

The right to self-determination of people with disabilities: Challenges to the implementation of the Legal Capacity Reform in Portugal

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Presentation plan

- Brief presentation of the EQUAL project
- Supported Adult Regime – What is it? What changes has it brought?
- The implementation process
- From formal commitments... to practice – the voices of the actors
 - Strengths
 - Limits, challenges, and constraints
- Final notes

EQUAL – Equality before the law and the right to self-determination of people with intellectual and psychosocial disabilities in Portugal: an exploratory study

Goals

- 1) Explore the barriers, challenges and opportunities that result from the implementation of the Supported Adult Regime (Law No. 49/2018);
- 2) Analyse the implications of formal and informal restrictions on rights and freedoms, citizenship and social participation of persons with disabilities;
- 3) Foster public debate on the right to self-determination of persons with intellectual and psychosocial disabilities;
- 4) Strengthen the status of Disability Studies and the Sociology of Human Rights in academia in Portugal.

EQUAL – Equality before the law and the right to self-determination of people with intellectual and psychosocial disabilities in Portugal: an exploratory study (EXPL/SOC-ASO/1326/2021)

Duration: 18 months

Promoter: ISCSP/ULisboa.

Partners:

- Centre for Social Studies (CES), University of Coimbra
- FENACERCI
- FNERDM
- HUMANITAS
- Procuradoria-Geral da República (Ombudsman)
- Provedoria de Justiça (Attorney General's Office)
- Conselho Superior da Magistratura (Superior Council of the Judiciary)

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Methodology

Collection and analysis of court decisions in 3 counties

- 752 cases (3 counties – Lisbon, Évora, Viana do Castelo)
- Adults 18-55 years-old | 10.02.2019 to 10.02.2023
- 6 case studies (2 per type of measure decreed)

31 semi-structured interviews

- Judges and public prosecutors
- Institution directors and staff
- Experts
- Families
- September 2022 to March 2023

4 focus groups

- Persons with intellectual and psychosocial disabilities
- April-May 2023

Inclusive and human **rights-based** research

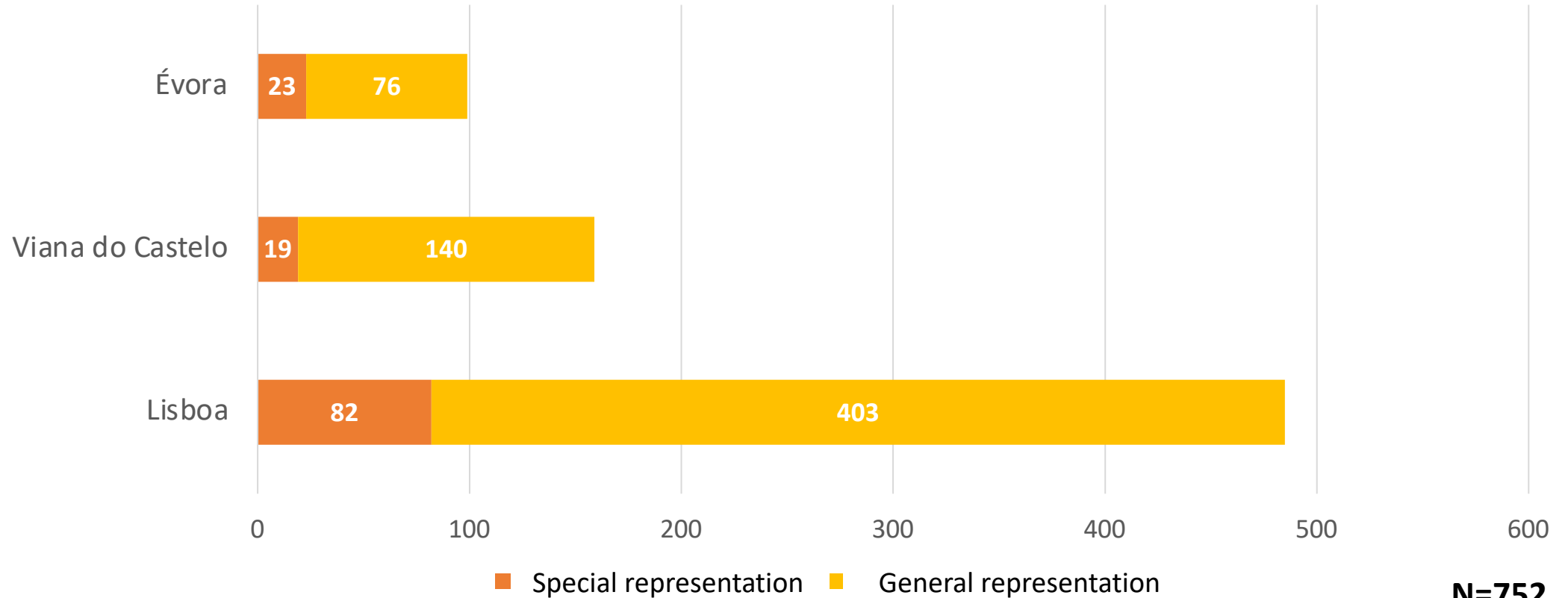
Brief presentation of the Supported Adult Regime (Law 49/2018)

- Following the adoption of the **Convention on the Rights of Persons with Disabilities** (UN, 2007) – focuses on the social participation of persons with disabilities and on changing attitudes;
- It eliminates the previous Regimes of Interdiction (or "civil death") and Incapacitation;
- Support measures as a **'tailor-made suit'** - "*The support ...aims to ensure ... the full exercise of all their rights and fulfillment of their duties...*" (art. 140, para.1), and "*... is limited to what is necessary.*" (art. 145, para. 1)
- Focus on the **autonomy and will** of the beneficiary:
 - Support **required by the beneficiary**, or by third parties with his/her permission;
 - **Personal and direct** hearing of the beneficiary;
 - The beneficiary **chooses** the support person.
- **Two types of decision – general representation and special representation.**

Supported Adult Regime

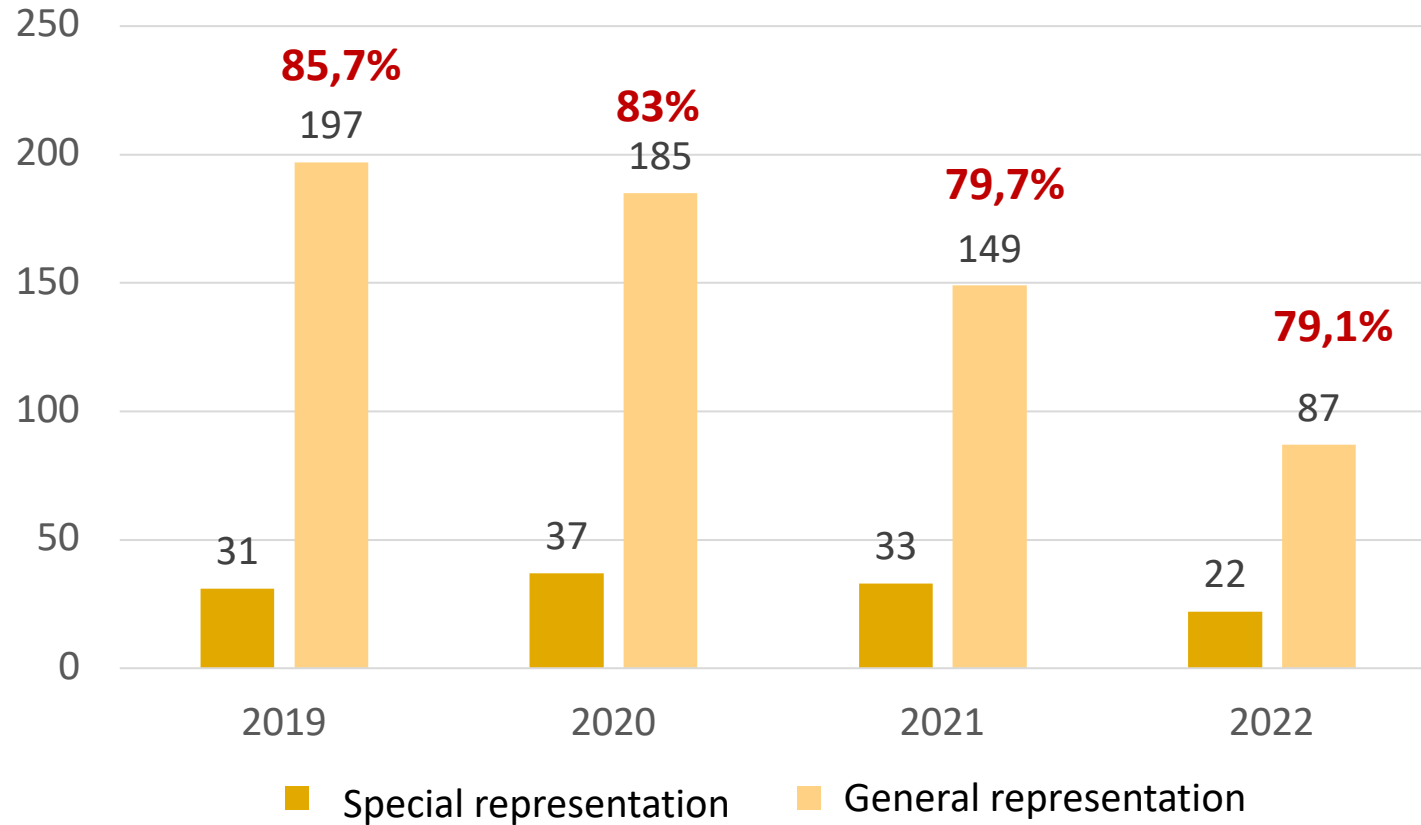
Court decisions in 3 counties (beneficiaries 18-50 years-old)

2019 - 2022



General representation: **82,3%**
Special representation: **16,5%**

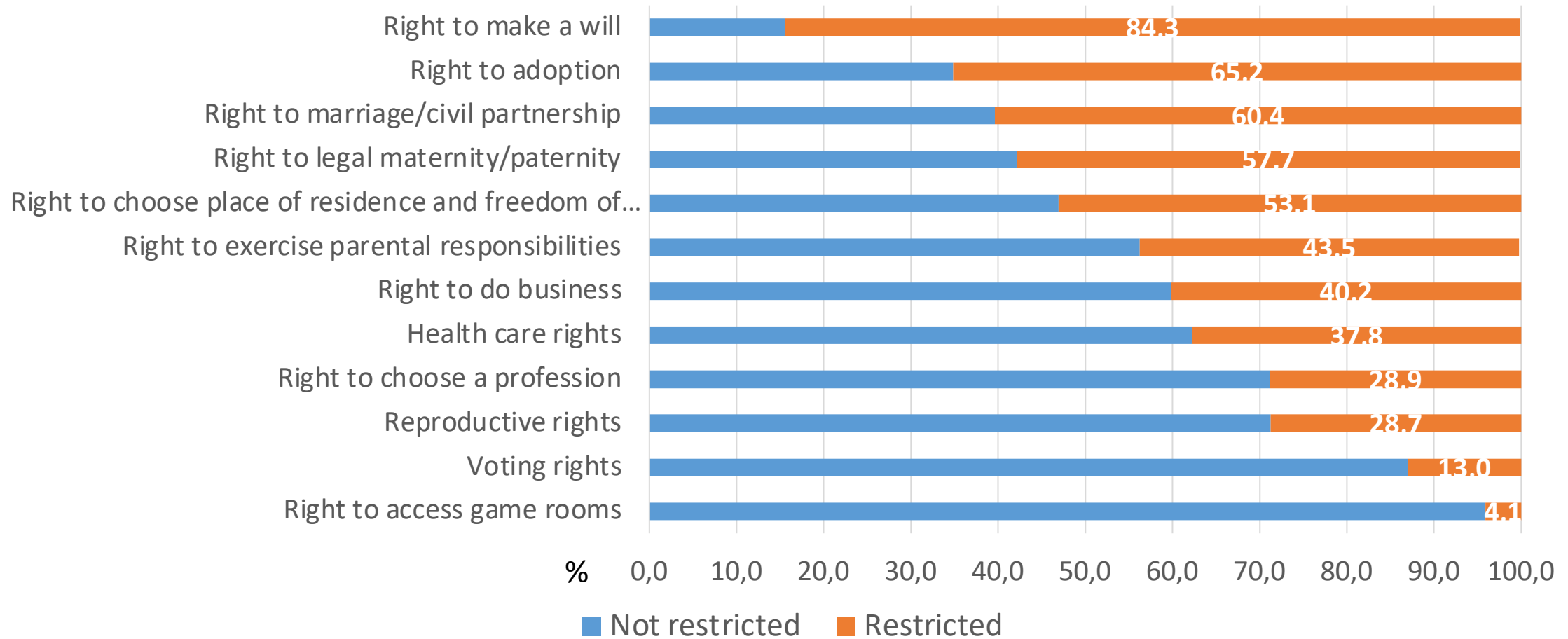
Supported Adult Regime Evolution 2019-2022, per type of measure



N=750

Supported Adult Regime

Restrictions on personal rights (2019-2022)



From formal commitments... to practice

a) Strengths

- **Law represents a positive paradigm shift**

*I think ... the spirit [of the law] is much better, **much more innovative, much more respectful.** (B4 Expert)*

- **Concern with standardization of procedures**

*The **Public Prosecutor's Office** itself created an **observatory** in which all of us, magistrates, contribute with issues, not only in terms of **standardization of procedures** (...) this observatory is fundamental to identify the different types of procedures and then, in terms of the Public Prosecutor's Office, it is possible to give some hierarchical guidelines to say do so, standardize procedures by doing this, this and that... (C6 Public Prosecutor)*

From formal commitments... to practice
b) Limits, challenges, and constraints

1. Recent legislation

Look, (...) the regime is from September 10, 2019, isn't it? (...) It's still relatively recent, isn't it? They are probably still (...) refining and improving the procedures. (A7 Technical Director)

2. Inaccuracies in the law and inconsistency in its application

[There are] several interpretations, including in relation to direct hearings. There are courts that summon the person to come to court; others that go and meet the person; others still that order the expert report to be made from a distance and without the presence of the magistrate. (C6 Public Prosecutor)

From formal commitments... to practice
b) Limits, challenges, and constraints

3. Insufficient resources in the courts

We [Public Prosecutor's Office] at this time do not have the human resources for all these cases. (...) Because if I deal with them as I previously did with the Interdiction cases, of course I can quickly get 100 cases done, and keep my caseload controlled. Now, I can't deal with Supported Adult cases like I used to deal with Interdiction files, because that's not what is intended. (C5 Public Prosecutor)

And then we [Judges] must give an answer, because if we do not give an answer, in the First Instance there goes the Judicial Inspector, which was my case, and "ah, there are some delays here!", "Ah, but I had to read the Convention", and he says, "you don't have to read it, it's the law!". (C1 Judge)

From formal commitments... to practice
b) Limits, challenges, and constraints

4. ...and time and workload pressures

(...) This new law clashes with the need to do everything faster, faster and faster. Because this law is necessarily slower. Therefore, what I see is the lack of compatibility between going through all steps that the new law requires and at the same time respecting the urgency it imposes. (B4 Expert)

*(...) In relation to [medical] experts, **the more reports you write, the more you earn, the more sick people you see in the hospitals, the better doctor you are, the more cases you finish, the better magistrate you are.***

(...) This is the new reality! (B4 Expert)

From formal commitments... to practice
b) Limits, challenges, and constraints

5. Lack of training and the persistence of a paternalistic and medical model of disability

***This is a human rights issue!** (...) Now, [in Law Schools] Human Rights are addressed (...) as a minor issue, it is not a specific course. (...) **There is a lack of initial training** ... (C1 Judge)*

*Our paradigm is a paradigm of care – ‘**I know what is good for you**’. (B4 Expert)*

***Minds take time to change, don't they? Mentalities are not changed with decrees or laws.** I think that, for example, and I can speak at the level of the judiciary, I see that there are colleagues who still look at the new Regime as if it were, in short, the same thing as Interdiction - it only changed the name. (C5 Public Prosecutor)*

From formal commitments... to practice
b) Limits, challenges, and constraints

6. Problems and constraints external to the judicial system

Lack of articulation between services

*Everyone comes here with a referral from Social Security [that] in order to receive a certain pension, you need to have Supported Adult recorded on the birth certificate. **Wrong, it has nothing to do with it, does it?** (C6 Public Prosecutor)*

Inadequacy or insufficiency of existing social services

*The **inadequacy of social services, with typologies that have not changed for years and that do not respond at all to what people need today.** (B1 Social Worker)*

*Imagine a service provider that already has insufficient resources and has to ensure this support. Now, that's difficult because it means that if they have 50 clients, they may have **someone who is a tutor and who provides this support for... 5, 6, 7 or 8 [supported adults] (...)** And that often **diminishes and standardizes the support, rather than individualizing it.** (A2 Chairman of the Board)*

Final notes

- The Supported Adult Regime represents an important legal achievement and is closer to the disability human rights paradigm.
- Given that it's a recent law, the new paradigm is not yet internalized in the social representations and practices of the social, medical and legal actors.
- Important constraints remain, inside and outside the judicial system.

Final notes

- Clues for reviewing/improving the implementation of the legislation:
 - ✓ Transition of these processes to Family and Juvenile Courts, Justices of the Peace or even its own jurisdiction?
 - ✓ Creating multidisciplinary teams to assist the Public Attorney's Office in the preparation of Supported Adult cases.
 - ✓ Clarification and standardization of procedures (e.g., what is considered in the assessment; how the beneficiary can be heard).
 - ✓ Inspection mechanisms, with powers to investigate non-compliance by the support person in institutional and family contexts.
 - ✓ Assess the possibility of creating a pool of professionals who can ensure the follow-up of people without an identifiable and reliable support network.

And mostly important...

- **Empower persons with disabilities** to learn about and claim their rights, notably through peer support;
- Continue monitoring and assessing the implementation of the law.

Thank you.

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