



GAMES

People with Intellectual Disability in Portugal

Report

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Prevalence, Education, Employability and Social Exclusion

In 2011, the last nation-wide census in Portugal, the data regarding disability (based on diagnosis) were replaced by data regarding the individual's self-assessment of functionality, based on the dynamic interaction between the person and the context. About 17,79% of the citizens, over five years old, referred having major or total difficulties in performing at least one of the six daily activities (see/vision, hear, walk, memory/concentration, shower/get dressed, understand/make themselves understood). In population over 65 years old, this number increases to 49,51%. The daily life activity more often pointed out as difficult is walking (25% in the above five years old group; 27% in the above 65 years old group), followed by see/vision (23% in the above five years old group; 19% in the above 65 years old group); and memory/concentration (17% in the above five years old group; 15% in the above 65 years old group) (INE, 2012, p.27).

Considering that such data does not establish a panorama regarding the citizens with disability, neither regarding people with Intellectual Disability (pwID), it is important to consider the number regarding the financial support granted by the state to such people. In 2018, 93916 citizens with disability (or their families) received social security's financial support, with an average of 62,37 euros for each citizen, and a total 89931,1 spent by the state in this type of payment (FFMS, 2019a; 2019b; 2019c).

In the field of education (basic and secondary), the Portuguese educational system suffered profound changes in the 2018/2019 school year, with the replacement of the previous Special Education Needs (SEN) legal framework by the new Inclusive Education Legal Regime. This approach is based on a flexible curriculum, in the continuous monitoring of the implemented interventions, and in a constant dialogue between stakeholders (family, school, support teams), and replaces an approach based on diagnosis and categorization of students as the main intervention motor (Decreto-lei nº 54/2018). Such changes are believed

to better fit in the Convention on the Rights of Persons with Disabilities premises, signed by Portugal in 2007, which commits states to the promotion of “an inclusive education system at all levels” (Pinto & Pinto, 2018, p. 12). On the other hand, in the field of higher education, only about half of higher education institutions foresee adaptations and resources to support students with disabilities (Pinto & Pinto, 2018, p. 21). In 2016/2017, 1644 student with disabilities enrolled in higher education, 91% in public institutions and 9% in private institutions (Pinto & Pinto, 2018, p. 20). Data regarding their achievement and inclusion in higher education institutions are still needed.

Regarding employability, the Portuguese legal and political frameworks include measures to support employment and vocational training aimed at people with disabilities, regulated by a specific government program (*Programa de Emprego e Apoio à Qualificação das Pessoas com Deficiência*). Additionally, since 2001 an employment quota system for people with disabilities was implemented in public administration (Pinto & Pinto, 2018, p. 24). Nevertheless, in 2016, the activity rate of people with disabilities in Portugal was much lower than that of people without disability (66,7% and 85,7%, respectively). At that time, people with disability represented 0,51% of the human resources, in companies over 10 employees, and in 2017 represented 2,41% of the public administration employees (Pinto & Pinto, 2018, p. 6).

In 2016, the risk of poverty or social exclusion was significantly higher in people with disability, both in the 16-64 age group (38,2%; 16% higher than in the same age group without disability), as in the 65 and above age group (24,8%; 8,2% higher than in the same age group without disability). These values are also higher than the European Union (EU) numbers for both age groups (Pinto & Pinto, 2018, p. 47). Noteworthy is the lack of statistics and specific numbers, related to pwID to support priority setting and policy-making to such population.

Paradigm shifts, intervention and institutions

As in other countries, in Portugal the social paradigms related to pwID evolved from social charity to social citizenship (Fontes, 2009). Such paradigm shift was mainly organized in four chronological phases, exclusion – segregation – integration – inclusion (Emygdio da Silva, 2009), accompanied by an evolution in the type of responses and interventions made available to pwID. Another important evolution was in the assessment and characterization of this population, from a medical point of view, mainly based on diagnosis and psychometry, to an assessment based on the description of the subjects' functionality, despite the underlying neurodevelopmental causes of the disability (Emygdio da Silva & Coelho, 2014). These changes framed the above-mentioned changes in the educational system, and mainly conceptualize interventions in this field as providers of the necessary support to help pwID overcome difficulties, as well as strategies to remove the barriers faced in their daily lives (Emygdio da Silva & Coelho, 2014). Nowadays, the interventions are being increasingly developed considering the subjects with ID as active agents in their lives, highlighting the role of self-concept (Fonseca et al, 2019), self-determination (Leitão, 2015), empowerment and social participation (CRPG & ISCTE, 2007), as central to autonomy and well-being.

In Portugal, the interventions and responses to pwID are mainly divided in the ones conceived to include children and youth and the ones conceived to adults. In the field of early childhood, the public policies are mainly framed in the Childhood Early Intervention National System (*Sistema Nacional de Intervenção Precoce na Infância – SNIPI*). This system includes children younger than six years old, assessed by multidisciplinary teams, that develop and monitor individual intervention programs, developed considering the subject specific needs. This system intends to be of universal access, is coordinated by the Health Ministry and aims to harmonize the children's inclusion in preschools, kindergartens and other educational responses (Decreto-lei nº 281/2009).

When a kid enters the educational system, after 1st grade, the individual supports, interventions and adaptations to the learning process are framed in the above-mentioned Inclusive Education Legal Regime (Decreto-lei nº 54/2018). These interventions are negotiated between the schools' multidisciplinary teams and the professionals from the Resources Centres for Inclusion (*Centros de Recursos para a Inclusão* - CRI). This type of centres are a recent type of social support to pwID, specifically children and youth, coordinated by People with Disability's Non-Governmental Organizations (PDNGO), and funded by the Ministry of Education. CRI's multidisciplinary teams are typically composed by psychologists, occupational therapists, speech therapists and physiotherapists (Pinto, 2015).

In the field of adult intervention, there are several types of interventions available on the public system, funded by Social Security (*Segurança Social*) and coordinated by PDNGO. The inclusion on each subject on a type of intervention largely depends on the support needs (considering the level of autonomy), but also on the existing support networks (mainly family) and the available vacancies in the system, that are frequently below the citizens' needs (Pinto & Pinto, 2018, p. 56). The existing types of interventions/social support include: protected employment; adapted vocational training; domiciliary support to daily life activities; occupational activities centres (*Centros de Atividades Ocupacionais* – CAOs); and residential support (including autonomous homes and fully supported homes) (DGSS, 2018).

Even though autonomous homes are a type of support much more framed in the above discussed empowerment paradigm, the number of users is residual ($N = 348$), when compared to the number of pwID included in fully supported homes ($N = 6659$) (Pinto & Pinto, 2018, p. 57). CAOs are also a very relevant type of social response for pwID with 15558 users in 2018 (Pinto & Pinto, 2018, p. 58). Its intervention is intended to include individuals above 16 years old with severe disabilities, aiming to promote significant

occupational activities, self-esteem, autonomy, activities of daily living support, and the transition to employment (when applicable) (DGSS, 2018).

Multidisciplinary teams in this type of intervention models frequently include: social workers; psychologists; occupational therapists; speech therapists; physiotherapists; psychomotricity technicians; nurses; psychiatrists; neurologists; and general practitioners, that cooperate in the development of individual interventions plans, formal instruments aimed at organizing, operationalize and integrate all responses to the development needs and potentials identified together with the user (SS, 2007).

Main Institutional Stakeholders and Projects

In addition to the pwID and their families, there are several stakeholders in Portugal who work to guarantee the rights and well-being of these people at macro level. When considering citizens above 16 years old, the main funder in the field of support to pwID is, as above-mentioned, the Social Security system (*Instituto da Segurança Social - ISS*). Under this system the National Rehabilitation Institute (*Instituto Nacional para a Reabilitação - INR*) is one of the most relevant stakeholders, with the mission of ensuring the planning, implementation and coordination of national policies to promote the rights of people with disabilities (Decreto-Lei n.º 31/2012).

Although most of the funding to pwID support and interventions is mainly from government institutions, such as ISS or INR, these institutions have a more regulatory role, being the social equipment and interventions leaded by PDNGOs. According to INR, in 2019 there are 193 registered PDNGO in Portugal.

Most of the existing PDNGOs were created in the 70s by parents, professionals and other carers of pwID, and are called CERCIs, even though they are not the only institutions in the field. All over the country, 52 CERCIs ensure direct and indirect support to almost eight

thousand pwID, through several types of interventions. FENACERCI is another crucial stakeholder, being a federation of all the CERCIs, with the mission to ensure the quality and sustainability of the associated institutions and having an important role in the fields of ethics, human rights, training, research development and dissemination (FENACERCI, n.d.).

There are also other relevant projects to the rights of pwID in Portugal such as: the disability and human rights observatory (*Observatório da Deficiência e Direitos Humanos – ODDH*), aiming to “follow-up the development of disability policy in Portugal and Portuguese-speaking countries and to promote participatory processes of monitoring and promotion of disability rights” (ODDH, n.d.); and the project Support Model to Independent Living (*Modelo de Apoio à Vida Independente – MAVI*), financed by the government and aimed at providing support to people with disabilities in their own home, by specialized carers (Decreto-Lei n.º 129/2017).

In the field of action-research, and although there a lack of projects in this field compared to other areas, it is possible to highlight some developments, such as the IDP LIVING project (funded by Erasmus+); the MINCE project (funded by Erasmus+); or the TOPSIDE project (funded by the European Commission DG Education and Culture – LifeLong Learning Programme). Most of these projects mainly aim at the promotion of social inclusion, through participatory processes and through the creation of conditions to an independent life for pwID.

References

CRPG – Centro de Reabilitação Profissional de Gaia & ISCTE – Instituto Superior de Ciências do Trabalho e da Empresa (2007). *Enhancing the Quality of Life of People with Disabilities – A Strategy for Portugal*. Vila Nova de Gaia, Portugal: CRPG.
Retrieved from: <http://www.cprg.pt/estudosProjectos/Documents/Estudos13.pdf>

Decreto-lei nº 281/2009, 6th October. *Diário da República nº 193/2009 – Série I*. Lisbon,

Portugal: Ministério da Saúde. Retrieved from:

<https://dre.pt/application/conteudo/491397>

Decreto-Lei n.º 31/2012, 9th February. *Diário da República nº 29/2012 – Série I*. Lisbon,

Portugal: Assembleia da República. Retrieved from:

<https://dre.pt/application/conteudo/175305>

Decreto-lei nº 129/2017, 1st August. *Diário da República nº 194/2017 – Série I*. Lisbon,

Portugal: Trabalho, Solidariedade e Segurança Social. Retrieved from:

<https://dre.pt/application/conteudo/108265124>

Decreto-lei nº 54/2018, 1st August. *Diário da República nº 129/2018 – Série I*. Lisbon,

Portugal: Presidência do Conselho de Ministros. Retrieved from:

<https://dre.pt/application/conteudo/115652961>

Direção-Geral da Segurança Social – DGSS (2018). *Proteção Social – Pessoas com*

deficiência. Lisbon, Portugal: DGSS. Retrieved from: [http://www.seg-](http://www.seg-social.pt/documents/10152/113014/Guia_protecao_pessoas_deficiencia.pdf/a23397)

[social.pt/documents/10152/113014/Guia_protecao_pessoas_deficiencia.pdf/a23397](http://www.seg-social.pt/documents/10152/113014/Guia_protecao_pessoas_deficiencia.pdf/a23397)

[ca-eace-426a-98e5-01dfbab4315a](http://www.seg-social.pt/documents/10152/113014/Guia_protecao_pessoas_deficiencia.pdf/a23397)

Emygdio da Silva, M. O. (2009). Da Exclusão à Inclusão: Concepções e Práticas. *Revista*

Lusófona de Educação, 13, 135-153.

Emygdio da Silva, M. O. & Coelho, F. (2014). Da deficiência mental à dificuldade intelectual

e desenvolvimental. *Revista Lusófona de Educação*, 28, 163-180.

FENACERCI (n.d.). *Fenacerci | O Movimento CERC* - O aparecimento das primeiras

CERCIS. Retrieved from: <https://www.fenacerci.pt/web/fenacerci/movimento.html>

FFMS (2019a). *Prestações familiares da Segurança Social - Quantas famílias recebem o*

abono de família, a bonificação por deficiência ou os subsídios mensal vitalício, de

morte e funeral ou de assistência de terceira pessoa?. Lisbon, Portugal: PORDATA.

Retrieved

from:

[https://www.pordata.pt/Portugal/Presta%
c3%a7a+Social-122-453](https://www.pordata.pt/Portugal/Presta%c3%a7%c3%b5es+familiares+da+Seguran%c3%a7a+Social-122-453)

FFMS (2019b). *Valores mensais de algumas prestações familiares da Segurança Social - Qual o montante mensal que as famílias recebem da Segurança Social em abono de família, bonificação por deficiência ou subsídios mensal vitalício, de morte e funeral ou de assistência de terceira pessoa?*. Lisbon, Portugal: PORDATA. Retrieved from: [https://www.pordata.pt/Portugal/Valores+mensais+de+algumas+presta%
c3%a7a+Social-115-3453](https://www.pordata.pt/Portugal/Valores+mensais+de+algumas+presta%
c3%a7a+Social-115-3453)

FFMS (2019c). *Despesa da Segurança Social: subsídios à infância e à família, por tipo - Quanto gasta a Segurança Social com o abono de família, a bonificação por deficiência ou os subsídios mensal vitalício, de morte e funeral ou de assistência de terceira pessoa?*. Lisbon, Portugal: PORDATA. Retrieved from: [https://www.pordata.pt/Portugal/Despesa+da+Seguran%c3%a7a+Social+subs%
c3%adidos+%c3%a0+inf%
c3%a2ncia+e+%c3%a0+fam%
c3%adlia++por+tipo-121-445](https://www.pordata.pt/Portugal/Despesa+da+Seguran%c3%a7a+Social+subs%
c3%adidos+%c3%a0+inf%
c3%a2ncia+e+%c3%a0+fam%
c3%adlia++por+tipo-121-445)

Fonseca, I., Almeida, B., Roldão, S., Jesus, R., Lopes, J., Santos, S. (2019). Self-concept in persons with Intellectual and Developmental Disability in Portugal: A systematic review. *Análise Psicológica*, 37(1), 53-70. <http://dx.doi.org/10.14417/ap.1550>

Fontes, F. (2009). Pessoas com deficiência e políticas sociais em Portugal: Da caridade à cidadania social. *Revista Crítica de Ciências Sociais*, 86, 73-93.

Instituto Nacional de Estatística (INE) – Statistics Portugal (2012). *Censos 2011 Resultados Definitivos – Portugal*. Lisbon, Portugal: INE. Retrieved from: [https://censos.ine.pt/xportal/xmain?xpid=CENSOS&xpgid=ine_censos_publicacao_d
et&contexto=pu&PUBLICACOESpub_boui=73212469&PUBLICACOESmodo=2&sel
Tab=tab1&pcensos=61969554](https://censos.ine.pt/xportal/xmain?xpid=CENSOS&xpgid=ine_censos_publicacao_d
et&contexto=pu&PUBLICACOESpub_boui=73212469&PUBLICACOESmodo=2&sel
Tab=tab1&pcensos=61969554)

Leitão, G. (2015). Promoção da autodeterminação em pessoas com deficiências e incapacidades. Unpublished master's thesis, Faculdade de Psicologia e de Ciências

da Educação, Universidade de Coimbra, Coimbra, Portugal. Retrieved from:

[https://estudogeral.sib.uc.pt/bitstream/10316/32434/1/TESE%20MIP%20-%20Gra%
c3%a7a%20Leit%
c3%a3o.pdf](https://estudogeral.sib.uc.pt/bitstream/10316/32434/1/TESE%20MIP%20-%20Gra%c3%a7a%20Leit%c3%a3o.pdf)

ODDH (n.d.). *Goals*. Retrieved from: <http://oddh.iscsp.ulisboa.pt/index.php/en/2013-01-30-11-59-26/goals>

Pinto, C. F. (2015). A Importância do CRI na Promoção da Inclusão de Crianças com Necessidades Educativas Especiais: Estudo de Caso. Unpublished master's thesis, Escola Superior de Educação, Instituto Politécnico de Castelo Branco, Castelo Branco, Portugal. Retrieved from:

[https://repositorio.ipcb.pt/bitstream/10400.11/3067/1/Cristela%20Ferreira%20Pinto
TESE_FINAL.pdf](https://repositorio.ipcb.pt/bitstream/10400.11/3067/1/Cristela%20Ferreira%20Pinto_TESE_FINAL.pdf)

Pinto, P. C. & Pinto, T. J. (2018). Pessoas com deficiência em Portugal: Indicadores de Direitos Humanos 2018. Lisbon, Portugal: Observatório da Deficiência e Direitos Humanos - Instituto Superior de Ciências Sociais e Políticas. Retrieved from:

[http://oddh.iscsp.ulisboa.pt/index.php/pt/2013-04-24-18-50-23/publicacoes-dos-
investigadores-oddh/item/387-relatorio-oddh-2018](http://oddh.iscsp.ulisboa.pt/index.php/pt/2013-04-24-18-50-23/publicacoes-dos-investigadores-oddh/item/387-relatorio-oddh-2018)

Segurança Social – SS. (2007). Centro de Atividades Ocupacionais - Manual de Processos-Chave. Lisbon, Portugal: Segurança Social. Retrieved from: [http://www.seg-
social.pt/documents/10152/13475/gqrs_cao_processos-chave/4b052a99-b321-494f-
9735-16332f7d1a41](http://www.seg-social.pt/documents/10152/13475/gqrs_cao_processos-chave/4b052a99-b321-494f-9735-16332f7d1a41)