be employed to provide assistance under the Social Services Act. It is also common for relatives to be employed as personal assistants to their loved ones under LSS.” <https://www.socialstyrelsen.se/contentassets/3ffc6a1a8af415b8ff9dd8b2bc41040/2016-7-3.pdf>. *The circular Support for relatives Guidance for municipalities on the application of Chapter 5, Section 10 of the Social Services Act*.

C. Legal measures: God man d'assistance and Förvaltare de représentation.

When family support and LSS/SoL benefits are no longer sufficient to protect the interests of a person with a disability, Swedish law allows for the appointment of a legal representative in one of the two forms provided for in Chapter 11 of *the Föräldrabalk* (Parental Code, 1949:381):

Table 1: Swedish legal measures for the protection of persons.

Regime	Nature of power	Legal basis	Guiding principles
God man (guardian)	<i>Joint decision:</i> the representative acts with the consent of the person; no incapacity is created.	Föräldrabalk 11:4 §	The lightest measure, limited to the acts listed by the judge.
Förvaltare (administrator)	<i>Substitution:</i> the representative acts in place of the person for the acts specified in the judgment; the person loses their capacity to enter into contracts within this scope.	Föräldrabalk 11:7 §	Exceptional remedy after demonstration that a <i>god man</i> would be insufficient.

The establishment of guardianship measures in Sweden is based on specific criteria and a regulated procedure. It first requires a medical report certifying a permanent disability that compromises the ability to manage one's affairs⁵⁰. Following the principles of necessity and proportionality, the district court (*tingsrätt*) must demonstrate that no less intrusive alternative (such as assistance from a relative, benefits under the LSS or the appointment of an *god man*) is sufficient⁵¹. The person concerned is heard, unless this is medically impossible, and the judge

⁵⁰ "Before the court orders guardianship, it shall obtain a medical certificate or other equivalent report on the individual's state of health. This also applies in cases concerning the appointment of a guardian pursuant to Section 4, when the individual has not given his or her consent." *Parent and Child Code, Chapter 11, Section 17.*

⁵¹ "Guardianship may not, however, be arranged if it is sufficient to arrange for a guardian or for the individual to receive assistance in some other, less intrusive manner." *Föräldrabalken 11 chap. 7 §.*

obtains the mandatory opinion of the public prosecutor and the municipal guardianship authority (*överförmyndarnämnd*). If the person proposes a representative, the court gives priority to this choice, unless there are serious grounds for refusal⁵².

In 2024, Sweden had approximately 127,900 active representation mandates, of which nearly 81,000 concerned *god man* and approximately 22,000 concerned *förvaltare*, with the remainder relating to the protection of minors⁵³. These arrangements vary greatly from region to region⁵⁴.

SOU 2021:36 – *Gode män och förvaltare: en översyn* is a public report commissioned by the Swedish government with the explicit aim of preparing a reform of the legal representation system for vulnerable adults. Drafted by the *Ställföreträdarutredningen* and submitted to the Ministry of Justice on May 25, 2021, it follows in the tradition of *the Statens offentliga utredningar* (SOU), official reports that provide the legal and technical basis for future legislation. In over 600 pages, the report provides a comprehensive assessment of the functioning of *the god man* and *förvaltare* systems, highlighting numerous shortcomings: regional disparities in service quality, uneven controls, excessive processing times, lack of a national database, difficulties in recruiting and training representatives, and risks of financial abuse. In response, it proposes a series of structural legislative and administrative measures: the creation of a dedicated national authority, the establishment of a centralized register of mandates, the professionalization and mandatory training of representatives, the harmonization of their remuneration, the digitization of procedures, and, above all, clarification of the hierarchy of measures, in order to make the *förvaltare* a strictly subsidiary remedy. The stated objective is to ensure greater legal certainty, equal treatment between regions, and greater compliance with the principles of the United Nations Convention on the Rights of Persons with Disabilities, particularly about autonomy and legal capacity. This report now constitutes the essential technical and legal basis for any future legislative reform in this area. The resulting bill, which will be submitted to the Riksdag in spring 2025, would enter into force in stages between 2026 and 2028.

⁵² These grounds are mainly derived from case law, although *Föräldrabalken 11 kap 12 §* mentions that the suitability of the proposed person may be questioned and therefore refused.

⁵³ <https://overformyndarstatistik.lansstyrelsen.se/Statistik>

⁵⁴ <https://www.svt.se/nyheter/lokalt/stockholm/akut-brist-pa-gode-man-i-stockholm> "In Stockholm, there are around 8,000 people who need a so-called god man to help them with matters such as finances, contacts with authorities, and legal matters." In Stockholm County, there is a shortage of 8,000 "God man."

1.2.4. Governance and local implementation.

A. Competence of municipalities (kommuner) and role of the State and national agencies.

In Sweden, disability policy governance is based on a clear division of responsibilities between the local level (*kommuner*) and the national level (the state and its specialized agencies). The LSS Act assigns direct responsibility for the implementation of services to the municipalities⁵⁵, while the state provides support through partial funding and a regulatory function.

Sweden's 290 municipalities are legally required to guarantee access to the services provided for in the LSS. In practical terms, this means that they must not only finance these services from their own budgets, but also organize their operational implementation. They employ specialized staff (personal assistants, educators, occupational therapists, etc.), build or adapt housing, provide adapted transportation, and coordinate various forms of individualized support. Each application submitted by a user is subject to a formal assessment by the municipal social services, which results in the development of an individual plan (*individuell plan*) based on the person's needs, preferences, and objectives. This plan, which can be revised at any time, is the central instrument for planning assistance.

The state plays a subsidiary but necessary role. The Försäkringskassan (National Social Insurance Agency) directly finances personal assistance exceeding 20 hours per week, in accordance with the co-financing rule laid down in Chapter 51 of *the Socialförsäkringsbalk* (Social Security Code)⁵⁶. This funding is paid either to the municipality or directly to the user who chooses to employ their own assistants, illustrating the principle of self-determination. In addition, the State sets general guidelines through national agencies. The Socialstyrelsen (National Board of Health and Welfare) produces recommendations, methodological guides, and evaluation reports⁵⁷, while the IVO (*Inspektionen för vård och omsorg*) acts as an independent supervisory body. The latter is responsible for inspecting establishments, evaluating the quality of services, ensuring respect for fundamental rights, and handling reports of shortcomings.

This decentralized model is based on a dual approach: on the one hand, assistance is tailored to local needs through municipal evaluation; on the other hand, national consistency is ensured through state funding and regulation. This results in a high degree of flexibility in responding to

⁵⁵ Detailed in the LSS Act, *Chapter 15, Section 1*.

⁵⁶ "To be eligible for assistance compensation, the insured person must need personal assistance for an average of more than 20 hours per week for basic needs as referred to in Section 9a of the Act (1993:387) on support and service for certain persons with disabilities." *Social Insurance Code, Chapter 51, Section 3*.

⁵⁷ The *Socialstyrelsen* supports the local implementation of the LSS by developing practical guides, *webinars*, and educational materials for municipal professionals; this package constitutes a *kunskapsstöd*, i.e., a national methodological support system aimed at ensuring the harmonization and quality of support in the field of disability. The *kunskapsstöd* can be found at this link: <https://www.socialstyrelsen.se/kunskapsstod-och-regler/omraden/funktionshinder/>.

individual needs, but also requires a high level of coordination between the different levels of government in order to avoid regional disparities or legal inconsistencies.

B. Monitoring and evaluation.

The Swedish model for supporting people with disabilities is based on a balance between local responsibility and national quality standards. This balance is ensured by a dual system of control: internal, through individualized planning and monitoring mechanisms, and external, through appeals procedures and national inspection and evaluation mechanisms.

a) Internal mechanisms.

The main pillar of internal control is the individual plan (*individuell plan*, IP), which must be offered to each person eligible for LSS benefits when they are granted. This plan, defined in Article 10 of the LSS, is drawn up in consultation with the user and details the objectives, planned measures, implementation arrangements, and responsibilities. It reflects not only functional needs but also personal preferences, in a spirit of self-determination and contractualization. This plan is not set in stone: it must be reviewed regularly, at least once a year, and in advance if needs change. The municipality is required to adapt the plan if the person requests it, or if the conditions for implementation no longer correspond to the initial objectives. The Socialstyrelsen doctrine reiterates that this planning must be carried out *på den enskildes villkor*⁵⁸, i.e. "according to the conditions set by the person concerned," which confirms that the initiative always lies with the individual. The plan thus becomes a lever for the continuous improvement of local practices, while ensuring the traceability of the commitments made.

b) External mechanisms.

At the same time, the law guarantees users the right to appeal against any unfavourable decision or failure to respond by the social services. Municipal decisions can be challenged before the administrative court (*förvaltningsrätt*), which exercises judicial review of compliance with the rights under the LSS. This right of appeal ensures the effectiveness of benefits by challenging a refusal of assistance, a reduction in services, an inappropriate plan, or a failure to implement it. The courts can thus compel municipalities to comply with their legal obligations.

In addition, two national agencies are responsible for monitoring:

- *Socialstyrelsen* establishes guidelines, draws up recommendations, and regularly publishes assessments on the quality of services provided, compliance with the objectives of the law, and the living conditions of the persons concerned.

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- IVO (*Inspektionen för vård och omsorg*) carries out independent inspections of social institutions and services. It can investigate reports, carry out unannounced checks, and require corrective measures in the event of non-compliance. Its public reports highlight good practices and shortcomings and play an important incentive role.

To strengthen this evaluation at the national level, the Swedish authorities have begun creating centralized databases, including a national LSS register⁵⁹. This register aims to document the number of beneficiaries, the types of benefits granted, their duration, processing times, and to detect any regional inequalities. These data feed into both national policy-making and public research, while providing performance indicators for local authorities.

2.2. France.

2.2.1. National legal framework: fundamental principles.

A. The 2007 law: refocusing on the protected person.

The reform of March 5, 2007 (Law No. 2007-308), which came into force in 2009, constitutes a significant change in French law on the protection of adults. Breaking with a model inherited from minor law based on pure substitution, it reaffirms the central place of the protected person as a subject of law and, as far as possible, an actor in their own life.

Prior to this reform, any person deemed incapable had their rights transferred to a representative, in a process of legal dispossession. The 2007 reform breaks with this assimilation to childhood incapacity: it establishes the principle that protective measures must support the person, not replace them. The aim is to base French law on a balance between protection and autonomy: it limits the logic of representation to what is strictly necessary and, whenever possible, promotes forms of support that respect the person's wishes.

It thus enshrines several fundamental principles:

- The protected person must be involved in any decision concerning them, to the extent of their capacity (Art. 459 of the Civil Code)⁶⁰ ;

⁵⁹<https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-register-of-municipal-support-and-service-for-persons-with-certain-functional-impairments>.

⁶⁰ "Except in the cases provided for in Article 458, the protected person shall take decisions relating to his or her person alone, to the extent that his or her condition permits." Law 2007-308.

- The judge must order an individualized and proportionate measure, defined according to the specific situation, with a strictly defined scope of action (Art. 471⁶¹ and 495⁶²);
- Any measure must be temporary, appropriate, and as non-restrictive as possible, with periodic review (Art. 428⁶³, and 442).
- The principle of subsidiarity is affirmed: judicial measures may only be taken as a last resort, if no family or voluntary solution is sufficient (Art. 428).

The reform also introduces two innovative extrajudicial tools.

- The future protection mandate, which allows for the appointment of a third party in the event of future incapacity, by means of a notarized deed or private agreement (Articles 477 to 494)⁶⁴
- Family authorization (2016), which allows a relative to represent the person with the authorization of the judge, without formal guardianship or curatorship (Art. 494-1 et seq.)⁶⁵.

B. Current legal framework.

The French legal system applicable to persons with disabilities is currently based on a complex interlocking of several regimes, which reflect different approaches to support: one based on

⁶¹ “Art. 471. – At any time, the judge may, by way of derogation from Article 467, list certain acts that the person under guardianship is capable of performing alone or, conversely, add other acts to those for which the assistance of the guardian is required.” Law 2007-308.

⁶² “Art. 495. – Where the measures implemented pursuant to Articles L. 271-1 to L. 271-5 of the Social Action and Families Code for the benefit of an adult have not enabled that person to manage their social benefits satisfactorily and their health or safety is thereby compromised, the guardianship judge may order a judicial support measure intended to restore the autonomy of the person concerned in the management of their resources.” Law 2007-308.

⁶³ “Art. 428. – The protective measure may only be ordered by the judge in cases of necessity and when the interests of the person cannot be sufficiently safeguarded by the application of the rules of ordinary law on representation, those relating to the respective rights and duties of spouses and the rules of matrimonial regimes, in particular those provided for in Articles 217, 219, 1426 and 1429, by another less restrictive judicial protective measure or by a future protection mandate concluded by the person concerned.” “The measure shall be proportionate and individualized according to the degree of impairment of the personal faculties of the person concerned.” Law 2007-308.

⁶⁴ “Any adult or emancipated minor who is not subject to guardianship may appoint one or more persons, by the same mandate, to represent them in the event that, for one of the reasons provided for in Article 425, they are no longer able to look after their own interests. [...]The mandate shall be concluded by a notarial deed or by a private deed.” Law 2007-308.

⁶⁵ “Where a person is unable to act on their own behalf due to a medically certified impairment of their mental or physical faculties that prevents them from expressing their will, the guardianship judge may empower one or more persons chosen from among their ascendants or descendants, brothers and sisters or, unless they no longer live together, the spouse, the partner to whom they are bound by a civil partnership or the cohabiting partner to represent them, assist them under the conditions provided for in Article 467 or to perform one or more acts on their behalf under the conditions and in accordance with the procedures provided for in this section and those of Title XIII of Book III which are not contrary to it, in order to safeguard their interests.” Law 2007-308.

legal representation in the event of impaired faculties, the other on social and medico-social support with a view to inclusion. The entire system is enshrined in the Civil Code, the Social Action and Families Code (CASF), and additional texts relating to health and fundamental rights. French civil law distinguishes between three main types of protection for adults:

1. ⁶⁶Judicial protection measures: these include judicial protection, guardianship, and trusteeship. These arrangements require a medically certified impairment of mental or physical faculties that prevents the person from expressing or carrying out their wishes. They are ordered by the protection judge, based on an expert report, and are limited in terms of their duration, purpose, and intensity. Curatorship provides assistance for important acts, while guardianship establishes a system of representation for civil acts. These measures remain based on a partially substitutive approach.
2. Extrajudicial and advance measures: the advance care directive (mandat de protection future)⁶⁷ allows a person to designate in advance, within a contractual framework, the person who will take care of them and manage their affairs if they become incapacitated. ⁶⁸Family authorization (habilitation familiale) allows a relative, with the authorization of a judge, to assist or represent a vulnerable person without the need for guardianship or curatorship. These systems aim to preserve decision-making autonomy and avoid systematic judicial intervention.
3. Medical and social support services: governed by the Social Action and Families Code (CASF), these services regulate the work of departmental disability centres (MDPH), disability benefits for adults (AAH), medical and social institutions (ESMS), support services (SAMSAH, SAVS), and disability compensation benefits (PCH). These measures are part of national solidarity and are granted upon administrative request, without affecting legal capacity.

These schemes are set out in a general framework established by the Law of February 11, 2005, on equal rights and opportunities, participation, and citizenship for people with disabilities. This founding text introduced a definition of disability based on the interaction between impairments, activity limitations, and environmental barriers. It also established the principle of universal accessibility and the MDPH as a one-stop shop.

⁶⁶ "Any person who is unable to act in their own interests due to a medically certified impairment of their mental or physical faculties that prevents them from expressing their will may benefit from the legal protection measures provided for in this chapter." Art. 425 of the Civil Code.

⁶⁷ Art. 477 et seq. Civil Code

⁶⁸ Art. 494-1 et seq.

C. Alignment with the Convention on the Rights of Persons with Disabilities (CRPD).

France signed the Convention on the Rights of Persons with Disabilities (CRPD) on March 30, 2007, and ratified it on February 18, 2010, which, under Article 55 of the Constitution, gives it authority over the laws. Article 12 of this convention sets out an important requirement for countries to implement after ratification: it recognizes the right of all persons with disabilities to be recognized as subjects of law and to exercise their legal capacity on an equal basis with others in all areas of life.

However, despite this ratification, French law remains structured around the concept of impaired capacity and is still largely based on representation mechanisms, particularly in the context of guardianship. The current legal system does not explicitly recognize legal capacity as an inalienable right, but allows for its reduction or transfer to a third party in certain situations. This approach deviates from the human rights-based model promoted by the CRPD, which emphasizes support for decision-making rather than substitution.

In its concluding observations of September 2021, the UN Committee on the Rights of Persons with Disabilities strongly criticized France's maintenance of substitute legal representation regimes, such as guardianship, considering them contrary to Article 12 of the Convention on the Rights of Persons with Disabilities⁶⁹. It expressly called on France to repeal these provisions, replace them with decision-making support mechanisms based on the will and preferences of the persons concerned⁷⁰, and train all professionals involved (judges, representatives, social workers) in the effective recognition of the legal capacity of persons with disabilities⁷¹.

⁶⁹ "25. The Committee notes with concern: (a) Legal provisions, particularly article 459 in the Civil Code denying the right of persons with disabilities to equal recognition before the law and establishing deprivation of legal capacity and autonomy through guardianship and wardship, on the basis of medical assessments of person's mental capacity; (b) The absence of supported decision-making mechanisms compatible with the Convention, and measures that perpetuate substitute decision-making and fail to recognize the will and preferences of persons with disabilities." Committee on the Rights of Persons with Disabilities (CRPD) – *Concluding observations on the initial report of France*, adopted on September 7, 2021 (ref. CRPD/C/FRA/CO/1).

⁷⁰ "26. The Committee recommends that the State party, in line with the Committee's General comment No.1 (2014) on equal recognition before the law: (a) Review its understanding of legal protection measures and adopt the human rights model of disability ensuring the equal recognition of persons with disabilities before the law and repealing provisions allowing for substituted decision-making; (b) Redirect organizational and financial resources from substituted decision-making to develop supported decision-making mechanisms that respect the dignity, autonomy, will, and preferences of persons with disabilities, regardless of the level or mode of support they may require." Committee on the Rights of Persons with Disabilities (CRPD) – *Concluding observations on the initial report of France*, adopted on September 7, 2021 (ref. CRPD/C/FRA/CO/1).

⁷¹ "7 (e) The lack of awareness of the rights of persons with disabilities among policymakers, government officials at the national and municipal levels, legal and other professionals, including judges, teachers, medical, health and other professionals working with persons with disabilities." Committee on the Rights of Persons with Disabilities (CRPD) – *Concluding observations on the initial report of France*, adopted on September 7, 2021 (ref. CRPD/C/FRA/CO/1).

Many French institutions have echoed these concerns. For example, the Defender of Rights, an independent constitutional authority responsible for ensuring that public administrations and bodies respect rights and freedoms, has argued in several reports for a transformation of the legal protection system based on respect for fundamental rights, active participation, and support in decision-making⁷². The National Consultative Commission on Human Rights (CNC DH), in its opinion of June 22, 2023, recommended a change in the legal paradigm, stating that “recognition of the right to legal capacity is a prerequisite for full citizenship for persons with disabilities⁷³.”

Thus, while the 2007 reform marked an important step forward, it remains incomplete in light of international standards. France has not yet made the conceptual shift required by the CRPD, namely the abandonment of substitute decision-making mechanisms in favor of a universal model of support for the exercise of legal capacity.

2.2.2. Guiding principles of French legislation.

D. Respect for the will and the person.

Since the 2007 reform, French law has increasingly affirmed the principle of respect for the will, personal freedom, and dignity of the protected person. Article 459 of the Civil Code explicitly states that “The protected person shall alone take decisions concerning his or her person to the extent that his or her condition permits.”

This formula constitutes a partial reversal of the old paradigm of protection: the measure no longer aims to replace the person, but to accompany them, while respecting their choices, lifestyle, and preferences. Even under guardianship, certain personal decisions (such as the choice of place of residence, emotional relationships, or refusal of care) must, unless there is clear danger, be taken by the person, or at least not be imposed on them against their will.

When deciding whether to initiate a measure, the judge must take into account the wishes expressed by the person concerned⁷⁴. They must also ensure that the content of the measure does not unnecessarily deprive the person of their remaining autonomy. They may therefore

⁷²https://www.defenseurdesdroits.fr/sites/default/files/2023-08/ddd_rapport_majeurs-vulnérables_20160929.pdf.

⁷³“While the ‘objects of care’ approach focuses on compensation measures (including, in particular, financial assistance) granted to vulnerable persons, the rights-based ‘subjects of rights’ approach aims to enable every person to enjoy all their fundamental rights in practice.” CNC DH report, May 25, 2023 <https://www.cncdh.fr/sites/default/files/2023-12/Les%20Essentiels%20Politiques%20publiques%20Handicap%2C%20dec%202023.pdf>

⁷⁴“Art. 432 of the Civil Code: “The judge shall rule, after hearing or summoning the person to be protected...” Art. 459 Civil Code: “The protected person shall take decisions relating to his or her own person alone, to the extent that his or her condition permits. (For judicial support measures) Art. 495-2 Civil Code: “The judge shall rule after hearing or summoning the person concerned.”

adapt the scope of the guardianship or curatorship to the specific situation, listing precisely the acts requiring assistance or representation.

In concrete terms, respect for the wishes of the person concerned is demonstrated by the almost systematic hearing of the person when the measure is initiated, reviewed or lifted (unless this is medically impossible)⁷⁵ by the possibility for the person to anticipate and designate a trusted third party via a future protection mandate⁷⁶, and by the obligation on the guardian or curator to act “with respect for the individual freedoms, fundamental rights, and dignity” of the protected person⁷⁷.

E. Necessity, proportionality, and subsidiarity.

The implementation of legal protection measures in France is strictly governed by three fundamental principles limiting public intervention: necessity, proportionality, and subsidiarity (as in Sweden). These principles, affirmed by the 2007 reform, aim to preserve the freedom of the individual as much as possible and to regulate any restriction of their rights. These principles are enshrined in Article 428 of the Civil Code:

“Judicial protection measures may only be ordered by a judge in cases of necessity and when the interests of the person concerned cannot be sufficiently safeguarded by the implementation of a future protection mandate concluded by the person concerned, by the application of the rules of common law on representation, those relating to the respective rights and duties of spouses and the rules of matrimonial property regimes, in particular those provided for in [Articles 217, 219, 1426 and 1429](#), or by another less restrictive protective measure.

The measure shall be proportionate and tailored to the degree of impairment of the personal faculties of the person concerned.

Article 428 of the Civil Code provides that a protective measure is only possible when it is established, by a detailed medical certificate drawn up by a registered doctor, that the person suffers from a lasting impairment of their mental or physical faculties that prevents them from looking after their own interests. In other words, the mere presence of a disability or frailty is not sufficient: a concrete need must be demonstrated. Legal protection therefore remains an exceptional measure adopted only in cases of proven necessity.

To guarantee the principle of subsidiarity, before ordering a judicial measure, the judge must give priority to the least intrusive solutions. Article 428 specifies that no protective measure may be taken if the interests of the person can be safeguarded by a less restrictive means.

⁷⁵“The judge shall rule after hearing or summoning the person to be protected...” Civil Code, Art. 432; see also Art. 495-2 for judicial support measures.

⁷⁶“Any adult or emancipated minor [...] may appoint one or more persons [...] to represent them in the event that [...] they are no longer able to look after their own interests.” Civil Code, Art. 477.

⁷⁷“This protection shall be established and ensured with respect for individual freedoms, fundamental rights, and human dignity.” Civil Code, Art. 415.

Any measure must be “proportionate and individualized” to the degree of impairment of the person’s faculties, again according to the same article. The judge therefore chooses the most appropriate regime (legal protection, guardianship, trusteeship) and may precisely define its scope (adapted guardianship, partial trusteeship). The measure is limited in time (five years maximum, with some exceptions: Articles 441 of the Civil Code) and is subject to periodic review, particularly if the person’s situation changes.

F. Inclusion and citizen support.

Since the law of February 11, 2005, French legislation on disability has been based on an explicit objective of social inclusion, equal rights, and citizen participation (⁷⁸). It recognizes the need to adapt society to the limitations of the individual, rather than placing the burden of adjustment solely on the individual.

This principle of inclusion underpins all public policies aimed at people with disabilities: education, employment, housing, culture, accessibility, and civic life. It requires a shift in legal thinking: it is no longer just a matter of protecting vulnerable people, but of enabling them to live like everyone else, with everyone else, and to fully exercise their rights.

With regard to inclusion in social and political life, persons under legal protection (guardianship or trusteeship) retain their fundamental rights, unless expressly provided otherwise. Since the reform of March 23, 2019, all protected persons now have the right to vote, without the judge being able to derogate from this (Art. L.5 of the amended Electoral Code). Similarly, persons under guardianship or curatorship may marry, enter into a civil partnership or divorce, unless the guardian objects or judicial authorization is required⁷⁹. They may express their wishes regarding healthcare, end-of-life care, and life choices, within the framework of their autonomy. To give effect to these principles, France relies on a system of personalized support and access to rights. The law of February 11, 2005, established the Departmental Houses for People with Disabilities (MDPH) as one-stop shops for administrative procedures. These centres are responsible for conducting comprehensive needs assessments, developing personalized compensation plans (PPC), and facilitating access to rights (PCH, AAH, vocational guidance, etc.). This model aims to provide coordinated, person-centered care. At the same time, medical and social establishments and services (ESMS), social support services (SAVS) and independent living support services (SAMSAH), as well as legal guardians for adults (MJPM), participate in

⁷⁸“All persons with disabilities are entitled to the solidarity of the entire national community, which guarantees them, by virtue of this obligation, access to the fundamental rights recognized to all citizens and the full exercise of their citizenship.” Law No. 2005-102 of February 11, 2005, Art. 2.

⁷⁹ Articles 460 to 462 of the Civil Code.

comprehensive support by aiding with daily management, administrative procedures, and important decisions. This support must respect the life choices, confidentiality, and dignity of the individuals concerned⁸⁰.

Despite these measures, judicial protection (in particular guardianship) can, in practice, restrict the effective exercise of certain rights, such as opening a bank account, signing a lease, entering into a contract, or completing administrative procedures. While these restrictions are legally regulated, they can be perceived as a barrier to inclusion when the person is not involved in the decisions or when the measures are disproportionate.

2.2.3. Support mechanisms: from informal assistance to guardianship.

A. Voluntary and extrajudicial mechanisms.

French law provides for several mechanisms to organize legal support without resorting to judicial protection measures. These mechanisms, known as voluntary or extrajudicial, aim to preserve people's autonomy by giving them the opportunity to anticipate or delegate certain acts to trusted third parties, outside the direct control of the judge. Their existence embodies the principles of subsidiarity, self-determination, and proportionality, offering a flexible alternative to guardianship or trusteeship arrangements.

Created by the law of March 5, 2007⁸¹, the future protection mandate allows any adult (or emancipated minor) to designate in advance one or more representatives to act on their behalf on the day when they are no longer able to look after their own interests due to a deterioration in their faculties. The mandate may be concluded by notarial deed: in this case, it may cover all acts, including those relating to the disposal of property. Or it may be concluded by private deed, using an approved standard form: in this case, it is limited to acts of administration. This mechanism makes it possible to preserve the free choice of representative, to promote advance and personalized care, and to avoid lengthy legal proceedings.

The mandate only comes into effect after a medical certificate establishing the impairment of faculties has been produced and filed with the court registry. Once activated, the representative exercises their functions in accordance with the wishes expressed, in accordance with the terms of the mandate. They must report annually on their management to the judge if the mandate so provides, or in the event of an audit.

Introduced by the order of October 15, 2015⁸², family authorization allows the judge to authorize a family member (spouse, ascendant, descendant, brother, or sister) to represent a vulnerable

⁸⁰Civil Code, Articles 477 to 497.

⁸¹Art. L.311-3 of the CASF.

⁸² Civil Code, Art. 494-1 et seq.

person without formally initiating a judicial protection measure such as guardianship or curatorship. This authorization requires three things: a medically certified impairment of faculties; the consent of the person (if they can express it); and the agreement of the entire family concerned.

The judge determines precisely the acts for which the authorization is valid: these may be a single act (e.g., sale of real estate), a series of acts, or a general representation. Family authorization allows for a quick, flexible, and proportionate response that respects family ties and the desire to avoid the stigma sometimes associated with guardianship or conservatorship. It does not give rise to regular judicial monitoring, except in cases of dispute or reported abuse.

B. Judicial protection measures.

When voluntary mechanisms or informal support are no longer sufficient to protect the interests of a vulnerable person, French law allows, as a subsidiary measure, the use of judicial protection measures. These measures are ordered by the protection judge and aim to protect the person while limiting the exercise of their rights as little as possible. They are part of a graduated and individualized support approach, depending on the degree of impairment.

The Civil Code provides for three main regimes: judicial protection, guardianship, and trusteeship. Each is based on a medically certified impairment of mental or physical faculties, established by a detailed certificate drawn up by a doctor registered on a prefectural list⁸³.

Legal protection⁸⁴ is a temporary and minor measure intended to protect a person who retains most of their capacity but may be vulnerable at times. It may be implemented either by a simple medical declaration or by a court decision, pending a more serious measure. The person retains the exercise of their rights, but their actions may be challenged retrospectively if they are deemed inappropriate in their best interests. They may be accompanied by a special representative for certain specific actions. This regime is often used in emergency situations, or to avoid a more intrusive measure when the impairment is temporary.

Next comes guardianship⁸⁵ (is a system of assistance in important civil matters. It is intended for people whose faculties are impaired but who retain sufficient capacity of discernment. The guardian does not replace the person, but assists them in acts of disposition (e.g., borrowing, selling property, making donations, etc.). There are three levels of guardianship (provided for by law): in simple guardianship, the person manages their own day-to-day affairs but must obtain the guardian's consent for acts of disposal; in enhanced guardianship, the guardian receives income, pays expenses, and thus ensures day-to-day financial management; finally, in a customized guardianship, the judge can tailor the list of acts requiring the guardian's assistance to

⁸³ Civil Code, Art. 431.

⁸⁴ Articles 433 to 439 of the Civil Code.

⁸⁵ Art. 440 to 472 of the Civil Code

the specific situation of the person being protected. Guardianship strikes a balance between protection and autonomy, allowing the person to remain actively involved in the management of their affairs.

Guardianship⁸⁶ is the most restrictive regime, intended for persons who need to be represented on a continuous basis in civil matters. The guardian acts on behalf of the person in all matters, except for those that are strictly personal (marriage, consent to medical treatment, etc.). However, the judge may adjust the guardianship, allowing the person to retain the exercise of certain rights if their condition permits. The guardian is required to draw up an inventory of the person's assets, prepare a provisional budget, and report annually on their management. Although still in force, this regime is strongly criticized by international bodies because it is based on a logic of substitution, which is contrary to Article 12 of the CRPD.

C. Institutional implementation: families, professionals, and guardianship bodies.

The practical implementation of legal protection measures in France is based on a complex institutional organization involving families, professional representatives, and authorized guardianship structures. The judge appoints the person or body responsible for implementing the measure, based on their abilities, emotional closeness, or the best interests of the protected person. This choice is strictly regulated by the Civil Code and the Social Action and Families Code (CASF) to ensure personalized, ethical, and supervised support.

Article 449 of the Civil Code stipulates that the judge must give priority to members of the family of the person to be protected—spouse, civil union partner, ascendants, descendants, brothers, and sisters—when appointing a guardian or curator. This choice is based on a presumption of trust and emotional continuity deemed beneficial. However, this appointment is not automatic: the judge must verify that the person in question has the necessary skills, that they act exclusively in the interests of the person being protected, and that they freely accept this role (except in certain cases, particularly in relation to guardianship of children). In the event of absence, unavailability, or conflict within the family, the judge appoints a professional legal representative.

Legal representatives for the protection of adults (MJPM) are professionals authorized by the State to exercise legal protection measures. They may be independent (registered individually on a prefectural list), employees of an associative guardianship service (such as the UDAF or ATMPH), or agents of public institutions, particularly in the social, medico-social, or hospital sectors. Their activities are governed by Articles L.471-1 to L.472-11 of the Social Action and Families Code (CASF). To be authorized, MJPMs must complete an approved training course,

⁸⁶ Art. 440 to 473 of the Civil Code.

obtain prefectural approval after consultation with the public prosecutor, and undergo ongoing monitoring of the quality of their support, management, and professional conduct.

Regarding fees, legal representatives for the protection of adults (MJPM) are remunerated according to a national scale, calculated based on the resources of the protected person's in, the workload involved in the measure (simple or enhanced guardianship, tutorship, etc.) and any monthly contribution from the person concerned. Associative guardianship services are partially funded by departmental councils, while regional health agencies (ARS) are responsible for their administrative and budgetary oversight.⁸⁷ From a legal standpoint, MJPMs must draw up an initial inventory of the protected person's assets, prepare an annual budget, and regularly submit management accounts to the judge. In the event of misconduct or mismanagement, they may be held civilly liable and may be removed from office at any time if the interests of the protected person so require. Judicial oversight is provided by protection judges, who rule on major decisions (such as the acceptance of an inheritance or the sale of property), review annual reports, and may hear the protected person at any time.

2.3. Germany.

2.3.1. The legal framework for assistance to persons with disabilities.

A. General framework.

Germany has a structured legal system that expressly recognizes the rights of persons with disabilities and organizes their participation in social life on the basis of constitutional, international, and sectoral standards.

The fundamental basis of this system is the German Basic Law (*Grundgesetz*), in particular Article 1¹, which proclaims that "human dignity shall be inviolable," and Article 3(3), which prohibits any discrimination on the basis of disability.

No person shall be discriminated against or given preferential treatment on the basis of sex, ancestry, race, language, homeland or origin, faith, religious or political opinion. No person shall be discriminated against based on disability⁸⁸.

These constitutional principles apply throughout the Federal Republic and form the basis for public inclusion policies.

At the international level, Germany ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2009. The CRPD influences the interpretation of domestic law, particularly in the requirement to guarantee independent living, full participation, and inclusion

⁸⁷ Civil Code, Art. 503

⁸⁸ German Basic Law, Art. 3 §3.

in all areas of society, such as education (Article 24) and working life (Article 27). The Convention has also influenced the work of German legislators.

In terms of legislation, the main instrument is the ninth book of the German Social Code (*Neuntes Buch Sozialgesetzbuch – SGB IX*), which was extensively reformed by the *Bundesteilhabegesetz* (BTHG) [Federal Participation Act], which came into force between 2017 and 2023. This text aims to guarantee persons with disabilities a subjective right to participation through coordinated and person-centered services. SGB IX structures the actions of public and private charitable actors around a central principle: the personalization of rights with respect for the dignity and autonomy of the individual.

Persons with disabilities or at risk of disability receive benefits under this book and the laws applicable to rehabilitation organizations to promote their self-determination and their full, effective, and equal participation in society, and to prevent or remedy disadvantages⁸⁹.

In line with the German federal model, the practical implementation of SGB IX is largely the responsibility of the *Länder* and local authorities (*Landkreise*, cities). The *Länder* adopt specific implementing laws (*Ausführungsgesetze*) and designate the competent authorities (*Träger der Eingliederungshilfe*), generally at the sub-regional level. This level of decentralization leads to considerable territorial heterogeneity in the organization of services, while in theory allowing for better adaptation to local needs.

Finally, the implementation of the right to participation relies heavily on the involvement of associations and charities (*Wohlfahrtsverbände*), following the principle of subsidiarity enshrined in Article 72 of the Basic Law⁹⁰. These actors play a major role in providing support services under agreements with the public authorities.

In summary, the German legal framework combines standards based on different values (constitutional, international, and legislative) with a decentralized, partnership-based, person-centered architecture. Understanding the specific support mechanisms (presented in Part III) requires a clear understanding of this legal, institutional, and territorial framework.

The legal framework established by the German Basic Law, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and Book IX of the Social Code (SGB IX) is not limited to institutional organization or a list of benefits. It is based on a coherent set of guiding principles that shape all public policies relating to persons with disabilities.

The German system thus explicitly recognizes the right to a self-determined and independent life, to participation in society on an equal footing, to free choice of support services, and to

⁸⁹ "People with disabilities or people at risk of disability shall receive benefits in accordance with this book and the benefit laws applicable to rehabilitation providers in order to promote their self-determination and their full, effective, and equal participation in society, and to prevent or counteract disadvantages." §1 SGB IX.

⁹⁰ In particular: "In areas of concurrent legislative competence, the *Länder* have the power to legislate as long as and to the extent that the Federation has not exercised its legislative competence by means of a law." German Basic Law, Article 72 §1.

individual consideration of needs. These principles are not mere normative references: they form the basis for interpreting the law, provide a framework for the actions of the competent institutions, and can be invoked as subjective rights.

These guidelines, whose scope has been strengthened by the reform of *the Bundesteilhabegesetz*, will be analysed in greater depth. They provide insight into the design choices made in the German system: a decentralized, contractual structure rooted in subsidiarity and committed to full citizenship for persons with disabilities.

B. A systemic reform: the *Bundesteilhabegesetz*.

The German legislative framework underwent a profound transformation with the adoption of *the Bundesteilhabegesetz* (BTHG), a wide-ranging reform that came into force in stages between 2017 and 2023. This reform responded to a twofold imperative: to bring domestic law into line with Germany's international commitments, in particular the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and to rebuild a fragmented system around modern structural principles.

Until 2016, integration assistance for persons with disabilities (*Eingliederungshilfe*) fell under SGB XII, i.e., social assistance law. It was subject to strict means testing and strongly influenced by an institutional approach. The BTHG overhauled SGB IX, which is now entirely dedicated to participation rights, and transferred *Eingliederungshilfe* to a separate legal field with no direct link to a person's economic resources.

This reform introduced or consolidated several fundamental principles of the current system:

- The right to self-determination, now enshrined in § 1 SGB IX, which affirms that everyone has the right to lead an independent and self-determined life, participating fully in society.
- The *Wunsch- und Wahlrecht* (§ 8 SGB IX), the right to freely choose one's lifestyle and services, reinforced by procedural guarantees (individualized plan, appeals, etc.).
- The principle of comprehensive participation, extended in § 4 SGB IX: the right to participation extends to housing, culture, education, and parenting, and no longer only to professional integration.
- The principle of proportionality and personalization, requiring benefits to be tailored to each person's situation, and the obligation for *Träger* to respect their wishes and life plans.
- The separation of housing assistance and participation assistance, effective since January 1, 2020, aims to avoid forced placement in residential facilities.

An additional component of the reform concerns the right to legal guardianship (*Betreuungsrecht*), which will also be modernized on January 1, 2023, in parallel with the BTHG. The new system aims to substantially strengthen the freedom of action and choices of persons subject to legal representation, following Article 12 of the CRPD (the right to exercise legal responsibilities). From now on, guardianship can only be established if it is strictly necessary (Section

1814(3) of the BGB), and the choice of guardian must always be in line with the wishes of the person concerned (Section 1816(2) of the BGB).

The guardian's mandate is now limited to supporting personal decisions, by the principle of orientation towards the will of the person (§ 1821 Abs. 2 BGB), and any guardianship measure may only be adopted if other forms of support (family, mandates, social services) prove insufficient (§ 8 BtOG–E in comb. § 1814 BGB). Guardianship courts are now required to hear the person concerned directly, take their wishes into account, and ensure that the guardian complies with them (§ 1862 in conjunction with § 1821 BGB).

This reform improves the quality of guardianship, since only persons who meet certain qualification criteria can become professional guardians (§ 23 BtOG), and approved guardianship associations are now recognized as preferred support partners in the supervision of guardianship (§ 1860 BGB). This aspect of the law helps to bring the German system into line with the requirements of the CRPD and extends the logic of the BTHG by placing respect for the choice and will of the individual at the heart of legal intervention.

At the institutional level, the reform requires the Länder to designate competent bodies (*Träger der Eingliederungshilfe*) according to various models. These bodies are now required to draw up an individualized participation plan (§ 19 SGB IX) with the person concerned, which becomes the legal basis for all services provided. This plan is a tool for contractualization and monitoring, ensuring continuity of support.

The completion of the reform in 2023, with the full entry into force of Sections 90 to 150 SGB IX, marks the transition from a social assistance system to a rights-based, person-centered system rooted in the principles of the CRPD and geared toward full inclusion in society.

2.3.2. The guiding principles of the system.

A. Self-determination as a guiding principle.

We have seen that the principle of self-determination (*Selbstbestimmung*) is fundamental to the German legal framework. It commits all public policies to recognizing the right of the persons concerned to freely choose their way of life, their place of residence, their career path, and the forms of support appropriate to their needs. The new Book IX of the SGB introduces a reference to this objective of self-determination in its first paragraph (see *below*).

This development is closely linked to Germany's accession to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the Convention enshrines the right of every person to live independently, to choose their place of residence, and to have access to mainstream support services.

The States Parties to this Convention recognize the right of all persons with disabilities to live in society, with the same freedom of choice as other persons, and shall take effective and appropriate measures to facilitate the full enjoyment of this right by persons with disabilities [...], including by ensuring that:

a) Persons with disabilities have the opportunity to choose, on an equal basis with others, their place of residence and where and with whom they will live, and are not obliged to live in a particular living environment [...];

c) Social services and facilities for the general population are available to persons with disabilities on an equal basis with others and are adapted to their needs⁹¹.

German law explicitly aims, through SGB IX, to transpose these requirements into domestic law, guaranteeing persons with disabilities the capacity to make decisions on the services they receive, as well as their central role in the development of their support.

The corollary of self-determination is the principle of full and effective participation in social life (*Teilhabe am Leben in der Gesellschaft*), in the broadest sense: cultural, civic, family, and professional. Section 4 of SGB IX thus broadens the scope of participation benefits far beyond mere integration into the labour market to include participation in training, cultural and sporting activities, and neighbourhood life. This comprehensive vision marks a break with a purely remedial or medical conception of disability.

Participation benefits include the social benefits necessary, regardless of the cause of the disability, to:

1. eliminate, remove, or mitigate the disability, prevent its worsening, or mitigate its consequences [...]
2. to ensure long-term participation in working life in accordance with the person's abilities and preferences,
3. to promote personal development in a comprehensive manner, and to enable or facilitate participation in society and a life that is as independent and self-determined as possible⁹².

The participation of persons with disabilities in decisions affecting them is not only a social policy objective; it is conceived as a fundamental right with binding legal force. It implies that the person concerned is involved in all decisions affecting them, including in situations of cognitive or mental vulnerability. It also means that the competent authorities must be able to assess the claims of individuals at their true value, which do not have absolute value but must be taken into account. The right to participation must therefore be accompanied by appropriate communication and legal representation where necessary, so as not to undermine the principle of autonomy.

B. Free choice, subsidiarity, and personalization.

The German system of support for persons with disabilities is based on a close link between the principles of freedom of choice, subsidiarity, and personalization of services. These principles guide public action by ensuring that support respects both the will of the individual and the requirements of proportionality in the implementation of assistance.

⁹¹ CRPD, Article 19.

⁹² "Participation benefits include the social benefits necessary, regardless of the cause of the disability, to 1. avert, eliminate, or reduce the disability, prevent its worsening, or mitigate its consequences [...], 3. to secure participation in working life in accordance with their inclinations and abilities on a permanent basis, or 4. to promote their personal development in a holistic manner and to enable or facilitate their participation in society and a life that is as independent and self-determined as possible." Section 4 SGB IX.

The *Wunsch- und Wahlrecht* (right to choose), set out in Section 8 of SGB IX, guarantees all persons with disabilities the right to freely choose the type, location, and form of support offered to them, provided that this does not place an excessive burden on the competent authority.

(1) The legitimate wishes of the persons receiving benefits shall be taken into account in the decision on benefits and in their implementation. [...]

(3) Benefits, services, and facilities must offer recipients the greatest possible scope for organizing their own lives and must promote their self-determination.

(4) Participation benefits are subject to the consent of the beneficiary⁹³.

This freedom applies to fundamental decisions such as the type of accommodation (independent living, shared accommodation, institutional care), the choice of educational institution or home care provider. In this respect, German law goes beyond a standardized approach to provide services that are as closely tailored as possible to the individual needs of each person receiving care.

This right is governed by the principle of subsidiarity, which is based in particular on Articles 28, 30, and 72 of the Basic Law and is also reflected in SGB IX. This principle implies that care should always be provided at the level closest to the person, whenever possible (based on the idea that greater proximity generally leads to more appropriate action). Thus, when it comes to the practical arrangements for caring for people with disabilities, local actions and policies are preferred to federal legislation, which is too ill-suited to specific circumstances. According to a broad interpretation, the principle of subsidiarity also implies that public intervention should only take place as a last resort, when personal, family, or community resources are no longer sufficient. Where necessary, these interventions are carried out in partnership with recognized charitable organizations (*Wohlfahrtsverbände*) such as Caritas, Diakonie, or Lebenshilfe, which act as delegates on the basis of agreements with the public authorities (§ 75 SGB XII, § 94 SGB IX).

This framework is supplemented by a principle of proportionality, which is enshrined in German constitutional law (case law of *the Bundesverfassungsgericht*, the German constitutional court). This principle requires that measures adopted to support a person with a disability must be tailored to their actual condition: they must not be too light (in which case the person would be abandoned by the public authorities) or too heavy and restrictive (even if it is sometimes necessary to reduce a person's capacity to exercise certain rights because of their disability). Persons with disabilities under guardianship, for example, do not have the right to perform certain legal acts on their own because the judge has determined that they are not sufficiently autonomous. The German Constitutional Court has ruled on this principle of proportionality in another context, stating that any infringement of individual rights must be justified by compelling reasons and must remain proportionate to the objective pursued:

⁹³ §8 SGB IX.

The prohibition of discrimination set out in Article 3, paragraph 3, sentence 2 of the Basic Law cannot be applied without restriction. Where a person, precisely because of their disability, lacks certain mental or physical abilities that are essential for the exercise of a right, the denial of that right does not constitute a violation of the prohibition of discrimination.

Legal differentiation that is unfavourable to persons with disabilities is therefore permissible only if there are compelling reasons for it.

The adverse effects must be strictly necessary to take account of the specific characteristics of the disability⁹⁴

This principle is also found in Sections 104 et seq. of SGB IX, which require that support measures be strictly necessary and appropriate and tailored to the specific situation, “taking into account the characteristics of the individual case, the personal situation, the social environment, and the resources available” (Section 104(1)).

The personalization of services, a key principle of the BTHG, stems directly from this requirement of proportionality, which means that assistance is determined not on the basis of administrative categories, but because of the personal goals and abilities of the individual, as identified in the participation plan.

Thus, the combination of free choice, subsidiarity, and proportionality aims to build a balanced system that respects people’s wishes while also ensuring that the responses provided are appropriate and accountable.

C. Real equality and social inclusion.

German law aims to achieve real equality of access to rights, social life, and citizenship, in accordance with constitutional texts and the CRPD, Article 5 of which requires States Parties to guarantee not only legal equality but also *de facto* equality by taking the necessary measures to correct structural inequalities.

Social inclusion, defined in Section 4 of SGB IX, is an objective in the support provided to persons with disabilities. The aim is to enable everyone to “participate in all aspects of life in society,” including in the areas of housing, culture, leisure, parenting, and emotional life. The system aims to prevent segregation by ensuring that persons with disabilities have access, as far as possible, to mainstream facilities.

This principle is reflected in particular in the guarantee of choice of place of residence, enshrined in § 8 SGB IX (*Wünsch- und Wahlrecht*). People must be free to decide whether they wish to live alone, as a couple, in a shared apartment, with their family or in an institution. Any restriction on accommodation constitutes a violation of the right to self-determination. In practice, the BTHG reform has strengthened this requirement by clearly separating housing benefits from support services (Section 134 SGB IX) to prevent the two from being imposed together by default. This distinction makes it possible to separate the choice of place of residence (financed

⁹⁴ BVerfGE 99, 341 (Jan. 19, 1999), §56.

by SGB XII) from other choices relating to integration services (financed by SGB IX), thereby strengthening people's self-determination.

By extension, respect for family and emotional life is a fundamental element of real equality. Article 23 of the CRPD recognizes the right of persons with disabilities to "maintain their fertility, marry, and found a family." German law is therefore supposed to protect family ties, including in cases of dependency or institutionalization. The wording of § 104 SGB IX, in its post-BTHG version, suggests that housing and care services should be designed in such a way as to respect people's wishes to live with a partner or within their family:

Due consideration shall be given to personal, family, and local circumstances, including the type of housing desired [...].

If accommodation outside a specialized facility is possible, it should be given preference if the beneficiary so wishes⁹⁵.

However, there are still limitations to the implementation of these principles. Despite legal guarantees, it is sometimes difficult in practice for collective reception facilities to meet all these requirements: inability to accommodate a spouse, separation of couples when changing facilities, for example.

Real equality and social inclusion remain, for the time being, a goal toward which German public authorities and reception organizations must strive. These principles require a robust legal framework, but also constant vigilance with regard to the practical arrangements for support, so that the rights proclaimed are truly effective.

2.3.3. The practical organization of support.

A. Supported housing and alternative forms of housing.

In Germany, inclusive housing is playing an increasingly important role in social participation policies, offering a concrete response to the right to independent living proposed by SGB IX. Non-institutional forms of collective living that respect individual choice are encouraged.

The association *Inklusiv Wohnen Köln e. V.*, founded in 2013 and active since 2017 in Cologne-Rodenkirchen, offers mixed shared accommodation (people with disabilities and students) in a self-organized community. The students provide daily assistance in exchange for free rent, while people with disabilities receive individualized professional support, funded in the form of *Eingliederungshilfe* (integration assistance), with a personal budget (participation plan § 19 SGB IX).

The association is a legally recognized service provider (*Träger*), providing services as *Fachleistungen* (*specialized services*) in accordance with § 78 and § 104 SGB IX, while the housing remains independent (i.e., non-institutional). For dependent persons, the services can be supplemented by funding under SGB XI when the level of care requires it. This model complies

⁹⁵ § 104 (3) SGB IX.

with the principles of SGB IX relating to *personenzentrierung* (person-centered measures) and enables certain persons to exercise their right to choose their place of residence (§ 8 SGB IX). This is not an isolated initiative: it is part of a wider movement known as *Integriertes Wohnen* (integrated living), which is also being rolled out in Bielefeld, for example. The *Bielefelder Modell*, developed since the 1990s by Alt und Jung Nord-Ost e.V. in cooperation with the BGW company, offers accessible housing with local social services. These solutions offer an alternative to closed care facilities (always with a view to deinstitutionalization). These projects combine independent housing, outpatient services, cafés, and common areas, enabling self-determined living and a certain degree of social integration even in cases of dependency.

These projects are funded by a variety of stakeholders. Local authorities (*Landkreis* or *Stadt*) draw up the participation plan (§ 19 SGB IX), while *social welfare organizations* (*Wohlfahrtsverbände*) and private charities manage the housing, provide educational support, and coordinate with social services. These organizations sign multi-year agreements with the social security authorities on the basis of § 75 SGB XII, extended to SGB IX benefits, which guarantees stable support over time.

B. Access to social, professional, and cultural life.

SGB IX offers a structured set of services dedicated to the professional integration and social participation of people with disabilities.

Firstly, Section 4 SGB IX, which defines the purposes of participation benefits, specifies that these must aim to ensure participation in working life (to the extent of the individual's abilities)⁹⁶. More specifically, Section 49 SGB IX provides a framework for employment benefits (*Leistungen zur Teilhabe am Arbeitsleben*): vocational preparation, job retention, appropriate training, and supported employment (*unterstützte Beschäftigung*) must be tailored to the individual's abilities and local context, using a personalized approach.

The *Integrationsfachdienste* (IFD, specialized integration services), provided for in § 49 (6) SGB IX, provide intensive support to people who need assistance at work. They assess individual abilities, advise employers on the accessibility of jobs, provide on-the-job training, intervene in crises, and offer long-term follow-up. Their mandate is contractually regulated by multi-year agreements, ensuring effective coordination between public services, employers, and rehabilitation institutions.

Germany also has structures that offer sustainable jobs to people with disabilities in specialized workshops to enable them to enter the labour market. These organizations are called *Werkstätten für behinderte Menschen* (sheltered workshops). Despite the promise of offering a professional life to people who are difficult to employ due to their disability, these structures have been criticized. One particular criticism is that pay is generally lower than in the mainstream labour market. Furthermore, there seems to be a risk of creating a persistent divide between normal companies and workshops for people with disabilities. The UN Committee on the Rights

⁹⁶ §4 (1.2) SGB IX.

of Persons with Disabilities indicated to Germany in 2015 that this system did not fully comply with the genuine inclusion promoted by Article 27 of the CRPD.

The Committee is concerned about:

- a) Segregation in the labour market;
- b) Financial barriers that prevent persons with disabilities from accessing or integrating into the regular labour market;
- c) The fact that persons placed in sheltered workshops are not prepared or encouraged to integrate into the regular labour market⁹⁷.

Social or cultural participation is governed by §§ 76 to 84 of SGB IX. § 76 (2) specifies that social benefits include “access to suitable housing, assistance services, specialized educational interventions, foster care, as well as assistance in acquiring and maintaining practical skills, communication, etc.”⁹⁸ .” They must enable the person to develop their independence in their social environment, in accordance with the plan established (§ 19 SGB IX).

C. Decentralized governance based on partnerships.

Support for people with disabilities is based on a highly decentralized organization. While the federal government defines the legal framework through SGB IX, concrete implementation is ensured by the Länder and local authorities, in close partnership with large charitable organizations recognized as being of public utility (*Wohlfahrtsverbände*) such as Caritas, Diakonie, Lebenshilfe, and the German Red Cross. These partnerships reflect the principle of subsidiarity presented above.

Section 94 of SGB IX requires each *federal state* to designate entities responsible for organizing integration assistance (*Träger der Eingliederungshilfe*). In most cases, this task is performed by the districts (*Landkreise*) or municipalities. In some *Länder*, such as Hesse, a regional body—the *Landeswohlfahrtsverband Hessen (LWV)*—is responsible for coordination at the *state* level. It establishes agreements with local authorities to better tailor services to local needs, in particular by supporting inclusive housing projects and home-based services.

The *Wohlfahrtsverbände* play a central role in this structure: they directly manage many services (housing, employment support, social and cultural activities) in conjunction with the local social authorities (*Sozialämter*). The personal budget (§ 29 SGB IX) allows beneficiaries to finance individualized services within these schemes.

⁹⁷ CRPD/C/DEU/CO/1, § 49.

⁹⁸ § 76 (2) SGB IX.

2.4. Comparative analysis.

2.4.1. Strengths and weaknesses of the IVASS model in light of European experiences.

A. Strengths.

The Valencian model promoted by IVASS has several significant advantages in the European landscape of support systems for people with disabilities. These strengths lie in its institutional structure, its intervention logic, and the budgetary momentum it has managed to generate.

Firstly, IVASS stands out for its specific legal form as an integrated operator: as a *medio propio instrumental* de la Generalitat Valenciana (instrument of the Valencian Regional Government), it acts both as the direct executor of regional public policies and as the sole provider of a large part of the medical and social services. This organization allows for strong operational responsiveness, unified practices across the territory, and good coordination between strategic decision-making and technical implementation, which contrasts with the more fragmented situations observed in France or Germany.

Secondly, the SAPEMA (*Servicio de Apoyo a la Persona en el ejercicio de su capacidad jurídica*) scheme is a particularly noteworthy innovation in the field of guardianship. It brings together multidisciplinary teams of lawyers, social workers, economists, and psychologists, enabling comprehensive support for persons under guardianship, focused on their life plans and taking into account the diversity of their needs. This cross-disciplinary approach, which is not solely legal in nature, goes beyond the more strictly administrative forms still in place in France and in some German Länder.

Thirdly, IVASS benefits from a dense and structured territorial network, which includes 21 occupational centres, nine residences, several centres for people with mental health disorders, and an emerging network of guardianship housing. Although there is room for improvement, this coverage ensures physical accessibility of services throughout the Valencian region, particularly in rural areas.

Furthermore, IVASS's budgetary situation is a significant lever. Since the launch of the Convivint plan (2021–2025), the annual budget has increased significantly, reaching more than €71 million in 2023, with a structural cash surplus and significant investment capacity. This financial strength allows for the gradual recruitment of staff, the renovation of infrastructure, and the rollout of pilot projects, partly co-financed by European structural funds (ESF+, ERDF), bringing it closer to the investment dynamics observed in Sweden and Germany.

Finally, it should be noted that IVASS has incorporated the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) into its official guidelines, particularly regarding respect for the will of the individual, the promotion of independent living, and the fight

against institutionalization. Although not yet systematized, these references point to a fundamental orientation towards self-determination, in line with the most advanced European standards.

B. Weaknesses.

Despite these strengths, the IVASS model also has several structural limitations that may hinder the full implementation of the rights of persons with disabilities and the effectiveness of public action.

A first weakness lies in a form of institutional fragmentation, despite the internal unity of the IVASS. Coordination with other key actors—including capacity judges, municipalities, families, and associations—remains imperfect. Unlike France, where departmental councils for the protection of adults allow for some consultation between institutions, or Germany, where guardianship courts play an active filtering role, the IVASS's external coordination remains weak and informal.

Secondly, the Valencian model suffers from a lack of harmonized national guidance. Where Sweden has regulatory and standard-setting authorities (Socialstyrelsen, IVO) and Germany relies on the Unified Social Code (SGB), Spain operates through autonomous communities with a high degree of regulatory autonomy. While this decentralization promotes local adaptation, it also leads to inequalities in access and treatment due to the lack of a common national foundation. In terms of supply, capacity remains limited in certain key facilities. For example, the number of places in supervised accommodation (29 places) remains largely insufficient to meet the needs of the province of Valencia. People are often referred to more cumbersome collective structures, which is at odds with the objective of deinstitutionalization set out in the legislation.

In terms of human resources, although recruitment has taken place in recent years, teams remain under pressure, with management ratios that are sometimes too low, difficulties in retaining professionals, and a lack of structured training policies. This situation affects both the continuity of support and the quality of services.

Finally, IVASS does not yet have a systemic evaluation system based on qualitative indicators. Internal audits are limited, and feedback from users or families is not very institutionalized. Unlike in Sweden or certain French practices, the voices of those receiving support remain poorly structured in governance and planning mechanisms.

2.4.2. Good practices observed in the German, Swedish, and French systems.

A comparison with disability support systems in Germany, Sweden, and France reveals several particularly fruitful practices that IVASS could usefully take into consideration. These practices,

which stem from different legal and cultural contexts, nevertheless converge on shared objectives: promoting autonomy, protecting legal capacity, and ensuring dignified, flexible, and inclusive support.

A. In Sweden: self-determination as the basis for public action.

The Swedish system is based on the *LSS* (Lagen om stöd och service till vissa funktionshindrade), a framework law that guarantees a range of services to persons with disabilities on the basis of subjective rights. This framework gives rise to a reverse supply logic: it is not the person who has to adapt to the system, but the service that must adjust to the individual needs expressed. This results in a strong emphasis on personalized support, particularly through personal assistance, where users can recruit their own assistant, or even a relative, to help them live in ordinary housing. This choice-centered approach enhances people's freedom to live their lives as they wish.

In addition, Sweden has developed national steering instruments, including centralized databases (such as the *LSS* register), which make it possible to monitor the evolution of situations, evaluate services, and enhance transparency. Those concerned are also invited to participate actively in the development of their support plan and even in strategic decisions at the local level through organized consultative mechanisms. This model illustrates the advanced implementation of the principle of participation enshrined in the Convention on the Rights of Persons with Disabilities.

B. In Germany: graduated measures and flexible support.

The German system is characterized by a culture of proportionality and respect for the will of the individual, which is reflected in particular in the central role played by guardianship courts (*Betreuungsgericht*). Before ordering a *Betreuung* measure (assistance or representation), the judge must demonstrate that less intrusive forms of support—such as family, voluntary, or contractual support—are not sufficient. This requirement for justification ensures that substitute measures are limited to what is strictly necessary, in accordance with the CRPD.

Germany has also introduced an innovative “personal budget” system, which allows persons with disabilities to use public funding according to their own choices to organize their daily lives (hiring an assistant, equipment, home support). This mechanism offers great flexibility while empowering users.

Finally, local authorities play a key role, particularly the *Landkreise* (districts) and large cities. They are responsible for planning, contracting, and managing services, in conjunction with a network of public, voluntary and private actors. This proximity allows for the fine-tuning of

measures to local contexts, while building on the national standards set by the Social Code (SGB).

C. In France: legal framework, role of departments, and modernization of practices.

Although still marked by a protectionist approach, the French system has made several interesting advances. On the one hand, legal guardians for adults (MJPM) are subject to strict supervision, with regular checks by judges, state-regulated fees, and health monitoring by regional health agencies (ARS). This rigor helps prevent abuse and ensure a certain degree of consistency in practices.

On the other hand, departmental councils play a strong role in coordinating efforts at the local level: they finance and oversee programs such as SAVS (social support services), SAMSAH (medical and social services), and inclusive housing programs, which aim to enable people with disabilities to live independently while receiving flexible support. These initiatives are part of a process of gradual deinstitutionalization.

In addition, the French legal framework has introduced voluntary and extrajudicial mechanisms (future protection mandates, family authorization) that give concrete expression to the principles of subsidiarity and anticipation, and the 2019 reform guaranteed all protected persons the right to vote. These developments demonstrate an effort to balance protection and respect for the will of the individual, while strengthening citizen inclusion and the personalization of measures.

2.4.3. Avenues for development for IVASS based on foreign examples.

A. Structural changes.

Greater territorialization of services via municipalities.

One of the most striking lessons of the German model is the central role played by municipalities in the practical organization of personal services. Municipalities, whether *Landkreise* or large cities, are responsible for planning, contracting, and financing a large part of the support measures, in conjunction with local associations and service providers. In France, too, departmental councils are responsible for the operational management of home help and inclusive housing services. Although regional in nature, IVASS could forge closer operational partnerships with municipalities in the Valencia region by involving them in the management of local services, the location of sheltered housing, and the assessment of social needs at the local level. This territorialization would strengthen the responsiveness, adaptability, and relevance of responses by anchoring the mechanisms as closely as possible to social and geographical realities.

Strengthen inter-institutional coordination.

A second avenue for development concerns strengthening IVASS cooperation and coordination with other social, judicial, and territorial actors. Although IVASS enjoys an integrated status within the *Generalitat Valenciana*, its relationship with capacity judges, municipalities, local social services, and families remains largely informal or fragmented. In comparison, France has set up departmental consultation bodies bringing together representatives, judges, departmental councils and associations, while Germany relies on local coordination conferences supervised by municipalities. The IVASS could thus initiate a regional structure for dialogue and strategic steering, responsible for streamlining pathways, clarifying the responsibilities of each party and better coordinating judicial measures with social services. This development would help reduce institutional silos and ensure a more tailored response to the needs of those receiving support.

Building a sustainable human resources strategy.

The third area for improvement concerns the structuring of a sustainable human resources policy within IVASS. Although significant efforts have been made in recent years to recruit staff and upgrade positions, teams remain under considerable pressure, with a lack of continuing training, limited mobility, and uneven professional recognition. For example, Sweden has set up training programs, career support tools, and an active policy to support family caregivers, who can sometimes be integrated into teams as contract assistants. It seems that IVASS would benefit from developing a comprehensive skills management strategy, including upgrading the qualifications of professionals, retaining staff in the long term, and establishing links with the voluntary and municipal sectors. This policy could be extended to recognize the role of family caregivers through financial support, temporary respite care, or direct employment schemes inspired by Nordic models.

Establish a culture of qualitative evaluation.

Another lever for change is to establish a culture of evaluation based not only on quantitative administrative data, but also on qualitative indicators relating to quality of life, effective autonomy, subjective well-being, and user satisfaction. Spain does not yet have systematic shared observation tools at the regional level, unlike Sweden, which relies on national registers such as the LSS-registret. The IVASS could create an autonomous regional observatory responsible for producing regular analyses of the trajectories, expectations, and living conditions of the people monitored. Building on partnerships with universities and representative associations, this observatory could document the real effects of the measures put in place, guide future policy

decisions, and pave the way for continuous and shared evaluation of the quality of public social services.

Support social and digital innovation.

As an operational public body, IVASS has a structure that is conducive to experimenting with new forms of support. Drawing inspiration from calls for projects launched in France and Germany under European funds, it could initiate pilot schemes in the areas of home automation, digital monitoring of support plans, supported employment, and support for caregivers via online platforms. Similarly, the use of technology could be better integrated into everyday practices, whether to facilitate communication for non-verbal people, automate certain logistical tasks, or strengthen coordination between stakeholders. By mobilizing European funding (ESF+, Horizon Europe), forging partnerships with social enterprises or technologic, and promoting grassroots initiatives, IVASS could assert a pioneering role in inclusive innovation at the regional and national levels.

B. Evolution of support measures.

Establish a genuine gradation of protective measures.

At present, the Valencian system tends to contrast full legal capacity with judicial guardianship measures, without always exploring more flexible or progressive alternatives. The French (legal protection, simple guardianship, reinforced guardianship, tutorship) and German (modularity of *Betreuung*) experiences show that it is possible to design a range of measures adapted to the evolution of a person's situation. Such a gradation would allow for the rigorous application of the principle of proportionality, choosing the least restrictive measure possible at each stage. The IVASS could therefore initiate a discussion with the competent judges to promote lighter, temporary, or specific forms of support, thereby reducing infringements of legal capacity while securing the living environment.

Diversify the range of support services and promote home living.

The second avenue for change concerns the diversification of support services and the effective promotion of home living. Although IVASS has an extensive network of occupational centres and residences, alternative solutions to institutionalization remain marginal. However, experience in Sweden shows that it is possible to support people with disabilities in ordinary housing with the help of personal assistants, including those recruited directly by the user. Germany, for its part, has developed flexible forms of shared housing and introduced a "personal budget"

system allowing for the allocation of individualized resources. IVASS could thus strengthen the development of “*viviendas tuteladas*” (sheltered housing), but also experiment with new forms of shared accommodation, direct rental housing with support, or enhanced home support. In conjunction with local authorities and families, it would be possible to better respond to the desire for independence expressed by many people, without compromising on the requirements of protection and continuity of care.

Develop tools for anticipating legal support measures.

With a view to prevention and legal autonomy, IVASS could promote anticipatory instruments enabling individuals to designate in advance a trusted third party to represent them in the event of future incapacity. Similar to the “*mandat de protection future*” in France or the “*Vorsorgevollmacht*” in Germany, these mechanisms make it possible to fully respect the wishes of the individual while reducing the need for more intrusive judicial measures. Their development would require close collaboration with notaries, judges, and social services, but they would help to secure people’s futures, reassure families, and ensure that support measures are triggered within a framework that has been decided and prepared in advance.

C. Evolution of care.

Increasing the participation of those receiving support.

Care provision could evolve towards direct participation by those receiving support and their families in defining, implementing, and evaluating support mechanisms. While IVASS has demonstrated a willingness to listen to users, this participation often remains implicit, unstructured, and unevenly implemented across institutions. Conversely, several European countries have institutionalized mechanisms for consultation, expression, and shared decision-making. For example, Sweden organizes user councils in day centres, with the right to give opinions on the organization of activities. France, for its part, provides for advisory councils in medical and social institutions and involves families in the governance of certain schemes such as inclusive housing. The IVASS could therefore generalize the presence of user councils in its structures, create joint committees including families and professionals, and involve the people concerned in strategic planning bodies. These steps would help consolidate the principle of self-determination in practice, and not just in theory.

Strengthening the role and support for family caregivers.

Finally, the French and Swedish documents highlight the growing importance of family caregivers as the primary circle of support for individuals. In France, family empowerment allows relatives to be legally involved in the protection of the individual; in Sweden, mechanisms such as *anhörigstöd* or caregiver leave offer concrete and recognized support to caregivers. The IVASS could follow this path by establishing a regional family support system: easier access to information, home respite services, psychological support, and even opportunities for supervised direct employment. By valuing the role of relatives, we would strengthen both the natural fabric of solidarity and the ability of institutions to focus on the most complex situations.

Part Three — Recommendations.

3.1. Recommendations for IVASS.

3.1.1. Digitization of guardianship management.

Feedback indicates a lack of efficiency in communication between people under IVASS guardianship and the authority responsible for guardianship (SAPEMA). Requests (e.g., for expenses) are sent to SAPEMA using standardized forms filled out by the director of the centre where the person is staying, which creates an additional intermediary between the user and the guardian. In addition, these standardized forms do not allow for the wishes of users to be accurately recorded. This could undermine the autonomy of the people concerned.

In view of this problem, it is suggested that the possibility of setting up a secure messaging application be explored, enabling persons under guardianship to easily make requests and guardians to process them in a more appropriate manner.

This platform should enable:

- Instant transmission of requests.
- Requests to be sent directly by users, without necessarily going through the centre director
- Automatic sorting according to responsibilities (local guardian, general manager).
- Electronic signatures for validated authorizations.
- Less standardized requests.

It is therefore recommended to look into developing a digital tool with the following features:

1. Continuously accessible messaging.

- Each person under guardianship can send a request (e.g., “buy pants”).
- The guardian receives an immediate notification and can authorize or forward the request.

2. Intelligent filtering of requests.

- The platform identifies whether the request should be handled by the local center director or the general manager.
- If the request is assigned incorrectly, it is automatically redirected.
- The application automatically excludes requests that require validation by a judge.

3. Categorization between ordinary and extraordinary expenses.

Regular expenses (e.g., transportation tickets, hairdresser) can be pre-authorized (as is already the case) to avoid repeated steps. Already today, there are so-called “ordinary” requests that are authorized once and do not need to be authorized again for each similar action. The application should be able to maintain this. However, the difference between “ordinary” and “extraordinary” can be blurred. For example, the purchase of a pair of pants may be considered an

ordinary expense. However, accepting the purchase of a pair of pants as an ordinary expense should not mean that the person under guardianship can buy a pair of pants every day.

The platform must therefore detect potential abuse, such as buying a pair of pants every day, and refer it to the guardian. However, automation, while improving efficiency, must not lead to the dehumanization of support. Some so-called “out-of-category” requests require human judgment.

For example, when a person under guardianship asks to buy a house. The platform may automatically reject the request as “out of reach.” However, the guardian could have analysed this request, put it into a personal context, and discussed it with the user. Thus, the guardian should never be reduced to an executor of automated decisions, but should remain a human support figure, capable of listening and adapting.

The use of AI for this application would allow for greater personalization without replacing the human connection. Artificial intelligence can be integrated to:

- Facilitate sorting,
- Recall precedents,
- Alerting to unusual cases.

However, the final responsibility for processing must remain with humans, in accordance with the ethical principles of guardianship.

Ultimately, this platform would enable:

- A reduction in the number of intermediaries between the user and SAPEMA,
- Save time for professionals,
- Improved responsiveness to urgent requests.

However, its deployment must be accompanied by strong ethical safeguards to prevent the automation from getting out of hand and to preserve the human nature of the guardian’s mission.

3.1.2. Individualization of care.

This recommendation is rooted in the principle that care should be individualized as much as possible, which guarantees the quality of care and a better fit for the individual.

The principle of individualization can be applied to IVASS on three main levels: the care facility, the workshops offered, and individualized follow-up.

Specialization of facilities.

IVASS already groups its centres according to the pathologies of the people they care for, for example, depending on whether the disability is acquired or congenital. This approach is already very effective in ensuring more efficient and targeted care.

However, the same condition can lead to different levels of dependency. IVASS is therefore also considering dividing centres according to the level of dependency. For example, the main criterion for obtaining a place in shared accommodation is the right level of independence.

It is recommended to continue along these lines, aiming to diversify the types of facilities and specialize them as much as possible.

Individualization of workshops.

The workshop is designed as a structure with therapeutic, occupational, and social objectives (it promotes interaction between users). Consequently, the workshop must always be proportionate to the person's abilities in order to avoid exclusion.

If a person is given a task that is too difficult for them, this will affect their sense of self-efficacy (Bandura, 2003⁹⁹). A low sense of competence can affect self-esteem and cause feelings of shame. In an institutional setting, caregivers must take care to avoid situations where derogatory comparisons are possible. This discomfort is reflected in behaviour such as isolation, self-critical comments, and a decline in the quality of social relationships.

Conversely, if a person is given a task that is below their skill level, they may feel infantilized because their skills are not valued enough. Once again, comparison with the rest of the group can impact self-esteem. This can manifest itself in behaviour such as isolation, withdrawal, critical comments towards other participants, etc. This type of behaviour can impact the quality of social relationships within the group.

The task must therefore be tailored very carefully to the person's skills.

This means that for each person, the division into groups must take into account as much as possible:

- The person's areas of competence. This refers to the cognitive and motor skills that are preserved or impacted in the person.
- The prospect of development of their abilities. Due to certain disabilities, some skills are lost permanently. Offering workshops targeted at these skills will therefore only set the person up for failure, with no prospect of progress. On the contrary, certain abilities can be worked on with a view to development or maintenance, for a better outcome.

⁹⁹ Bandura, A. (2003). *Self-efficacy: The feeling of personal effectiveness*. De Boeck.

- The person's interests, in accordance with Article 30.2 of the UN Convention¹⁰⁰. The primary consideration is to take the person's requests into account. This consideration is taken into account a priori in the choice of workshop, then by observing the person's behaviour in the workshop and consulting with the person.

In practical terms, the requirement for individualization means that smaller workshops with a maximum of five participants, accompanied by a caregiver, are necessary. This therefore requires a larger number of caregivers. This model is preferable to group workshops, which do not respect the wishes and skills of each individual. It is also important to ensure consistency in the workshops and the caregivers who run them, in order to promote a safe environment and enable social bonds to form within the groups.

Appointment of a personal caregiver.

To ensure individualized follow-up, it is suggested that a system of designated caregivers be established for each person receiving care.

There is already a legal obligation for the judge to check every three years that the care measure is still appropriate for the person's situation. This timeframe seems very long, and it is recommended that more regular monitoring of each user's situation be put in place. The designated caregiver could act as a liaison with the judge to advocate for a review of the care measure when the person's situation seems to warrant it.

The aim is to ensure more personalized support, carefully considered in consultation with a designated caregiver. This measure will enable the person to communicate their requests more directly and regularly.

This is because the people receiving support are in contact with several caregivers, and the appointment of a designated caregiver would ensure regular follow-up and enable changes in behaviour to be noticed.

For example, it is sometimes difficult to assess the well-being of non-verbal people in centres. These individuals cannot explicitly express their experiences, but their feelings can be observed through their behaviour, particularly through overall changes in mood. Only regular, personalized monitoring can enable reliable observation.

In practical terms, each person cared for within a facility would have a designated caregiver. The same caregiver may be responsible for several people, due to material constraints.

It is recommended that regular appointments be scheduled, at least once a week, lasting half an hour, for example. This time could be taken by caregivers in parallel with workshops. For

¹⁰⁰ Participation in cultural life, recreation, leisure, and sports: "2. States Parties shall take appropriate measures to enable persons with disabilities to develop and realize their creative, artistic, and intellectual potential, not only for their own benefit, but also for the enrichment of society."

example, in a centre with 40 people and eight permanent caregivers who could serve as referents, each caregiver would be responsible for five people. This would mean 40 appointments per week, eight per day, four per morning. Two appointments could be scheduled in parallel with each workshop, with two caregivers carrying out the follow-up.

The activities during this individual time are tailored to the needs and requests of the individual. This is a special time during which the individual can choose what they want to talk about. Some people will be able to express their opinion explicitly about the quality of their care. For those who are unable to do so (e.g., nonverbal individuals), the exchange will allow the caregiver to implicitly gauge their satisfaction with the care (changes in mood and stress over the weeks, self-harm, withdrawal, changes in social relationships, etc.).

Beyond appointment times, the primary caregiver would keep a closer eye on these individuals during shared activities (meals, workshops). Some individuals who require less handling or attention in their care can sometimes slip through the cracks and feel neglected compared to those considered “problematic.” This measure therefore helps to rebalance the attention given by caregivers to all those in their care.

This solution, already deployed in countries such as Sweden with *personal assistants*, offers many advantages in terms of care. First, regularity and face-to-face contact provide a reassuring environment. The need for supervision and reference points can be quite significant for many disabilities. In addition, it gives people the assurance of having a trusted person to whom they can report their difficulties, needs, and requests within the institution.

Nevertheless, to be implemented, this resolution requires that certain limitations be considered. Ideally, more than one individual meeting per week should be scheduled, but IVASS faces limitations in terms of funding, recruitment, and staff training. In addition, this measure requires organizational adjustments to allow for these meetings, for example, in parallel with workshop sessions. Finally, it may require the recruitment of additional staff per institution to allow caregivers to free up this time.

If the appointment measure is not feasible because it is too costly and difficult to implement, it still seems appropriate to retain the idea of an individual contact person, with less regular appointments, for example. This follow-up retains the benefit of distributing caregivers’ attention fairly among those in their care.

3.1.3. Participation in decision-making.

Creation of a social life council.

One major challenge facing IVASS is reconciling the need for an institutional framework with respect for personal autonomy. The framework should not be seen as an infringement of autonomy, but as a prerequisite for it. The aim is to find a way, with, to involve people in decision-making, within their limits and in a way that values their abilities.

In France, the Social Life Council (CVS) model was designed with this objective in mind.¹⁰¹ "It is a forum that allows users, residents, and their families to communicate and discuss all aspects of their living conditions, care, and accommodation." It is also a privileged setting where people can have their rights respected (those provided for in the CRPD).

It is composed of four members, who may be representatives of the people receiving support, families or caregivers, healthcare professionals, or IVASS managers. As many people as necessary may be included in the council, but the law requires that more than half of them be representatives of the people receiving support. It is recommended that the CVS be composed of representatives of the persons receiving support, IVASS managers, healthcare professionals, and family representatives, given that family participation is a major concern in the support of users. In France, the CVS may include representatives of associations of persons with disabilities or caregivers. Within the IVASS framework, associations such as *CERMI* and *Plena Inclusión* could be incorporated into the CVS.

The council meets three times a year in each institution to report on the requests expressed by the people receiving support and their relatives during previous meetings. Relatives are free to organize themselves to pass on their feedback to their representative. And the people receiving support are consulted during workshops in the week before the council meeting. A sheet is circulated in the workshops and people are asked questions during discussions, which allow them to suggest ideas for improvement.

The establishment of these councils within IVASS seems particularly relevant to addressing the problem of indirect communication between IVASS's central administration and the people receiving support. Indeed, it has been observed that feedback on the situation of the people receiving support is often provided through a caregiver. Institutionally, this system, which is already effective in France, allows needs, difficulties, and criticisms to be reported in a constructive manner. It provides a neutral, free forum for discussion, focused primarily on the well-being of the people receiving support, who make up the majority of the council.

However, there are limitations to the implementation of this system that must be taken into account. First, implementing this system can take time, which can be demotivating for those

¹⁰¹<https://solidarites.gouv.fr/sites/solidarite/files/2023-12/FAQ-Conseil-de-la-vie-sociale-nov-2023.pdf>

involved, who are volunteers. It is therefore important to emphasize the benefits of this system to teams, family members, and those receiving support.

Furthermore, it should be borne in mind that the people with disabilities who will represent the CVS will not necessarily be representative of the entire population receiving assistance. Participation in these councils often requires sustained attention and communication skills. Representatives of people with disabilities often have skills that are above average for the group and are therefore not representative of all situations. This is why the stage of gathering opinions within groups is essential.

The participation of non-verbal persons with disabilities should also be taken into account, who may be assisted by a caregiver (see *above*). Finally, in order to respect people's attention and concentration spans, it is recommended that the condition of persons with disabilities be taken into account in the practical organization of meetings (e.g., do not schedule meetings that are too long and allow for breaks).

Subsequently, it would be possible to set up a central council bringing together representatives from each of the CVSs in the different centres. This system would make it possible to take stock of the care systems that work, learn from each other, and improve care overall. This council could eventually adopt best practices and share ethical considerations across all centres.

3.1.4. Social and professional inclusion.

Social inclusion.

The social inclusion of persons with disabilities is recognized as a fundamental human right. The CRPD (Article 3(c)) affirms the right to full and effective participation in society. Such participation is a condition for personal autonomy and relational integration (Ho, 2008).

However, active inclusion in social life is difficult to achieve. People under guardianship, particularly those with intellectual, cognitive, or psychological disabilities, are at increased risk of marginalization. Guardianship, when applied without consultation on the person's life plan, can increase isolation and even render the person invisible.

The IVASS therefore has a major role to play in coordinating legal protection and inclusion. It is not enough to provide security or care: an environment must be created that allows people to choose their relationships, lead an emotional, cultural, and civic life, and participate fully in the community. This social involvement also promotes self-esteem, psychological well-being, and the exercise of rights.

To this end, mechanisms promoting encounters and reciprocity with society must be put in place in ordinary settings: schools, cultural venues, neighbourhoods, public institutions, and community networks. Educational and intergenerational partnerships can be established (such as meetings between schoolchildren and people with disabilities), provided that these projects

are designed with the people concerned, in accordance with their pace and wishes, particularly through CVS (consumer participation committees).

The development of relational volunteering is also recommended. Networks of trained volunteers can be mobilized to combat isolation through visits, correspondence, or long-term mentoring. In France, a model has been put in by the association LADAPT, where volunteers accompany people with disabilities into employment.

This type of initiative could be adapted to IVASS, drawing on local community networks and integrating these actions into municipal calls for projects or partnerships.

Raising awareness in society.

At the societal level, social inclusion cannot be achieved without a transformation of collective perceptions of disability. This is why Article 8 of the CRPD explicitly calls on States Parties to raise awareness throughout society in order to combat discrimination against persons with disabilities. However, in many contexts, the public image of disability remains closely associated with so-called “mild” conditions, which are perceived as easier to integrate into society (such as motor or sensory disabilities). So-called “severe” disabilities, linked to intellectual, mental, or psychological impairments, often remain invisible or poorly understood, particularly when these situations involve guardianship or legal support. This lack of representation fuels fear and prejudice and contributes to the marginalization of those concerned.

It appears that IVASS can take action to raise public awareness of the issues faced by people with disabilities. It would be useful to establish partnerships with schools in the region and other stakeholders involved in disability issues (e.g., local charities). This collaboration could take the form of workshops bringing together students and people living with disabilities, classroom presentations by people under guardianship or their caregivers, joint creative projects (exhibitions, forum theatre, podcasts), or educational modules on ethics, solidarity, and anti-discrimination.

Another lever that IVASS can use is the representation of disability in the media. Stories and images help to shape society’s perception of disability. The IVASS could actively support the production and distribution of films, documentaries, and podcasts about the lives of people with disabilities under guardianship. When presented authentically, these stories allow everyone to project themselves into the life stories of others, broaden their perceptions, and combat their own prejudices.

This requires the mobilization of educational, cultural, media, and institutional actors in Valencia at the regional level. But this cannot be achieved without a supportive national and international cultural climate on the issue of disability. This is why it is important for IVASS to continue participating in international projects on disability.

Finally, all these projects must always be thought out and organized with the participation of people with disabilities themselves. It is not a question of imposing a form of social inclusion on those receiving support that does not suit them or would cause them difficulties, but of facilitating links with mainstream society for those who wish to do so.

Professional inclusion.

It is up to IVASS to enable the people it supports to flourish in an active life that is suited to their abilities and meaningful to them. Article 27 of the Convention on the Rights of Persons with Disabilities (CRPD) recognizes the right of persons with disabilities to work on an equal basis with others in an open, inclusive, and accessible workplace. This right goes beyond the mere possibility of working: it implies the freedom to choose or accept employment under conditions that allow for a dignified life.

Despite these international commitments, the right to work often remains theoretical for many people with disabilities under guardianship. The activities offered within medical and social care facilities are sometimes of little value in the labour market. They take the form of workshops designed more to fill the day than to promote genuine professional fulfilment.

These workshops meet the needs of some people whose abilities do not allow them to enter the world of work. However, some of the people supported by IVASS would be able to take on more complex tasks or join vocational training programs if individualized support were put in place. It is important that IVASS does not become an obstacle to professional independence by keeping people in repetitive activities with no prospects for advancement.

Support must be tailored to everyone's abilities and motivation. Furthermore, it is essential to give meaning to the work of highly dependent people who are unable to integrate into a normal professional environment. For the right to work to be effective, it is not enough to offer an activity: it must be rewarding, educational, and contribute to society. It must nurture a sense of usefulness, strengthen self-esteem, and promote social ties.

With this in mind, IVASS is implementing concrete actions, such as involving people with disabilities in flea markets, neighbourhood markets, and private events (such as weddings), where they can sell their creations (soaps, ceramics) and interact with buyers. The exhibition of works produced in the workshops of the Marxalenes Occupational Centre at the neighbourhood library also aptly illustrated this desire for openness and recognition.

On the other hand, IVASS must also offer stimulating professional activities to motivated individuals whose abilities allow it. For people with higher cognitive, motor, or interpersonal skills, it is possible to consider adapted vocational workshops with enhanced support. These workshops should aim to develop transferable skills that can be used in normal professional contexts.

The French model of ESATs (Établissements et Services d'Aide par le Travail, or Work Assistance Establishments and Services) could be a source of inspiration for IVASS and the Generalitat Valenciana in their mission to promote the social and professional inclusion of people with disabilities.

ESATs are medical and social establishments that employ around 120,000 people with disabilities in France in light manual work (packaging, labelling, assembly, laundry, grounds maintenance) or administrative support (mail sorting, simple data processing). They act as subcontractors for private companies – including large companies such as L'Oréal – thus making a concrete contribution to the social and professional integration of the people they support.

In addition to its productive dimension, work in ESATs is supervised by medical and social professionals, as it also serves as a therapeutic tool. It provides structure to daily life, develops social skills, and promotes cooperation, task sharing, and learning to live together. Access to remuneration, even partial, reinforces people's sense of autonomy and social usefulness. In some cases, ESAT can also be a stepping stone to employment in the mainstream workplace, with progressive support.

The aim is not to transform IVASS into ESAT, but to consider structured cooperation with establishments specializing in professional integration, similar to ESAT, in order to broaden the range of activities available to those receiving support. This requires enhanced dialogue with the relevant institutions, in particular the *Generalitat Valenciana* and LABORA, to consider the creation or development of such establishments in the region.

The realization of the right to work for persons with disabilities under guardianship cannot rely solely on medical and social structures: it requires the creation of an integrated territorial ecosystem that mobilizes the skills of the various actors in the employment, health, and social sectors. It is essential to raise awareness among local private companies of the benefits of an inclusion policy, for example by offering financial or tax incentives for hiring. These decisions are the responsibility of the Generalitat Valenciana, but they will facilitate the IVASS's socio-professional support mission in the long term. It is therefore recommended that the IVASS open a dialogue with the Generalitat to promote solutions of this kind.

Finally, in accordance with Article 27 of the United Nations Convention on the Rights of Persons with Disabilities, public authorities have a duty to set an example in terms of inclusive employment. The IVASS can therefore actively advocate for the recruitment of people with disabilities in local public services: reception, document management, maintenance of communal areas, etc.

3.1.5. Integration of families.

A. Role of families prior to IVASS care.

The reception, housing, and guardianship services provided by IVASS are a fundamental support for families of people with disabilities in the Valencian community. These families are not always able to assume this responsibility alone, for economic, social, or organizational reasons. For example, a single mother working full-time cannot provide daily care for her disabled child unless she hires a home care worker at her own. It is precisely in such situations that the intervention of social services is essential.

However, IVASS is currently facing a structural challenge: demand far exceeds the capacity available in day centres and residential facilities. It therefore seems appropriate to consider what measures the public authorities could take upstream to support families who wish to continue caring for their disabled relatives before they need to call on IVASS services. Such a preventive support policy would undoubtedly help to relieve pressure on existing structures, while improving the overall efficiency of the public service. Beyond easing the burden on social services, it is *clearly* in the best interests of persons with disabilities to remain in the care of their families when they can do so, as stated in the preamble to the CRPD.

Convinced that the family is the natural and fundamental unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should be provided with the necessary protection and assistance to enable families to contribute to the full and equal enjoyment of the rights of persons with disabilities¹⁰².

However, this approach should not be to the detriment of the fundamental rights and interests of the persons concerned. While home care may be appropriate in certain situations, it cannot replace genuine social participation. Even persons with mild or moderate disabilities should not be confined to their homes, even if they are surrounded by a relative or a professional. The right to an active and inclusive social life is a fundamental principle, enshrined in particular in Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), which guarantees everyone the right to live in society with the same choices as others.

The recommendation made here is therefore not intended to reduce demand for places in day centres. These centres must not be sacrificed, as they fulfil a fundamental role (maintaining social ties) that families find difficult to fulfil on their own. More specifically, the aim is to strengthen the capacity of families to play an active role, particularly in the areas of accommodation and guardianship, where this is desired and possible. Such an approach is in line with the

¹⁰² CRPD, Preamble, x.

principle of subsidiarity, referred to in I.1, which calls for responsibility for support to be assigned to the level closest to the person concerned, provided that this level can assume it.

It is recommended that IVASS engage in enhanced dialogue with the *Generalitat Valenciana* to assess the modalities of an incentive policy, including financial incentives, for families who would like to assume guardianship or daily care themselves but are prevented from doing so for economic reasons. However, this partial delegation of responsibilities should not be implemented without prior and regular monitoring of the material, social, and emotional conditions offered to the person with a disability, in accordance with the applicable legal framework on protection and dignity.

B. Promote family inclusion as the foundation of social inclusion.

IFFD proposes an approach to the family as the basic unit of society: socialization begins with close relatives and then extends to wider spheres. Defending the social inclusion of persons with disabilities means first and foremost ensuring their inclusion and well-being within the family.

Given that centres are, by definition, spaces cut off from the family environment, it can be difficult for them to integrate. However, the time spent in an occupational centre represents a significant part of a user's daily life¹⁰³. The risk of a break between family life and life in the centre seems obvious.

Several problems can arise from a lack of continuity between family life and life at the centre. There may be a disruption in the daily habits of the person being supported (if these are not the same at the centre and home). There may also be a feeling of a lack of consultation among families, who may then tend to rely exclusively on the centre and abandon their responsibility for shaping the person's living environment.

The IVASS is already taking measures to combat the consequences of this withdrawal of families. For example, the Ruzafa centre, which cares for people with severe brain injuries, plans numerous activities to stimulate its users cognitively, as families do not necessarily make the effort to keep their disabled relatives occupied.

It is recommended that IVASS continue its efforts to promote this principle of family continuity. In concrete terms, solutions could include:

- Facilitating visits by families to centres.
- Giving families an advisory role, particularly in Social Life Councils (see *above*).

¹⁰³ Users are generally in occupational centers all day (working hours) every day except weekends.

- Seeking the views of families on the services provided by the centres and taking their recommendations into account. This could be done through questionnaires, meetings with family associations, etc.
- Ensuring that treatment reports (individual interviews, follow-up with the psychologist and medical follow-up) are properly communicated and explained to families.
- Inform families about the activities carried out and the daily progress of those in care so that they can follow their loved ones' daily lives.
- Provide precise information about the daily routines followed in the centres and the need for families to ensure that these are continued at home. For example, communicate meal times so that they do not change too much when the person returns home at the weekend.

Social service centres should serve as a daytime substitute for the family, not simply as a recreation centre to keep users occupied. Continuity between the family environment and the centre must therefore be ensured. To ensure that families continue to feel that they play a major role in the lives of their loved ones under guardianship and that these individuals feel integrated both in the centres and in their families, the various members involved in the life of the vulnerable person must be reminded of the importance of continuity in ensuring successful social inclusion.

Openness: Reflections on the current model of autonomy.

The issue of decision-making in care is closely linked to the concept of autonomy, which is particularly relevant in the context of disability. The challenge is to conceive of autonomy in terms of accompaniment and support for decision-making.

An initial response to this medical ethics question was the concept of "*shared decision-making*" developed in the 1990s in medical ethics. It assumes that decisions are made jointly by the doctor and the patient. However, this concept is also applicable in law, between the judge and the person being cared for. It is at the heart of Spain's transition from a system of guardianship to a system of curatorship, in which the person under curatorship is restored as the main decision-maker. This model responds to a system that has been criticized as overly paternalistic. In shared decision-making, autonomy is understood as "*the practice of obtaining informed consent, which provides patients with the opportunity to consider all relevant information and determine which healthcare alternative best fits their value system*" (Ho, 2008). Glyn Elwyn, an

American physician and researcher, proposes a concrete model of shared decision-making in three phases¹⁰⁴.

The first stage is the “*choice talk*,” which consists of clearly presenting one or more reasonable options and confirming the patient’s preferences from the outset.

The second stage is “*option talk*,” which involves detailing the available alternatives and communicating medical information in a way that is accessible to the patient. This stage is based on the principle of informed consent. This need is founded on the philosophical principle that there is no choice without alternatives.

Finally, the third step is the “*decision talk*,” in which the caregiver helps the patient express their preferences, prioritize them, and make an informed decision consistent with their values. The doctor or judge offers concrete support by summarizing the decision together and offering a review, if necessary, until the decision is implementable.

However, in certain situations, due to mental retardation caused by disability, it is sometimes legitimate to suspect that the information will not be understood. A particularly sensitive example, in which IVASS has successfully applied this principle of informed consent, is the question of choosing to have children. Contraception is not imposed by the guardian, but IVASS provides sex education courses, in conjunction with the university, to enable people to weigh up the consequences of their decisions and to have a realistic view of their ability to care for a child. This contributes to a shift from medical *paternalism* (Beauchamp & Childress, 1979), the former Spanish model in which the guardian had the right to force the person to undergo a medical termination of pregnancy, to a medicine of autonomy.

To comply with the “*option talk*” stage of care, IVASS suggests, for example, the alternative of getting a pet. While not an entirely equivalent option, this solution allows the person to feel that they are not being forced to refuse the only option presented, and contributes to a sense of self-determination.

Adopting a pet is therefore an interesting solution to offer internationally to people who are able to care for one. This solution also provides a realistic response to the right to found a family (Article 23 of the CRPD). While preserving this intrinsic right, the exercise of this right may be restricted due to lack of capacity or infertility caused by disability. This is obviously not comparable to starting a family, but it does meet the need for *care*.

Nevertheless, this model can still be considered paternalistic, in that it places the person with a disability in a position of dependency on the doctor or judge, who provides the information.

¹⁰⁴ Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal Of General Internal Medicine*, 27(10), 1361–1367. <https://doi.org/10.1007/s11606-012-2077-6>

However, the guardianship system itself cannot do without this paternalistic dimension, due to its intrinsic asymmetry. The aim of these three stages of shared decision-making is therefore to move from an authoritarian paternalistic model to a cooperative paternalistic model.

Anita Ho-Baillie, a researcher at the University of Sydney, offers a reflection on the current model of autonomy in disability, which she criticizes as being too individualistic¹⁰⁵.

Reflections on autonomy have their historical roots in philosophy. In classical thought, humans are social animals, and their autonomy cannot be considered independently of social relations¹⁰⁶. Autonomy should not be defined as the absence of social coercion, which is beneficial to social development. On the contrary, in modern philosophy, autonomy is thought of as the absence of external coercion. Anita Ho points out that this model has long dominated care.

While this model is theoretically coherent, according to the author, it is not suitable for the care of people with disabilities. This is because the model defines autonomy as independence in decision-making, whereas disability can cause dependence. The person then finds themselves in a situation where they need external support to exercise their rights. Depriving them of this external support would undermine their dignity. Thus, considering the care of a person without taking into account their dependence would be inappropriate medical ethics. A new type of autonomy must therefore be defined to account for these situations: relational autonomy.

The researcher draws on feminist literature to propose a new definition of autonomy that considers the importance of the social context in which individual decisions are made. In a way, this is a return to a classic model of autonomy, which the author calls "embodied" (Ho, 2008).

The authors propose to deepen our understanding of respect for autonomy through the concept of "relational autonomy" (Ho, 2008). *"Even if such powers are not directly coercive, they structure people's alternatives in such a way that certain options are never considered viable and other decisions must be made"* (Ibid.). At first glance, paternalism can be understood as a situation in which a dominant agent exercises power and imposes their choice on another. This is the model that was still permitted under the former Spanish guardianship system. However, according to Anita Ho (2008), this understanding of power relations is still too individualistic. *"It misses the influence of other external powers. It does not address how many subtle and yet powerful forms of influence, particularly the social structure and institutional framework, shape people's decision-making process."* The solution proposed by the authors is to create a social system organized in such a way that people have real opportunities to reflect on their sense of autonomy and freedom of choice. *"This individualist view does not ask how the social system ought to be organized to ensure that people have genuinely meaningful opportunities to critically reflect upon their priorities, freely develop attitudes towards them, and make healthcare*

¹⁰⁵ Ho, A. (2008). The Individualist Model of Autonomy and the Challenge of Disability. *Journal Of Bioethical Inquiry*, 5(2-3), 193-207. <https://doi.org/10.1007/s11673-007-9075-0>

¹⁰⁶ Aristotle, *Politics*, Book I, Chapter 2, 1253a

decisions that would realize their life plans accordingly. For example, in the problems identified at IVASS, we should not underestimate the fact that people are never asked directly about their experiences of guardianship. This silence passively shapes their sense of freedom to criticize their care. It is much more difficult for them to spontaneously complain.

Autonomy can then be co-constructed, and the caregiver or guardian can contribute to the person's capacity for self-determination. According to Ho (2008), the person remains autonomous in that they can express their preferences and revise their choices. Thus, small choices such as choosing menus, occupational workshops, or residences may seem insignificant, but they send the following message to the person: the structure respects your autonomy. It is these small structural arrangements that make the person feel free to express dissatisfaction when the structure no longer suits them.

This is why the French model of the Social Life Council seems to be an example to follow for a structure capable of providing people with a framework that values autonomy. The aim is for people to internalize the social norm that a problem can be expressed and received within the IVASS system.

In conclusion, in accordance with the principle of the UN Convention, IVASS must strive to respect people's autonomy and freedom. Nevertheless, it cannot ignore people's limitations to this participation. On the contrary, we argue that failing to take these limitations into account would be disrespectful of the person's abilities. We maintain that respect for autonomy is not incompatible with assistance, without which individuals would be in real difficulty. This autonomy must therefore involve a certain degree of paternalism, but one that is applied in a co-constructive manner between the caregiver and the person under guardianship.

3.2. Recommendations for the UN.

3.2.1. Collaboration between the actors involved.

The Convention on the Rights of Persons with Disabilities adopted by the UN in 2006, following on from the Universal Declaration of Human Rights of 1948, affirms the principle of equality between all persons, regardless of their state of health or disability, thereby committing States Parties to respect the obligation to guarantee equal access to fundamental rights.

These international commitments mean that Member States have a role to play in financing and monitoring facilities for the reception and care of persons with disabilities. The equal guarantee of fundamental rights is unconditional and cannot be diminished in the name of profitability: a withdrawal in favor of private, for-profit actors would introduce a breach of equal access to essential services, to the detriment of the most vulnerable, which would be contrary to the spirit of the treaties.

That said, it seems appropriate to consider the operational advantages that certain private actors can offer: more flexible structures, shorter decision-making processes, less hierarchical organization, etc. These advantages could help improve the effectiveness of the systems, if they are regulated and free from commercial interests.

With this in mind, it is preferable to favour hybrid models that combine the flexibility of private law with the guarantee of the general interest provided by public action. Public funding makes it possible to avoid the logic of profitability, which could lead private organizations to take decisions that are beneficial to their finances but detrimental to the quality of the service provided to people with disabilities.

In concrete terms, this means entrusting certain tasks to private non-profit actors, such as approved associations, while maintaining well-defined public oversight. These organizations could be financed (at least in part) by subsidies from the state, the region, or even the municipality, in a spirit of subsidiarity.

The Swedish system provides a good example of decentralized management: municipalities (*kommuner*) are responsible for assessing needs, proposing individualized support plans, and financing services, in accordance with the LSS Act (see *above*). The right to support is recognized as an enforceable subjective right, but its practical application varies from one area to another, depending on local policies and capacities. This local management is accompanied by frequent use of private providers for the delivery of services, particularly for personal assistance (*personlig assistans*), home help, and supported housing (*LSS-boende*). These providers may be for-profit companies, cooperatives, or associations, selected by the municipality through a licensing or tendering process. Even when the provider is for-profit, it is bound by strict specifications that guarantee the quality of the service. Beneficiaries can often choose between several public or private providers, which ensures that the system is based on freedom of choice and personalized services.

In Germany, the system works in a similar way in some respects, with highly decentralized management and collaboration between several levels (local and supralocal). Private actors are very well developed and seem to operate efficiently. Take the example of Caritas, a non-profit organization that provides other services in addition to guardianship for people with disabilities, but which manages to support and provide work for 685,000 people receiving assistance. It therefore seems possible, through collaboration with public authorities, to develop large-scale private actors capable of meeting the challenges of caring for people in need of social assistance.

These approved organizations will have to comply with strict specifications to ensure that the rights of persons with disabilities are respected. These specifications may, for example, impose standards for training, ethics, and monitoring of support staff, or minimum standards for the

comfort of reception centres (minimum number of staff per resident, health, and safety requirements for premises, etc.). Control mechanisms may be put in place to ensure the traceability of public funds used.

Ultimately, rather than maintaining a strict opposition between public and private, it seems more appropriate to promote a collaborative model based on the principle of subsidiarity, placing the protected person at the centre of the system. This type of organization, which is both flexible and structured, offers more favourable conditions for support that is adaptable and attentive to the specific needs of individuals, in line with the spirit of the 2006 Convention.

3.2.2. Respect for autonomy through the issue of housing.

Concrete solutions to guarantee respect for the autonomy of persons with disabilities.

In its 2006 charter, the UN emphasizes the commitment of Member States to respect, as far as possible, the autonomy of persons protected by a guardianship or curatorship system. The 1948 Universal Declaration of Human Rights stated in its preamble that recognition of the inherent dignity and of the inherent rights of all members of the human family is the foundation of freedom. In line with the Declaration, the 2006 Convention protects this inherent freedom of all human beings by recognizing the principle of autonomy for persons with disabilities. It is therefore the duty of Member States to ensure and protect this autonomy to the maximum extent possible. However, the disability of some persons may impair their ability to exercise this autonomy.

Protecting the autonomy of these persons means helping them to make their daily decisions freely despite their disability and avoiding imprudent or impractical choices that could have negative consequences for their lives.

When a person is placed under guardianship, the role of the guardian is precisely to help the person make these decisions. However, relatives may not wish or be able to provide guardianship. For this reason, many States are committed to establishing social services to help these people in their daily lives when their families are unable to do so.

To clarify the application of the principle of autonomy for people with disabilities, a distinction must be made between social assistance and social support. Assistance tends to help people with mental disabilities by sometimes substituting the will of the assistant for that of the person being assisted, thereby reducing their autonomy. Conversely, support seeks to promote the autonomy of individuals without erasing it. The decision remains with the individual, but the support worker is there to guide the decision-making process and its implementation. The relationship is more horizontal, with the support worker acting **with** the person being supported rather than acting **for** them.

Scope of application: housing

In order to best respect people's independence, it is recommended that independent living be promoted as the preferred care option. Wider availability of this type of housing would reduce the need for residential care homes, which, although adapted to people with severe disabilities, are less conducive to developing independence.

A sheltered home is individual or semi-collective housing intended for a protected adult (often under guardianship or trusteeship) who is capable of living alone but needs regular support for certain daily tasks. In practice, these sheltered homes can take the form of shared accommodation. While allowing a certain degree of independence, these homes remain supervised. For example, in some IVASS housing units always have a caregiver on site to assist residents when needed. These units are a good example of a support model where those receiving assistance play a leading role in their daily lives without being left to fend for themselves. This type of housing also respects residents' need for privacy and a sense of home. Residents have their own room and personal space and are not subject to a set routine (such as showering and bedtimes).

The residential care home offers personal assistance services but does not allow residents to participate in everyday decisions. In residential care homes, residents are not free to come and go as they please. The home is an enclosed space, monitored by a security service, and residents are not *at home*. Life in the residence is communal, with rules that apply to everyone. The day is organized according to a schedule set by the administration.

Because of this collective aspect, residents have much less autonomy than in sheltered housing. For example, in a residence, residents do not prepare their own meals, whereas in sheltered housing, residents do their own shopping and cook according to a set menu. This example illustrates the difference in autonomy in everyday activities.

In short, when the degree of disability allows it, it is essential to favour assisted living facilities, which offer a good balance between support and independence. Unlike collective structures, which are often more rigid, these accommodations allow protected persons to remain in control of their daily lives while benefiting from reassuring support. This model respects both their need for support and their right to a life that is as free and personal as possible, in line with the principles of autonomy enshrined in international texts.

3.2.3. Willingness and consent: Initial consent to support.

In accordance with Article 12 of the *Convention on the Rights of Persons with Disabilities* (2006), States Parties undertake to recognize that persons with disabilities have legal capacity on an

equal basis with others and to provide them, where necessary, with appropriate support to exercise that capacity.

In this regard, the reform of the Spanish legal framework brought about by Law 8/2021 of June 2 is a particularly relevant example of recognition of the will and autonomy of the persons concerned. It would be desirable for other States Parties to follow this example by establishing a civil procedure that ensures that the wishes of the persons receiving support are effectively taken into account.

Since this reform, Spain has introduced *voluntary jurisdiction* mechanisms enabling persons with disabilities to participate actively in the definition of support measures concerning them. The procedure includes a mandatory personal and in between the judge and the person concerned, during which the latter can express their wishes and preferences (Article 42 bis b, § 3, of the Voluntary Jurisdiction Act). On this basis, the judge can propose individualized support measures, which may include guardianship.

The aim is to seek an agreement based on respect for the person's wishes; recourse to litigation is only a last resort in cases of persistent refusal or manifest conflict (Article 42 bis b, § 5).

This mechanism is supplemented by a voluntary advance planning mechanism, known as *self-curatorship*, which allows any person with full legal capacity to designate in advance, by notarized deed, the person they wish to act as their guardian in the event of future need. This designation may be accompanied by specific instructions on the nature of the support envisaged. Although the judge retains the power to verify, at the time the measure is activated, that the conditions for its application are met and in the best interests of the person concerned, this mechanism strengthens both legal certainty and individual autonomy.

The Spanish framework thus provides a concrete illustration of the possibility of a system that complies with the requirements of the 2006 Convention. It demonstrates that a coherent balance between protection and self-determination is possible through personalized measures that respect the will of persons with disabilities. This model could therefore serve as a source of inspiration for States Parties that have not yet adapted their legislation to fully recognize the legal capacity of persons with disabilities in the context of support measures.

3.3. Recommendations for IFFD.

3.3.1. The status of the community of life.

Recommendation:

Creation of a legal status for communities of life to combat the social isolation of older persons with disabilities.

International legal context:

The United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), in Articles 19 and 23¹⁰⁷, enshrines the right of persons with disabilities to live independently, to be included in society, and to have respect for their emotional and relational life.

The issue:

A reality of structural isolation ignored by the law.

In fact, numerous testimonies collected by the IVASS (Valencian Institute of Social Services) highlight a little-known reality: that of aging persons with disabilities, often without spouses or children, who have been living in specialized institutions for many years. Over time, these persons form strong emotional bonds with other residents. These relationships, although not based on marriage or family ties, structure their daily lives and contribute to their well-being. However, when they are transferred to facilities for the elderly, these ties can be broken due to a lack of legal recognition. Unlike couples or close relatives, these relationships do not enjoy any protective status.

This legal loophole leads to increased social isolation, which is already severely felt by these individuals:

- They have often been unable to start a family due to their mental disability or their living conditions in institutions.
- Their emotional network is based mainly on relationships formed in the institution.
- In the event of separation, visiting rights are limited and reunification is almost impossible, especially when physical disabilities are also present.

Objective of the recommendation:

In view of this situation, it appears necessary to introduce a legal status of "life partnership" to legally recognize the bonds of cohabitation and lasting affection between people who have no family or marital ties. This status would aim to recognize a de facto situation: that of people who have shared a life together in an institution, in a relationship characterized by closeness, mutual support, stability, and an explicit desire not to be separated. It would not create any tax or property rights or inheritance obligations. Unlike marriage or civil partnerships, it would not be based on a contract or voluntary declaration, but on an assessment based on objective and human criteria.

The aim is to enable the legal recognition of these ties, so that they are systematically taken into account by administrative, social and health authorities in decisions on placement, transfer

¹⁰⁷ "States Parties [...] recognize the right of all persons with disabilities to live in society, with the same freedom of choice as other persons, and shall take measures [...] to facilitate full enjoyment of this right." CRPD Art. 19

"States Parties shall take effective and appropriate measures to eliminate discrimination [...] on the basis of equality with others, in respect of marriage, family, parental status and personal relationships." CRPD Art. 23

or reception. Any decision to separate should therefore be justified and accompanied by a thorough examination of alternatives that respect the wishes of the persons concerned. This principle should also be incorporated into policies to combat social isolation, in line with human rights commitments.

Concrete proposal:

Member States are recommended to consider:

1. The creation of a legal status of “life partnership” primarily for older people and/or people with disabilities who have no family.
2. The legal recognition by social and health services of situations of long-term cohabitation and non-family affection as a criterion to be taken into account in any decision on placement, transfer, or separation.
3. The obligation for the authorities concerned to justify any decision to separate people in a community of life and to systematically explore alternative solutions.
4. The inclusion of this principle in policies to combat social isolation, in conjunction with the human rights of vulnerable persons.

3.3.2. Impact of disability and guardianship on the family.

A disruption of family balance:

The announcement of a disability or the introduction of guardianship measures represents a significant change for the family. Family roles change: parents find themselves with new legal responsibilities and siblings must cope with unequal parental attention. This rearrangement of roles can cause imbalance in relationships, confusion about roles and sometimes conflict, particularly when it comes to finding a balance between protecting and supporting the autonomy of the person concerned.

At the same time, families face a triple pressure: (1) psychological, due to the constant state of alert and ongoing planning; (2) organizational, due to the multiple procedures and daily support required; and finally (3) financial, as guardianship entails expenses related to care, changes in housing, or reduced professional activity. These restrictions, combined with the feelings aroused by the circumstances—guilt, concern, exhaustion—have a lasting impact on family harmony, particularly in the absence of organized assistance.

Autonomy under constraint:

Although families are generally the first to support a person with a disability, their ability to intervene is often limited by the complexity of existing measures. The introduction of guardianship involves legal action, which can provide some legal certainty, but also creates a consider-

able administrative burden that is often difficult to manage. The increase in the number of people involved (judges, social services, healthcare professionals) can hinder the smooth running of care, due to procedures that are often lengthy and technical, and rarely take into account the specific needs of families.

Furthermore, guardianship itself is an ambivalent measure. On the one hand, it aims to protect vulnerable individuals; on the other, it can restrict their autonomy beyond what is necessary. This tension has repercussions for the family: when a professional guardian is appointed, relatives may feel excluded from decisions; when a family member takes on the responsibility, they are exposed to significant legal and moral liability, without always receiving training or support.

Social repercussions:

In addition to the impact on the immediate family, disability and guardianship have significant social consequences. Isolation is the first of these factors. The daily burden of care can make it difficult for caregivers to maintain a stable career, fulfilling social interactions, or active civic involvement. This withdrawal from social life is amplified by the lack of outside support, growing exhaustion, and insufficient institutional recognition of the role of families in protecting vulnerable individuals.

Furthermore, the impact of disability and guardianship varies greatly depending on socioeconomic circumstances and geographical location. Families in precarious situations or living in underserved areas face multiple obstacles: lengthy legal proceedings, lack of support structures, and a shortage of trained professionals. These inequalities create a double injustice: on the one hand, the rights of the protected person are more difficult to guarantee; on the other hand, families must compensate for the shortcomings of a fragmented system, often at the cost of invisible sacrifices that are poorly compensated. This reality remains largely underestimated by international organizations such as the UN, which generally issues demanding recommendations that can only be implemented by states with the necessary resources and infrastructure.

Keeping your child or placing them in an institution:

Families dealing with a child's disability often face a difficult choice between two options: taking on full care within the home alone, or placing the child in a specialized institution. Keeping the child at home preserves emotional ties, ensures continuity of education, and promotes a life plan based on inclusion. However, this decision requires constant availability and a heavy physical, mental, and financial burden, and can lead to isolation from the rest of society, especially when support services are inadequate. Conversely, using a specialized facility can provide material relief and appropriate professional care, but at the cost of a sometimes painful separation, feelings of guilt on the part of parents, and the risk that the family will gradually lose its central

role in day-to-day decisions. This alternative, often presented as a choice, is in reality conditioned by the means available, public policies, and the existence or absence of intermediate solutions based on home support, inclusive housing, or family respite services.

Conclusion:

The difficulties associated with disability and guardianship should prompt public authorities to offer social services that are truly tailored to the needs of those concerned, without undermining the role of the family. The family often remains an essential point of reference, providing emotional ties and a moral responsibility towards the person being cared for. In a spirit of subsidiarity, the family unit must retain a central role, even if it can legitimately receive assistance in exceptional situations such as disability and guardianship.

3.3.3. Enrichment of the resources offered by IFFD.

Highlight IFFD's work on disability on its website.

IFFD could highlight its commitment to disability on its website. This visibility would highlight the actions carried out (research, councils, training, listening centres, etc.) and reflect the specific realities of families affected by disability, which often face unique social, educational, and psychological challenges. Such an approach would strengthen the institution's inclusive dimension, while contributing to the recognition of family experiences that are still largely invisible.

Create a specialized listening centre on parenting and disability.

Parenting a child with a disability exposes parents to specific difficulties, which can add to the ordinary challenges of parenting. In this context, listening requires particular sensitivity and training. An unprepared listener may not be able to provide an adequate response, especially in emotionally charged situations.

Most of the helplines offered by disability associations in France are run by psychologists or healthcare professionals.

In addition to the support provided by healthcare professionals or psychologists, which is widely available through specialized organizations, the integration of *peer support* into helplines would be a valuable addition. Peer support refers to support provided by someone who has been through a similar situation and who uses their experience to help someone in difficulty. This form of support promotes identification, free expression, mutual recognition, and a stronger sense of social support.

Already used successfully in discussion groups (Chenu & Dautrey, 2025¹⁰⁸), this resource is underutilized in helplines, even though it shares the same objectives while offering greater flexibility: immediate accessibility, anonymity, and no logistical constraints (childcare, travel, etc.). IFFD's expertise in parent-to-parent listening would enable this model to be integrated in a credible and effective manner.

It would be appropriate for IFFD to expand its activities by extending the existing helpline to the field of disability. This choice is justified by the specific nature of its expertise: unlike associations specializing in disability, IFFD has in-depth knowledge of parenting and family dynamics.¹⁰⁹ This comprehensive approach makes it possible to understand the impact of disability not only on parents, but also on the entire family unit, particularly siblings, who are often affected indirectly and silently (Scelles, 1998).

In practical terms, this would involve creating a network of parents or relatives of people with disabilities who volunteer to listen to others. IFFD could set up a listening service specifically for parents of children with disabilities, using these peer support listeners.

The listening service should include a mention of siblings or children who are responsible for a disabled relative.

Guardianship situations vary. Sometimes it is the children or siblings of a relative who are guardians. With a view to inclusivity, IFFD could add a reference to brothers, sisters, and children on the website of the specialized listening service for families affected by disability.

However, it should be noted that the helpline does not allow for the same quality of relationship as a face-to-face meeting. This is why training specifically for parents of children with disabilities would also allow parents to benefit from face-to-face exchanges. IFFD could design a group discussion session as an integral part of the training.

Develop a project for IFFD to train families in guardianship.

A project could be considered within IFFD to offer training for families dealing with the guardianship of a loved one. This training would aim to support them in the many challenges they face daily, based on observations made at IVASS in particular.

The main difficulties identified are as follows:

- Significant administrative complexity, linked to the diversity of mechanisms (family authorization, guardianship, legal guardianship, legal proceedings), which is a source of confusion for families.

¹⁰⁸ Chenu, B., & Dautrey, M. (2025). Professional family peer support.

¹⁰⁹ Scelles, R. (1998). Siblings and disability: the influence of one person's disability on their brothers and sisters.

- A lack of information on the financial assistance available and the steps to take to access it.
- Difficult management of the mental burden.
- Feelings of parental guilt (linked to the fear of doing the wrong thing or not meeting the needs of one's child or loved one).
- Difficulty finding a place in a centre.
- The need to follow up with the centre and stay in touch with the loved one receiving care.

Thanks to its expertise in family dynamics, IFFD is particularly well placed to support and train families facing guardianship measures. Such training would enable them to anticipate common difficulties and respond to them in a structured manner. What distinguishes IFFD's contribution from that of associations specializing in disability is its holistic approach, which focuses on the family as a whole. The aim would be to preserve intra-family relationships and limit the impact of disability on family life, paying particular attention to the situation of siblings, who are often overlooked.

In practice:

This training could complement existing programs offered by national associations, which focus mainly on rights and available resources. IFFD would thus have the opportunity to address a dimension that is still largely overlooked: that of family balance in the face of disability. Depending on the situation, this would be aimed at parents of children with mental disabilities from childhood, or, in the case of disabilities acquired in adulthood, at the children, siblings, spouses, or parents of the person concerned.

The modules could focus on the following three situations:

- 1) "My child has a disability: how can I cope with this situation, access available resources, maintain family balance, and support my other children?"
- 2) "My child is reaching adulthood: how can I prepare for the transition, consider their independence, and organize legal and social support?"
- 3) "I am the guardian of a loved one: what resources are available to help me fulfil this role, maintain relationships, and lighten the load?"

The training would aim to help families maintain their relationship with their disabled loved one, limit the negative impact of the disability on family life, and anticipate or better cope with commonly encountered difficulties. It would be led by a team of trainers made up of experienced guardians—who are themselves close to a person with a disability and trained to share their experience—a lawyer specializing in the legal protection of adults, and peer-support parents who draw on their own family experiences.

Details:

- Duration: one weekend (without children), in person or remotely; all sessions are grouped together in a short format for ease of access.
- Cost: \$75 (same as other IFFD training courses), trainers work on a voluntary basis.
- Follow-up: post-training support to encourage peer exchange, answer any questions and refer participants to specialist resources if necessary.

Training content:

2. Administrative and legal framework

- Obtaining guardianship: procedures, rights, appeals, available subsidies.
- Identifying financial assistance and existing support mechanisms.
- Preparing for the transfer of guardianship with age: how to choose a successor (siblings, the state, etc.).
- Proposed decision-making tools (criteria scale).
- Complex cases: apparent autonomy of the loved one, limits of family intervention.

3. Family and relationship approach

- Reflection on family balance: preserving sibling relationships, regulating roles, preventing burnout.
- Communication with the relative: how to maintain the bond despite dependency?
- Psychological support: helping parents mourn the loss of their ideal child without reinforcing feelings of parental guilt.
- Support groups led by parents, without systematic recourse to a psychologist.
-

4. Interactive methodology (IFFD approach)

- Fictitious case studies: managing complex situations, collective reflection on autonomy, practical scenarios.
- Content tailored to different family profiles (parent, child, spouse).

Referral to personalized support from a professional, more specific training – Resources:

- Psychologist specializing in caregiving and disability
- Lawyer, solicitor, notary for guardianship contracts and family authorization
- Training courses run by national associations on disability, specializing in other family issues

By developing specific resources on disability, IFFD would have the opportunity to expand its work with families who are often isolated and facing complex challenges. Highlighting this reality

on its website, creating a specialized listening service, and offering training on guardianship would make it possible to provide consistent support focused on family balance and preserving relationships. IFFD's complementary approach, based on peer listening, valuing lived experience, and collective reflection, responds to a need that is still largely unaddressed by existing mechanisms. By providing practical tools, recognition for family caregivers, and an appropriate forum for discussion, IFFD would help to shift practices toward greater inclusivity and support. Strengthening its mission in the field of disability would be fully in line with its founding values, recognizing the diversity of family backgrounds and supporting their dignity.

Conclusion

This report reflects a common desire to consider the protection of persons with disabilities in terms of their dignity, autonomy, and inclusion in society. The analysis of the Valencian IVASS model, placed within a legal framework renewed by Law 8/2021, highlights the significant progress made by Spain in implementing the principles of the Convention on the Rights of Persons with Disabilities (CRPD). Far from being a substitute model, the support offered tends to focus on people's abilities and wishes, with a view to personalization and subsidiarity.

A comparison with the Swedish, French, and German systems reveals both similarities—around the principles of self-determination, proportionality, and participation—and structural differences. Some countries are more innovative in terms of deinstitutionalization, family integration, and the dematerialization of services. Others have a more centralized approach or rely more on public-private partnerships. These contrasts highlight the areas where the Valencian model could be improved, without denying its strengths.

The recommendations proposed aim to continue this momentum for reform. They encourage greater individualization of measures, a stronger role for families, administrative modernization of guardianship, and full social and professional inclusion of the people receiving support. Beyond IVASS, they also challenge international partners—the UN and IFFD—on their role in promoting a model of society that does not merely protect, but enables everyone to participate fully in community life.

At the intersection of law, ethics, and social practices, this work outlines a requirement: that support for the most vulnerable become a lever for transformation for all institutions.

Appendix.

Assessment sheet from the Valencian Institute of Social Services.

(For use by IVASS professionals)

Assessment based on the Sustainable Development Goals (SDGs) from the UN's 2030 Agenda.

1. Relevance (SDGs 1, 3, 4, 10).

A. Does the service really meet the needs of the target audience?

Yes, IVASS largely meets the needs of the target audience: for example, it works with *Labora*, the Valencian Community's employment agency, to try to meet the employment needs of people with disabilities who can work. The organization thus aims to strike a balance between social assistance and respect for autonomy, providing support without depriving those concerned of their decision-making capacity, particularly in the context of legal protection measures such as guardianship. In most cases, IVASS is able to fulfil this mission by working through its various centres and providing legal, economic, and social support to those under its guardianship.

However, demand in the Valencian Community continues to grow, and the institution is struggling to meet it fully, mainly due to a lack of places, despite a recent increase in staff numbers. Furthermore, in practice, considering the wishes and autonomy of individuals, although required by Spanish law, remains difficult to implement in some cases. It is not always possible to ensure perfectly individualized and regular monitoring, which is essential to respect the principle of proportionality. Communication between users and the professionals responsible for reviewing decisions in the context of guardianship remains imperfect, although the IVASS is striving to comply with the requirements of Law 8/2021.

Finally, a comparison of the services offered in different European countries shows that some structures offer more professional and socially inclusive activities than those offered by IVASS, which mainly offers activities for occupational purposes and could move towards more professional activities.

Despite these limitations, the Institute generally meets the needs of the people it supports, offering them, depending on their situation, day care, adapted housing or legal protection measures such as guardianship.

Areas for improvement:

-> Diversify the types of protective measures (see "Establish a genuine scale of protective measures," above 2.4.3.B).

-> Diversify the support offered (see “Diversify the range of support and promote living at home,” *above* 2.4.3.B).

-> Increase support for social and professional inclusion (see “Social and professional inclusion” 3.1.4).

B. Does the service meet social policy objectives (national or local)?

The social policy objectives that IVASS seeks to meet are those set out in principle by Spanish legislation, which underwent significant changes in 2021 to comply with the requirements of the CRPD (see 1.1 *above*). These objectives are respect for and consideration of the wishes of persons with disabilities, and the proportionality of the measures taken to the individual situation of each person.

2. Accessibility (SDGs 1, 3, 4, 5, 6, 10).

A. Is it easy to obtain a place in a centre?

1. Is the service easily accessible for beneficiaries (geographically, financially, administratively)?

No, not always, because IVASS centres are difficult to access, mainly due to a long waiting list caused by a lack of places. In general, the legal procedure for obtaining a place in a residential centre takes between three and six months. However, in urgent cases, provisional measures may be taken before the judgment, but this is exceptional.

In terms of financial accessibility, IVASS is a public service organization. This makes the service almost free, and therefore much more accessible than private solutions. Users can also apply for dependency assistance (under the *Ley de Dependencia*). The cost of the service is therefore not a barrier to access.

Geographical accessibility seems satisfactory, with a total of 36 sites spread across the community. However, the distribution is not uniform, which may limit accessibility, particularly for people living in rural areas. For some centres (such as day centres for dependent seniors), there is a bus service that allows people to easily reach the centre, even if they do not live in the immediate vicinity.

Areas for improvement:

-> Reduce pressure on the service by making it easier for people to remain in their own homes (see “Diversify the range of support services and promote home living” 2.4.3.B.2)

2. Does the service take into account social, linguistic, or digital barriers?

With regard to social barriers, i.e., difficulties for people with disabilities in navigating the facility and forming social relationships, all IVASS facilities have social professionals, such as psychologists and social workers. All users benefit from their services and their high availability.

Language difficulties are partially considered. Healthcare professionals are trained to deal with communication problems, and speech therapists are available in the facilities. However, most of the facilities visited do not seem ready to welcome foreign nationals or non-Spanish speakers.

3. Effectiveness (SDG 16, 17).

Does the service achieve its objectives?

Yes, most of the objectives have been achieved, including support for people under guardianship and curatorship. 6,000 people are under the responsibility of IVASS, and each of them receives individual support that enables them to receive the services they need. However, although the UN guidelines call for improving the autonomy of users, in practice it is difficult for the organization to meet its objectives of respecting this autonomy, as a balance must be struck between decision-making by the person with a disability and decision-making by healthcare professionals. A fair distribution must be made, while ensuring the consent of the persons concerned. The autonomy of people with disabilities is therefore a real challenge and a goal that IVASS must achieve.

4. Quality of support (SDGs 3, 4, 16).

A. Is the welcome respectful, individualized, and humane?

Yes, because having visited most of the IVASS centres in the city of Valencia, we have observed excellent human relations between healthcare professionals and users. The centre directors come from a healthcare background and are therefore very involved in the process of welcoming and supporting people under guardianship. As for the rest of the staff, both healthcare and support staff, they all maintain respectful, professional, but above all caring and often friendly relationships. However, the support could be more individualized so that no one is left behind during the workshops.

Areas for improvement:

-> Further specialize the facilities (see "Specialization of facilities" 3.1.2.A).

- > Tailor workshops to the needs of each individual (see "Individualization of workshops" 3.1.2.B)
- > Introduce individualized follow-up via the individual advisor (see "Establishment of an individual advisor" 3.1.2.C).

B. Are the professionals competent and well-trained?

Yes, each facility has adequate staff. The staff is diverse to ensure that patients' needs are met as comprehensively as possible. The management team often comes from a healthcare background, which enables them to be aware of situations on the ground. The rest of the staff consists of nurses, care assistants, psychologists, physiotherapists, speech therapists, and special education teachers.

However, the team is sometimes divided on the issue of respect for autonomy, which can undermine the quality of care.

Areas for improvement:

- > Offer training aimed at reflecting on the concept of autonomy (see "Reflection on the current model of autonomy" 3.1.6)

C. Are listening and support well implemented?

Yes, as confirmed by Rafael Sotoca and the centre directors, and as we observed during our visits, users' needs are listened to: for example, at the Marxalenes day centre, users meet every week for a roundtable discussion to discuss any changes that need to be made to their care. Healthcare professionals are also available to listen to them at all times.

Area for improvement:

- > Offer people more opportunities to participate (see "Participation in decision-making" III.1.III; and "Increase the participation of people receiving support" 2.4.3.C.1)

5. Coordination and networking (SDG 17).

A. Does the service work in partnership with other actors (medical-social, associations, institutions)?

Yes, in various ways. For example, the Carmen centre has partnered with the nearby municipal library to exhibit artwork produced by people with disabilities. This gives them real visibility. There is also COPAVA, an association that coordinates resources for people with intellectual

disabilities and organizes tournaments and sporting events for users. Cooperation with the *Hogares Compartidos* association also helps to develop a network of more independent shared residences, addressing housing capacity issues. Internationally, IVASS has deals with various actors, UN working groups, politicians, and social service directors, which allows it to compare and share its operating methods in order to improve them, as evidenced by its participation in the European ELISAN project.

B. Is it integrated into a regional approach?

On the one hand, IVASS is part of a certain regional approach, as it only covers the Valencia region, the province of Alicante and Castellón. This allows the institution to focus solely on this region, without having to refer to a national authority. However, a social service that is truly close to the people is a difficult ideal to achieve. While the city of Valencia has around 15 centres, the rest of the region is much less well served. As can be seen from the map extracts below, there is a big difference between the services offered in Valencia and its suburbs, and in the other areas covered by IVASS. This makes it difficult for users who do not live near these centres to benefit from their services.

Figure 1: Distribution of centres in the Valencia metropolitan area.

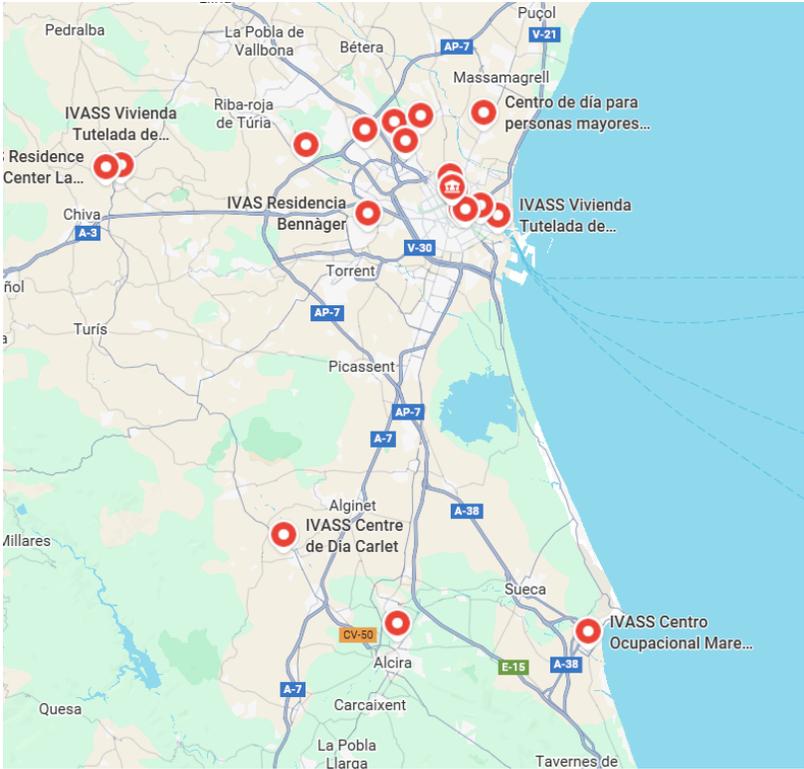


Figure 2: Distribution of centres in the Castellón metropolitan area

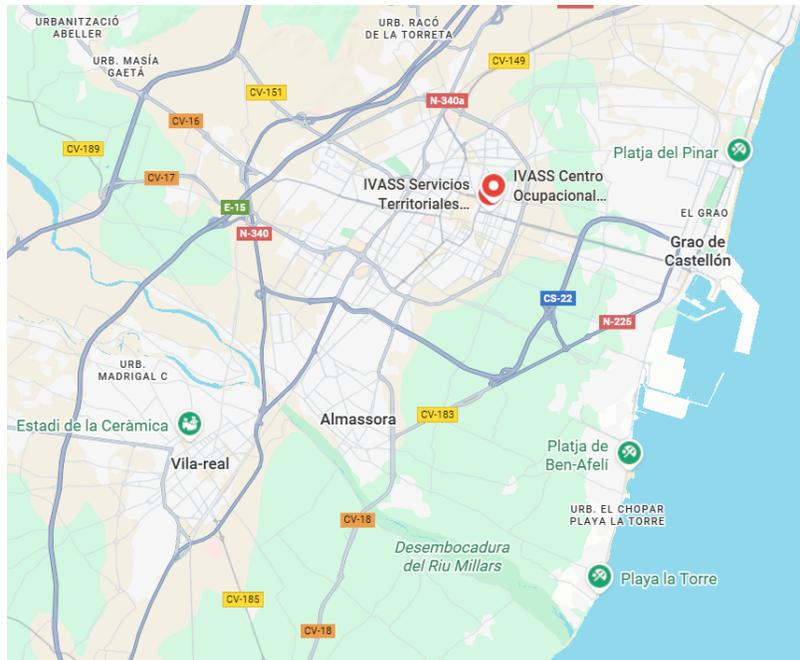
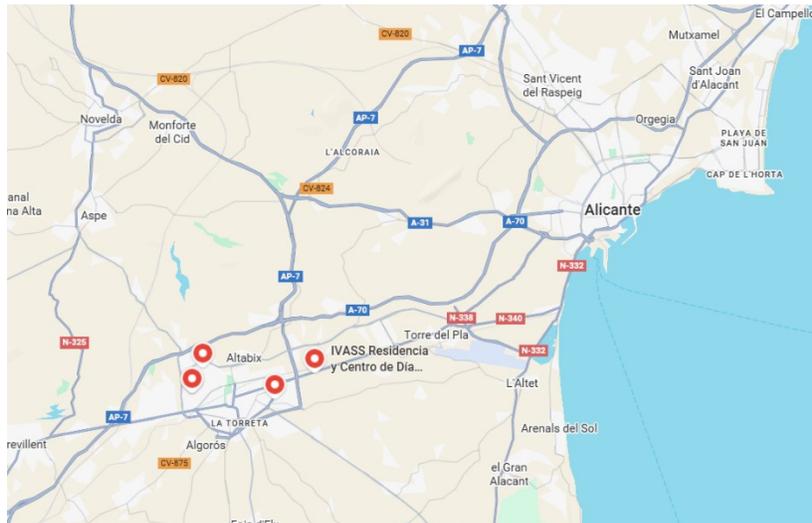


Figure 3: Distribution of centres in the Alicante metropolitan area



Finally, although the centres have a certain degree of autonomy, many decisions must be centralized at IVASS headquarters, which slows down the response time for users, even as the number of users grows.

Areas for improvement:

- > Regionalize services (see "Further regionalize services through municipalities" 2.4.3.A)
- > Digitize the management of guardianship (see "Digitization of guardianship management" 3.1.1)

C. Do centre directors have a strong impact on their structure?

Yes, centre directors have a great deal of freedom within their structure. This allows them to tailor their actions as closely as possible to users' needs and to promote local action as effectively as possible, while maintaining a certain identity in the way they operate. Their concern is the slow pace of dialogue between themselves and the hierarchy at IVASS headquarters. The response to the issues they raise is slow in coming, as is the response to all kinds of comments or opinions. This hinders their work with users.

Areas for improvement:

-> establish a regional structure for dialogue and strategic steering (see "Clarify governance and strengthen inter-institutional coordination" 2.4.3.A.2)

6. User satisfaction (SDG 16).

A. Is there an institutionalized system for criticism?

There are services such as CerMiCv, AspaceCv, and Plena Inclusion, which are associations for people with disabilities and are most often the point of contact for IVASS in the event of management issues. Open to all persons with disabilities, they count among their members a large number of IVASS users, which enables them to make their voices heard when necessary. However, the IVASS statutes do not provide for the mandatory consideration of criticism made by these associations.

B. Are users' views taken into account in the evaluation of the service?

As shown by the frequent user meetings in each centre, their voices are heard and taken into account. However, even though the service does its best to meet their expectations, it is sometimes difficult to respond in a timely manner, or even at all.

C. Is there a system for collecting opinions or complaints?

No, not as such. The service only has a telephone helpline, which is not necessarily adequate for the very large number of users.

Areas for improvement:

- > Creation of a Social Life Council (CVS) (see "Participation in decision-making" III.1.III; and "Increasing the participation of people receiving support" 2.4.3.C.1)
- > Collect user feedback via the individual caregiver referral system (see "Establishing an individual caregiver referral system." 3.1.2.C)

7. Ethics and respect for rights (SDGs 5, 10, 16).

Does the service respect fundamental rights (confidentiality, dignity, autonomy, privacy)?

Yes, IVASS makes it a point of honour to support people with disabilities with the utmost respect for their fundamental rights. However, it should be noted that the large number of users and the relatively limited number of staff sometimes make it necessary to take a general approach, putting overall efficiency before personal and individual needs. In addition, the link with families, which is a fundamental right, remains insufficient.

Areas for improvement:

- > Offer people more opportunities to participate through the Social Life Council (CVS) (see "Participation in decision-making" 3.1.3; and "Increase the participation of people receiving support" 2.4.3.C.1).
- > Further adapt protective measures to ensure maximum respect for fundamental rights (see "Establish a genuine scale of protective measures" 2.4.3.B.1).
- > Further integrate families (see "Strengthen the role and support of family caregivers" 2.4.3.C.2; and "Integration of families" 3.1.5).

8. Cost and efficiency (SDGs 8, 16).

Does the service use its resources rationally and equitably?

Yes, in most cases. It is difficult to get a clear picture of IVASS's financial management, but the service has dedicated managers and economic teams that enable rigorous management. However, after discussions with various staff members, it was noted that the different centres have a great deal of freedom in managing their financial resources, leaving open the possibility of excessive or unnecessary spending.

9. Innovation and adaptability (SDGs 9 and 17).

A. Is the service able to adapt to social change?

IVASS is aware of the challenges it faces in the coming years, namely the increase in the number of requests for guardianship and curatorship, but also the aging of the population. It is therefore focusing its attention on finding solutions to adapt to these challenges, in particular by developing the concept of autonomous shared residences and considering the introduction of a community living status for older people: this status would enable people who have lived together for a very long time in IVASS residences and do not wish to leave, to obtain a friendship status so that they can continue to live together in retirement homes and facilities adapted to the elderly. This would allow IVASS to free up space in its residences.

Avenues for improvement:

-> Establishment of a community living status (see “community living status” 3.3.1).

B. Does the service offer new solutions to persistent problems?

Overall, IVASS seems to be quite open to criticism and suggestions for improvement.

For example, one of the main problems addressed by IVASS is the issue of autonomy for people with disabilities. It is difficult for care facilities and guardians to find the right balance between paternalistic decision-making and respect for autonomy. To this end, procedures for listening, frequent meetings, and social integration have been put in place, but in reality, even if the intention is to respect their autonomy as much as possible, it is difficult to do so completely in practice.

However, IVASS is aware of its weakness and has taken certain measures: opening more professional integration offices, calling on young researchers to find the best solutions, and bringing new ideas to the European Parliament. In March 2025, IVASS director Maria José Rico presented the “*Disability Empowerment*” project to restore personal autonomy. The aim of this project is to restore this autonomy as far as possible and to “turn words into action to strengthen alliances between regions and ensure that people with disabilities can live full and independent lives,” in her words. The desire to make progress in serving people with disabilities is therefore deeply rooted and is likely to evolve for the better in the coming years.

Areas for improvement:

-> Support the search for innovative solutions (see “Supporting social and digital innovation” 2.4.3.A.5).

C. Is the service capable of questioning itself and innovating in its practices?

In order to best comply with European standards and UN sustainable development guidelines, IVASS is aware of the need to innovate and improve in order to offer the best possible service. This is demonstrated by the quality of the services described in this document, but also by the meetings between its director and the managers of the Hogares Compartidos association to further develop shared residences for people with disabilities, thereby promoting their independence. Its managers also attend strategic summits such as the ELISAN International Day to interact with other regional and international entities, and coordinate with the European Network for Inclusion and Social Action (ELISAN), which aims to promote the experience of local authorities in implementing social criteria within the Lisbon Strategy.

Areas for improvement:

-> Create systematic observation tools (see "Establish a culture of qualitative evaluation" 2.4.3.A.4).

10. Material conditions (SDGs 6, 9, 11).

A. Are the reception centres clean and well maintained?

Yes, each centre is very well maintained. Whether it be the common areas, individual rooms, bathrooms, workspaces, or outdoor areas, everything is remarkably well maintained and cleaned. We have not observed any hygiene issues or shortcomings in the facilities, which allows residents to live in a healthy and pleasant environment, which must be paramount in their care and for the respect of their dignity.

B. Are there enough caregivers?

Staffing levels vary. Some facilities lack certain types of caregivers, while others have enough to meet all their needs. The Ana Yutz day centre, for example, lacks psychologists to support its residents, while others, such as the Praga occupational centre in Rocafort, have all the staff they need to care for their residents, even during the summer months when care staff need to be replaced so they can take vacation. The recruitment problem stems mainly from budgetary restrictions imposed by the Ministry of Finance, despite a significant and very beneficial increase in the budget in recent years. In terms of demand for jobs, the outlook is optimistic: a total of 690 people have applied for nursing, kitchen, and infirmary positions at IVASS, and of the total number of applications, 469 were for nursing assistant positions, 150 for cooks, and 71 for nurses. Overall, IVASS is struggling to recruit psychologists and physiotherapists.

Areas for improvement:

-> Make employment more attractive for key positions (psychologists and physiotherapists) by offering better pay, benefits, accessibility, etc. (see "Building a sustainable human resources strategy" 2.4.3.A.3)

C. Are the premises spacious enough?

Once again, this depends on the centre. Most of the premises were designed to accommodate a certain number of users on a regular basis, which means that they are of a suitable size for their population. Others, however, have been converted and adapted to cope with the growing number of people under guardianship and curatorship cared for by IVASS. For example, the Ruzafa day centre was originally designed to accommodate small groups of young people with disabilities during educational stays. Now that it has to accommodate around 30 people, the premises have been adapted but are not at all practical for such activities. For example, the main staircase is old and does not meet current standards, preventing residents, who are elderly or severely disabled, from accessing the upper floor, which contains large rooms that are unfortunately unused.

Areas for improvement:

-> Where renovation is not possible, open new centres with better use of space.

D. Is the equipment suitable?

Yes, most of the equipment is in good working order to ensure optimal care for residents. Some centres, notably the one in Russafa, are even equipped with digital tablets for cognitive training sessions, which allow for interactive and stimulating activities for residents. However, we lack the knowledge to provide a relevant assessment of this criterion.

Areas for improvement:

-> Seek the expertise of an ergonomics firm on this subject.