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Disability and Independent Living in Portugal: policy changes and challenges

Fernando Fontes¹, Bruno Martins¹, Ema Loja², Mónica Lopes¹,
Joana Pimentel¹, Paula Pinto³, Silvia Portugal¹

1 - Centre for Social Studies, University of Coimbra, Portugal

2 - Faculty of Psychology and Education Sciences, University of Porto, Portugal

3 - Institute of Social and Political Sciences, University of Lisbon, Portugal

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This paper:

- 1. Setting the scene: disabled people's citizenship rights and opportunities in Portugal**
- 2. Disability policies in Portugal - promoting active citizenship?**
- 3. Independent Living for disabled people in Portugal: changes and challenges**



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1. Setting the scene:

1926 / 1974 – Dictatorship

civil and political rights revoked

Censorship

freedom of speech and freedom of gathering eradicated

labour rights limited

family models and gender roles imposed

Since 1974 – Third Republic

Construction of the Portuguese democratic regime

Reestablishment of civil and political rights

Recognition of disabled people as citizens

Welfare State development

The Portuguese Disabled People's Movement

Development

1920s – 1930s first organizations of disabled people (deaf and blind)

1972 – Portuguese Association of Disabled People (APD)

1974 – Association of Impaired War Veterans (ADFA)

1976 – National Association of People impaired in Work (ANDST)

1978 – 1st Meeting of Disabled People

1980 – 1st Congress of Disabled People

Coordinating Commission of Disability Organisations (CCNOD, later CNOD)

**1989 – Portuguese Association of Blind and Low Vision People
(ACAPO)**

1993 – Portuguese Federation of the Organizations of Deaf People

Disabled people in Portugal:

- **Higher health expenses** (double of non-disabled, however welfare-state health support is only 15% higher than non-disabled people)
- **Higher living costs** (Additional Living costs for DP in Portugal estimated 4103 € and 25 300 € per year)
- **Lower education levels** (37% of disabled people without formal education, compared to 26.4% of the general population)
- **More difficulties accessing the labour market** (Unemployment rate in Portugal – 1st trimester 2016: age active population = 12,4%; Youth people = 31%; disabled people = 45%)



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- **Lower activity rates** (2 times lower than non-disabled people; only 17,39% of people with at least 1 impairment of working age are employed)
- **Lower incomes** (working disabled people earn 37% than non-disabled people)
- **Higher poverty risk** (poverty risk of disabled people estimated to be 25% more than general population = 25.1% in 2016)
- **Higher physical barriers accessing society** (60% of people unable to walk or climb stairs living in buildings with 3 or more levels, have no lift and in 61% of the cases the main entrance is not wheelchair accessible) (**Decreto-Lei 43/82**)

Sources:

ICOR (2010); INE (2011); INE (2012); INE (2017); Pinto and Teixeira (2012); Portugal *et al.* (2010); Sousa, J *et al.* (2007)

**65,84% of disabled people are dependent on benefits
(INE, 2012)**

**!Problematic! Due to the reduced value of social benefits
and disability benefits in Portugal!**

Current major disability benefits:

Impairment lifelong pension – €177,64 / per month

Additional family support benefit in case of disabled children –
between €61,57 and €162,05

Special education benefit - €293,45 /per month

3rd person benefit – 101,68 /per month



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2. Disability policies in Portugal

Portuguese Welfare-state

- late development – post 1974
- *quasi*-welfare-state
- low levels of social protection
- low redistributive scheme
- low benefits
- non-universal
- based on diverse welfare-regimes
- balanced by a strong civil society

Characteristics of the Portuguese disability policies:

- **Needs-based not rights-based approach** (Law-Decree 160/80, 27/05/80) (distinction between contributory and non-contributory regimes; means-tested; different levels of generosity)
- **Low level of support provided** (low benefits, weak social redistribution, dependent on a strong civil society initiative and family dependency)
- **Lack of a unified disability policy** (several actors with articulation problems, different perspectives and responsibilities)
- **Presence of diverse and antagonist tendencies** (Containment, Compensation, Care, **Citizenship** – Drake, 2001)

Ex.

National disability anti-discrimination legislation (2006)

Announced changes in Portuguese disability policies: (October 2017)

- **Social Inclusion Benefit** (Prestação Social para a Inclusão -PSI)
3 components:

Basic component (cash benefit €264; universal access for people 18s old and above, with 80% or more of incapacity) - 2017

Complement component (additional cash benefit to combat poverty, on top of the basic component up to €423, means-tested) - 2018

Additional component – Majoração (cash transfer to support additional expenses resulting from the impairment; means-tested) – 2019

- **Independent Living Support Centers** (Centros de Apoio à Vida Independente - CAVIs) – Pilot project 2017-2020

Formation of CAVIs across Portugal
Hiring of Personal Assistances (PAs)



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3. Independent Living for disabled people in Portugal: changes and challenges

Means:

“all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community.”

(Barnes and Mercer, 2006: 33)

Doesn't mean:

That disabled people are self-sufficient, but that any practical support assistance required should be under disabled people's control.



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Principles of Independent Living for Disabled People:

- Self-determination
- Choice (where and how to live)
- Control (over support services – who, how and when provides support)
- Removal of disabling barriers from society

Challenges to the implementation of Independent Living for Disabled People in Portugal:

1 – Portuguese Society

- Prevailling disablism;
- Portuguese state features – delegation and over-reliance in civil society, inaction...;
- Long established and influential charity and NGO support system traditionally organised and managed by disability professionals;
- Characteristics of the Portuguese Disabled People's Movement (Lack of unity; Lack of collective spirit; Rooted till recently in the medical model; Political centrality of the impairment; Investment in 'first level demands'; lack of politicization; difficulty in mobilizing and reaching disabled people)

Challenges to the implementation of Independent Living for Disabled People in Portugal:

2 – Policy design

- Insufficient involvement of disabled people and their representative organizations in the framing of the measure (despite the earring process);
- EU funding (except for ineligible country áreas of Lisbon and the Algarve; time limited; money spending criteria compromises IL principles)
- non-direct payments to disabled people (limited choice and control over PA servisses and agents);
- Disabled People Limited Access (disabled people's abudget limit; 16 years old and above; minimum of 60% of incapacity; 5 days per week; maximum 40 hours of PA support per week (30% of people in each CAVI may exceed this maximum));
- Only open to the initiatives of Disability NGOs with the statute of IPSS – Private Institution of Social Solidarity (traditional service providers);

Challenges to the implementation of Independent Living for Disabled People in Portugal:

3 – Policy implementation

- Lack of politicization of disabled people in Portugal and lack of knowledge about Independent Living – may reduce initiatives;
- CAVIs initiatives dominated by traditional disability NGO sector (due to its greater dynamism in the identification of funding sources, greater awareness about policy innovation and qualified, full-time, human resources);
- Reproduction of country's asymmetries (geography of needs Vs geography of initiatives) and reproduction of disability and disabled people's stereotypes.
- Lack of integration between different government departments and education, employment, rehabilitation, housing, urban ... policies;
- Lack of political and financial investment to create sustainable and Independent Living promoting structures with positive changing effects in disabled people's lives.

Conclusions:

- ❖ **Disabled people's lives remain limited by a combination of physical, psychological and social barriers that prevent them from exercising their rights of citizenship and access an independent life as any other citizen;**
- ❖ **Disability policies in Portugal have been unable to challenge disablism and detach disability from poverty, dependency, inactivity...;**
- ❖ **Disabled People's Movement has been unable to coalesce into strategic political high impact disability demands;**
- ❖ **Success of new disability policies dependent on: the affirmation of the principle of social redistribution; adoption of the social model of disability and disability mainstreaming;**



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Thank you!

fernando@ces.uc.pt