

‘Nothing without us, not even research’: Opportunities and challenges of developing participatory research with persons with intellectual and psychosocial disabilities

11th ALTER Conference

**“Protection, autonomy, emancipation: an
(im)possible aliance?”**

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Paula Campos Pinto, ODDH e CIEG/ISCSP_ULisboa

Teresa Janela Pinto, ODDH e CIEG/ISCSP_ULisboa

Patrícia Neca, ODDH/ISCSP_ULisboa

Bárbara Maltez, ODDH e CIEG/ISCSP_ULisboa

Outline of the presentation

- The EQUAL Project
- Inclusive research in the EQUAL Project – the process
- Critical reflection:
 - (1) How do disabled and non-disabled researchers view their lived experiences of collaboration in this project?
 - (2) What ethical, methodological and practical challenges were faced and what opportunities were found?
 - (3) What lessons can be learned from this inclusive research design?

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

■ Key goals:

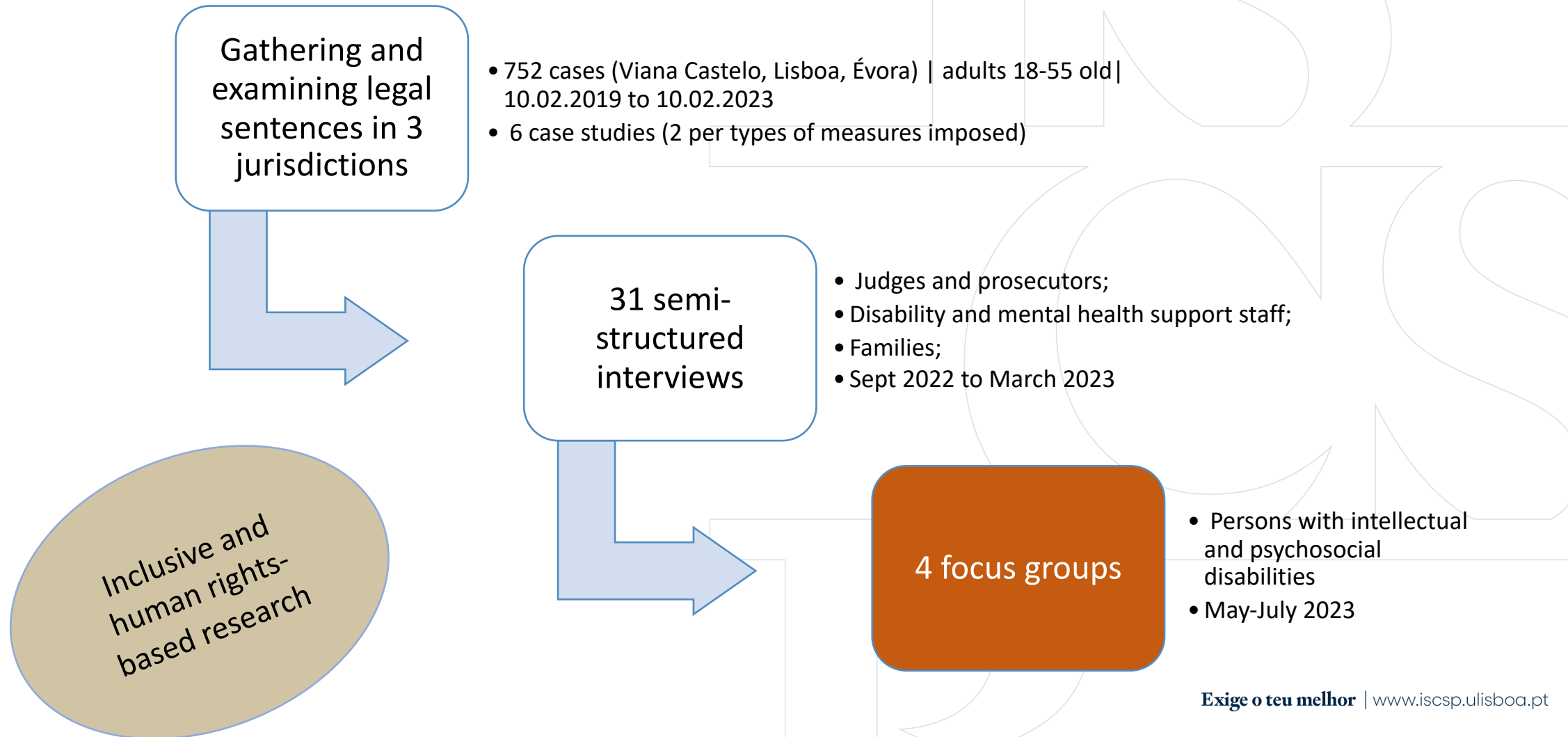
- 1) To explore the challenges, barriers and opportunities surrounding the implementation of Law 49/2018 in Portugal;
- 2) To examine the implications of formal and informal restrictions of rights and decision-making on the agency, citizenship and social participation of persons with intellectual and psychosocial disabilities;
- 3) To steer public debate about the right to self-determination of people with intellectual and psychosocial disabilities;
- 4) To strengthen Disability Studies and the Sociology of Human Rights status in the Portuguese academia.

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

- 24 months of duration
- Participating Institutions:
 - ODDH and CIEG/ISCSP, University of Lisbon (PI)
 - Centre for Social Studies of the University of Coimbra
 - FENACERCI
 - FNERDM
 - HUMANITAS
 - The Prosecutor General’s Office
 - The Ombudsman
 - The Superior Council of Magistrates

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Methodology



Inclusive research

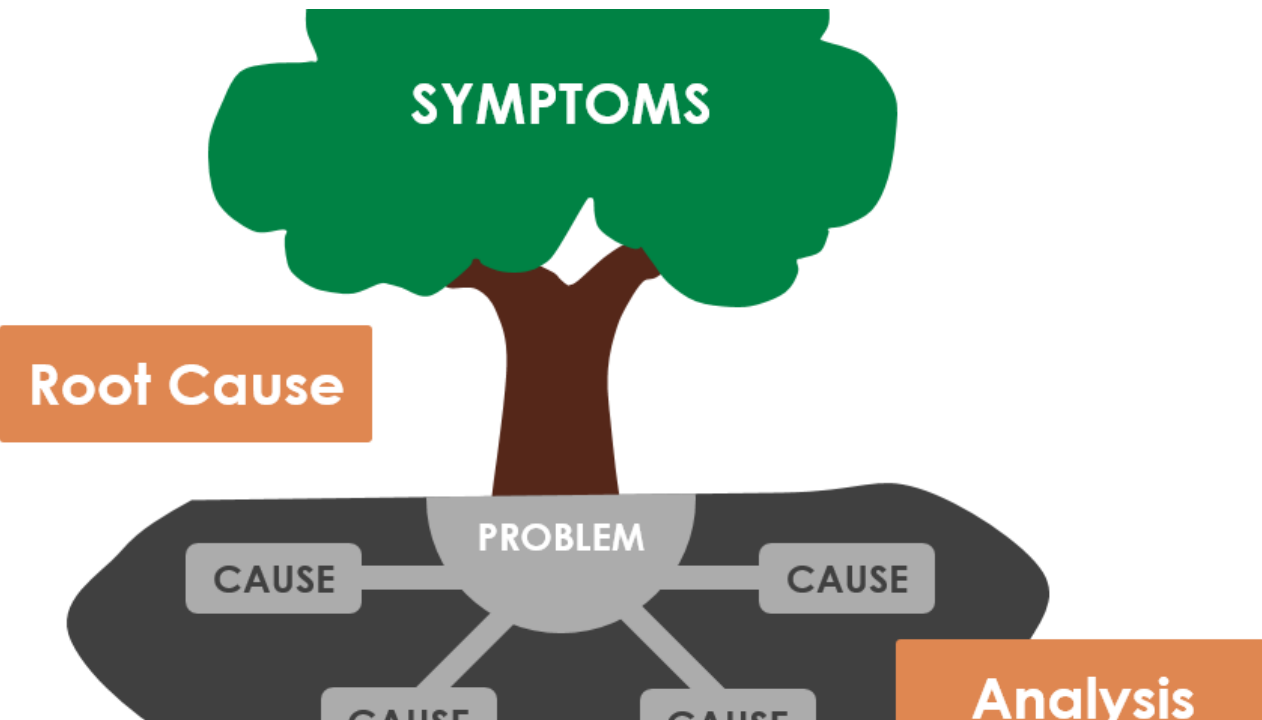
- When people with disabilities are involved and take an active role in the research **PROCESS** (e.g. Frawley & Milner, 2019; Strnadová & Walmsley, 2017; Grace, Haas, Hope, & Nind, 2022; Bigby, Frawley, & Ramcharan, 2014b; Hopklins, Johnson, & Minogue, 2014; García-Iriarte, McConkey, & Brien, 2014; Cumming, Knox, Parmenter, & Strnadová, 2014). An encompassing term that may take various forms (Chapman, 2014; Bigby, Frawley, & Ramcharan, 2014b):
 - **Emancipatory research** – persons with disabilities have control over the research
 - **Participatory research** – persons with disabilities do not have full control but take active part in the research
 - **Action-research** – persons with disabilities benefit from the outcomes and impact of the research, though they do not control it
 - **Collaborative research** – the research process is accessible and persons with disabilities participate in discussions throughout it

Inclusive research in EQUAL – the process

I) A series of working sessions:

1. Introducing the team and the goals of the EQUAL research project; what is inclusive research?





Inclusive research in EQUAL – the process

2. The CRPD and the right to self-determination. Activity: *Rivers of Life*
3. Regimes of interdiction and inabilitation; Law 49/2018. Activity : *Root Cause Analysis*

Inclusive research in EQUAL – the process

5. Complete life histories and gather tips for interview guides
6. What is photovoice? How are we going to use it in EQUAL?
 - **My choices** – objects I choose to have; things I choose to do; places I chose to go
 - **Barriers to my choices** – situations or events that I'm not allowed to do; things I want to have but I'm not allowed to)
7. Feedback from photovoice; preparation for Focus Groups





Inclusive research in EQUAL – the process

9. The co-researchers facilitated
the focus groups with the support
of the researchers



Inclusive research in EQUAL – the process

10. Co-researchers will participate in FG data analyses and reporting (e.g. presentation at the Final conference; co-production of an easy-read publication; documentary)



Critical reflection

(1) How do disabled and non-disabled researchers view their lived experiences of collaboration in this project?

A mutual learning experience, and a richer research

- *“I'm learning things for myself, making new friends, listening to other people who have the same things as us, learning different things. (...) I learned a lot of new things from other people, and I still hope to learn more.”* (Artur, co-researcher)
- *“It's been a good, positive, interesting experience. I never thought I'd be part of a project with such a large dimension, I'm doing my best, I'm learning things I didn't know.”* (Aretha, co-researcher)
- *“The participation of researchers with disabilities helped the research team to understand what is really relevant, by placing their voices at the center of the research process.”* (Patrícia, researcher)

(2) What ethical, methodological and practical challenges were faced and what opportunities were found?

Leave certainties behind and embark on the adventure

- *“The need to leave certainties and control over research planning behind and realize that inclusive research, although it guides us to where we want to go and how we want to get there, does not follow restrictive and predetermined paths. It implies many shortcuts, secondary paths, additional turns, which emerge during the research process itself and which we have to respond to. This could be said of all research, but becomes even more evident in inclusive research.” (Teresa, researcher)*

Time and budget constraints

- *“Inclusive research takes more time... and we don't always have the luxury of time. It is also expensive, and often the extra costs are not the typical ones in a research project. We've struggled a lot with those kinds of issues and although eventually we found ways to overcome them, they were very time-consuming and an unnecessary burden.” (Paula, PI)*

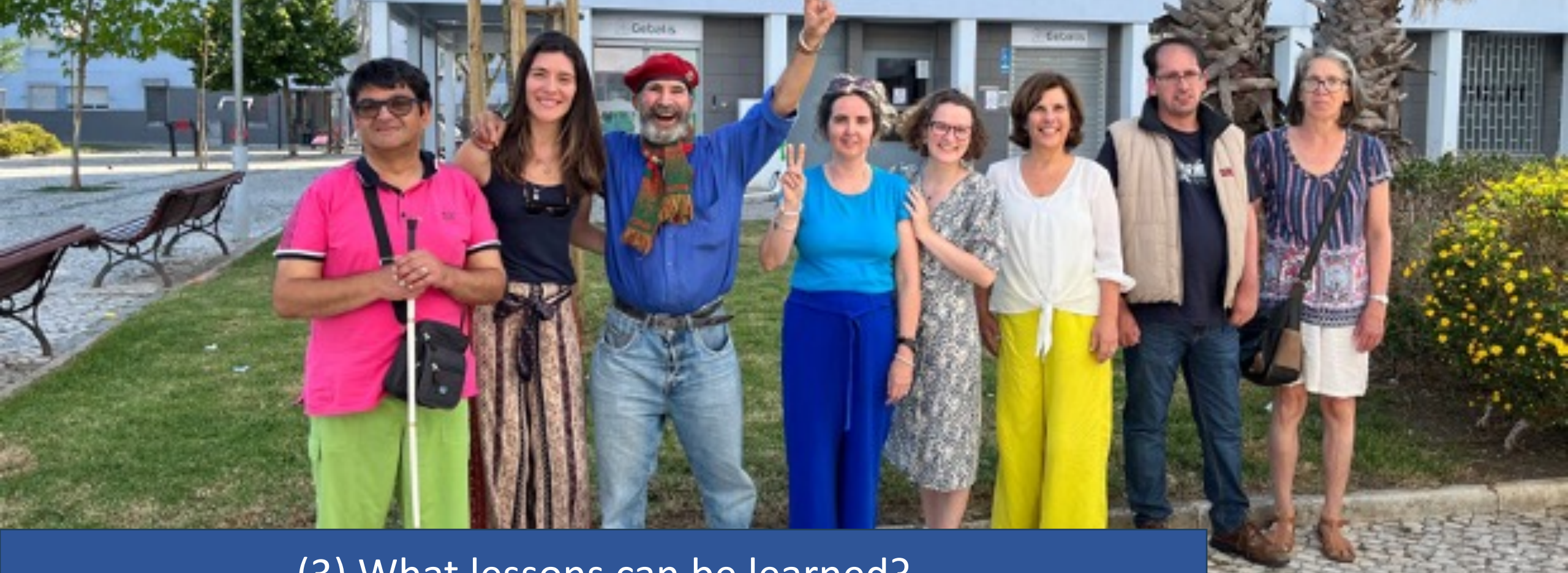
(2) What ethical, methodological and practical challenges were faced and what opportunities were found?

Ensuring accessibility throughout the research process

- *“As someone working for the first time on disability issues and as a member of a research team, the biggest challenge for me was to address everyone’s needs and make my communication accessible to all.”* (Bárbara, research assistant)

Ensuring that the research is truly inclusive

- *“I often questioned myself whether what we were doing was really inclusive research. Was I directing the research process too much? For one, the research question was decided before the involvement of the co-investigators and was non-negotiable since it had been contractually agreed with the funding agency. Not to mention the time and budget constraints... Under these conditions, how to ensure a truly inclusive research?”* (Paula, PI)



(3) What lessons can be learned?

- Reflexivity, sharing and openness as key ingredients
- Time is a fundamental resource too
- Definitely a worthwhile experience that we intend to pursue and expand

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Thank you.

Paula Campos Pinto
Teresa Janela Pinto
Patrícia Neca
Bárbara Maltez

mppinto@edu.ulisboa.pt
oddh@iscsp.ulisboa.pt



INSTITUTO SUPERIOR
DE CIÊNCIAS SOCIAIS
E POLÍTICAS
UNIVERSIDADE DE LISBOA

