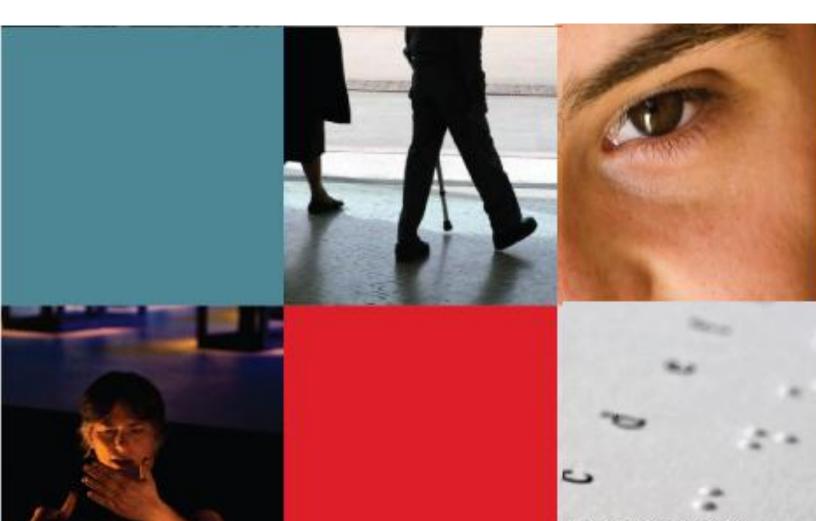
DISABILITY
RIGHTS
PROMOTION
INTERNATIONAL
Portugal

DRPI-Portugal Final Report



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^{2 |}

² In addition to the Advisory Board members, these entities were as follows: APPACDM-Gaia, Associação de Saúde Mental do Algarve (ASMAL), Associação Nacional dos Deficientes Sinistrados no Trabalho (ANDST), Associação Tempus, Silves Municipal Council, Porto Municipal Council, Fundação Irene Rolo and Novamente.

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Introduction

Rationale of the project

The latest United Nations estimates point to around 650 million persons with disabilities worldwide. Available studies in Portugal refer to percentages between 6.13% (2001 Census) and 9.16% (INIDD). This means that there are a significant number of persons in Portugal facing the challenges of disability every day. While the few studies carried out in Portugal to date disagree on the statistical extent of this population, they are in agreement on social inclusion and exclusion indicators, which suggest a scenario of discrimination and social inequality. Very low levels of school attainment and qualifications, low economic activity rates, accentuated patterns of segregation in the employment market for the few who have access to it and very low incomes are all features of the experience of disability in Portugal, that incipient research into the issue is beginning to reveal (Gonçalves 2003; Sousa et al 2007). These inequalities are accentuated by other aspects of social differentiation, such as age and gender (Pinto 2009).

This picture of exclusion and inequality is a demonstration of violation of fundamental human rights, but the truth is that in Portugal (as in other countries) persons with disabilities have remained 'invisible citizens' and this invisibility has done nothing to help make disability issues a priority for political action or social research. There is an urgent need to turn this situation around and this is the ideal time to do it. Recognising the countless barriers that persons with disabilities have to face all over the world, in 2006 the United Nations adopted the International Convention on the Rights of Persons with Disabilities and Optional Protocol³. The Convention and its Protocol garnered a considerable number of signatures from the outset (including Portugal) and came into effect in May 2008. They were ratified by Portugal in July 2009.

 $^{^{\}rm 3}$ Henceforward referred to as the Convention

They are therefore international legal instruments that are directly and immediately applicable under Portuguese law.

The new Convention does not create new or special rights for persons with disabilities. What it does is explain the extent to which all categories of human rights (civil, cultural, economic, political and social) apply to this group and identifies the areas in which adaptations are necessary for these rights to be exercised. The Convention therefore constitutes the beginning of a new stage in which we are all faced with the challenge of putting written guidelines into practice and creating actual conditions for all persons with disabilities to enjoy a life of dignity in full equality with other citizens.

Measuring progress will be essential in this process of legal and social change that the new Convention will be able to speed up. Indeed, the Convention contains provisions on the implementation of monitoring systems. For example, Article 33 (2) and (3) obliges States Parties to set up independent monitoring structures or agencies and involve civil society in general and persons with disabilities in particular in these processes:

States Parties shall (...) maintain, strengthen, designate or establish within the State Party a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention.

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

States Parties are also obliged to submit periodic reports on the measures taken to give effect to their obligation under the Convention (Article 35). The first report must be sent two years after the entry into force of the Convention in the country in question and subsequent reports must be submitted every four years.

It is thus mandatory to create appropriate instruments for collecting this information and set up inclusive mechanisms for monitoring existing policies

and any measures that are implemented. This is a task to which researchers, politicians and disability organisations all over the world are currently committed.

DRPI - Disability Rights Promotion International is a project that has been developing and testing methodologies for this work since 2002. DRPI involves broad partnerships that include universities, disability and other human rights organisations and representatives of official departments and has already started up pilot projects all over the world⁴. The aim of this project was to lay the foundations for the DRPI initiative in Portugal.

Partners involved

The DRPI-Portugal project is based on collaboration between the Centre of Administration and Public Policies belonging to the School of Social and Political Sciences at the Technical University of Lisbon, Fundação Calouste Gulbenkian and Instituto Nacional para a Reabilitação, I.P. in partnership with organisations representing all areas of disability. These organisations, which were indicated by Conselho Nacional para a Integração e Reabilitação de Pessoas com Deficiência, belong to the DRPI-Portugal Advisory Board. The Advisory Board was involved in all phases of the project and was particularly important in the selection of participants in training, the recruitment of potential interviewees, the discussion of the monitoring results and the drafting of recommendations. The following organisations are on the DRPI-Portugal Advisory Board (in alphabetical order): Associação de Cegos e Amblíopes de Portugal (ACAPO), Associação de Pais para a Educação de Crianças Deficientes Auditivas (APECDA), Associação Portuguesa de Deficientes das Forças Armadas (ADFA), Associação Portuguesa de Hemofílicos (APH), Associação Portuguesa de Deficientes (APD), Federação Portuguesa das

⁴ For access to reports and other information on the project go to www.yorku.ca/drpi

Associações de Surdos (FPAS), Federação das APPC, FENACERCI and Fundação LIGA.

Aims of the project

In order to ascertain the full extent of forms and processes of discrimination against persons with disabilities, the monitoring of DRPI projects involves three types of research:

- An individual focus, which entails collecting data on the human rights situation in the everyday lives of persons with disabilities
- A systemic focus, which involves studying national legislation, collecting
 and analysing government policies and programmes that impact the lives
 of persons with disabilities and gathering and examining case law on
 disability and assessing its compliance with the Convention's provisions
 and principles
- Focus on the media, to research how they address the issue of disability in order to ascertain how it is regarded in the collective imagination

Monitoring instruments were developed and tested for each of these areas. They were designed to document forms of disability discrimination in light of international human rights instruments and particularly the International Convention on the Rights of Persons with Disabilities.

The field of intervention of the DRPI-Portugal initiative was limited, as it was an annual project. The aim was essentially to lay the foundations for a system to monitor the rights of persons with disabilities in Portugal. One of the main tasks was translating, adapting and drafting DRPI training manuals, methodologies and data collecting tools into Portuguese to pave the way for

future systematic monitoring of laws and policies, social practices and media representations of disability in Portuguese society in light of human rights and particularly the International Convention on the Rights of Persons with Disabilities.

We considered it appropriate to illustrate the applicability of the DRPI monitoring method in a pilot scheme in which we could put into practice the project's tools and work principle. We chose two fields of intervention:

- a) **Capacity building of** persons with disabilities and organisations in the sector by means of training for participation in monitoring
- b) **In-depth interviews** to monitor individual experiences in access to human rights and analyse and discuss them

A third goal was added to these two, as a result of articulation with ANED – Academic Network of European Experts on Disability, in which the ISCSP research team is also involved in representation of Portugal. This project, which supports the implementation and monitoring of the Convention in the EU, has developed a tool for monitoring the Convention and we were asked to use it in Portugal. The data collected were utilised twice, not only to add to the ANED database but also to frame and cross-reference the results obtained in the DRPI in-depth interviews. We describe them in the second part of this report.

Methodology

An essential dimension of all DRPI projects is the empowerment and capacity building of persons with disabilities as individual and collective players by encouraging their participation in monitoring processes. This is achieved by directly involving disability organisations in all stages of the project.

As mentioned above, the member organisations of the DRPI-Portugal Advisory Board helped to select the participants in training and the recruitment of interviewees and assisted in the analysis and dissemination of data.

Three training courses addressed the monitoring process and the subject of disability from a human rights point of view and prepared the participants to use the DRPI interview script. The fact that the majority of these trainees were also persons with disabilities is an asset in the DRPI approach in that it creates an atmosphere of mutual trust, empowerment and empathy between interviewers and interviewees that facilitates the sharing of experiences while maintaining methodological integrity.

As part of the DRPI-Portugal project, 32 adults with different types of disability were interviewed in three regions of the country: Lisbon, Porto and the Algarve. The size of the sample was considered appropriate to the nature of the research, which focuses essentially on an understanding of the *sense*, *context* and *processes* in the human rights experiences of persons with disabilities. In light of this perspective, a qualitative approach using intensive, in-depth interviews of relatively small samples has been the choice in DRPI projects rather than a quantitative approach based on large samples. While it is true that the sample used is not statistically representative of the Portuguese population with disabilities, in view of the care taken in recruiting the participants and the meticulous qualitative method used to gather and analyse the data, we were able to obtain in-depth information giving a detailed picture of the obstacles facing persons with disabilities in the exercise of their human rights.

The participants were recruited through the partner organisations in a mixed approach combining the snowball technique, a sampling strategy recognised as able to reach marginal and isolated groups (Lopes et al, 1996), with

statistically non-representative stratified sampling (Trost, 1986). Trost's technique (1986) guarantees maximum diversity in the independent variables most relevant to the study objectives, thereby ensuring control of potential bias in the snowball sampling. Three independent variables were identified as being fundamental in this research: type of disability, sex and age group. A grid combining type of disability with each of the other two variables was constructed. Using the available statistics on persons with disabilities in Portugal, the desirable number of interview subjects was entered into the different cells in the grid. The snowball technique was used to recruit the participants from the partner organisations, taking account of the criteria set out in the grid. The interviews were only conducted after the potential interviewees had agreed and given their informed consent.

The semi-structured interview began with two comprehensive questions: "What has given you the most satisfaction in life in the last five years?" and "What are the main obstacles or barriers that you have had to face?" The interviewees normally mentioned two or three situations that the interviewers went into further for an understanding of their interconnections with human rights. This format had the advantage of allowing the interviewees to choose the subject they wished to address. Instead of imposing a battery of questions and preparing the respondents to focus on specific violations of their human rights, the DRPI interview script helped the researchers to understand the significance of human rights in the lives of persons with disabilities.

The interviews lasted around an hour and were recorded. They were then transcribed in full, coded and analysed with NVivo 8 software. A coding grid, which was also developed for the international project, was used in the coding and analysis of the data. The grid was made up a number of themes and subthemes, which in turn were divided into codes. The title of the main theme was *Implications on Human Rights*. The theme covered the interviewees' accounts from a human rights viewpoint. The subthemes categorised accounts

of their life experiences in eight fields: access to justice, education, privacy and family life, economic security and social support, information and communication, social participation, health, treatment and rehabilitation, and work. In each of these fields, the codes covered the existence or denial of five human rights principles: autonomy, dignity, participation, inclusion and accessibility, non-discrimination and equality, and respect for difference. The coding grid provided a detailed definition of the significance of each of these codes at its positive (compliance with the principle) and negative pole (violation or denial). In addition to this theme, individual responses to situations of abuse and discrimination and perceptions of the systemic causes of disability discrimination were also examined.

Some of the results obtained in the study are described below.

I. Monitoring of individual experiences in Portugal

Table 1 Sample characteristics

| CHAR | ACTERISTICS | MALE | FEMALE | TOTAL |
|--------------------|--------------------------|------|--------|-------|
| SEXO | | 17 | 15 | 32 |
| | 18-25 | 2 | 1 | 3 |
| AGE GROUP | 26-40 | 4 | 9 | 13 |
| AGE GROOP | 41-55 | 8 | 1 | 9 |
| | 56-70 | 3 | 2 | 5 |
| | Mobility | 10 | 6 | 16 |
| | Psychiatric | 0 | 2 | 2 |
| TYPE OF DISABILITY | Blind and low vision | 2 | 3 | 5 |
| TIPE OF DISABILITY | Deaf and hard-of-hearing | 1 | 2 | 3 |
| | Multiple | 2 | 1 | 3 |
| | Intellectual | 2 | 1 | 3 |
| | 1st Cycle | 4 | 1 | 5 |
| | 2nd Cycle | 3 | 3 | 6 |
| | 3rd Cycle | 3 | 1 | 4 |
| EDUCATION | Secondary | 2 | 3 | 5 |
| | Technique | 1 | 4 | 5 |
| | Higher education | 3 | 3 | 6 |
| | No education | 1 | 0 | 1 |
| | No occupation | 3 | 2 | 5 |
| | Paid occupation | 7 | 9 | 16 |
| OCCUPATION | Unpaid occupation | 4 | 3 | 7 |
| | Retired | 2 | 1 | 3 |
| | other | 1 | 0 | 1 |

1. Sample characteristics

Thirty-two interviews were conducted in three regions: Porto (9 interviews, or 28%), Lisbon (13 interviews, or 41%) and the Algarve (10 interviews, or 31%). The sample was balanced and diversified for the three independent variables considered relevant to this research (see Table 1). It comprised an adult population of both sexes aged from 18 to 70 years, with greater incidence in the 26-40 age group, which was also the most comprehensive. All types of disability were represented, though with a prevalence of mobility impairments.

In the majority of the cases (28), the interviewees had had a relatively long experience of disability, having been disabled for more than five years. The sample was also evenly distributed in all levels of academic qualifications, the highest being higher education. If we add to this indicator the fact that the majority of the interviewees had a paid occupation, we can conclude that this sample represented a relatively privileged group, with a higher standard of living that most persons with disabilities, as available statistics on the disabled population in general indicate low school attainment and employment (Sousa et al, 2007). The experiences of discrimination and human rights violations that this study identifies may therefore be even more significant.

2. Results

2.1 Access to the principles of human rights

"A person with a disability doesn't have the right to be happy, they think. We think we do. By birth or due to illness, a person has the right to be happy. Whether or not a person is disabled, whatever their race, a person has the right. Persons have to accept us as we are and the way we are." (Man, 31)

The individual human rights experiences reported by the interviewees covered all the fields of life analysed, with the exception of access to justice, though there was a greater preponderance of experiences in the areas of *social participation* (all interviews), *economic security and support services* (25 interviews or 78%) and *work* (19 interviews or 59%), as shown in Table 2. These three areas were thus the most relevant to the interviewees' quality of life.

Table 2 Human rights experiences by domain of life

| Domain of life | Number of persons | Percentage |
|-----------------------------------------|-------------------|------------|
| Social Participation | 32 | 100,0 |
| Income Security and Support Services | 25 | 78,1 |
| Work | 19 | 59,4 |
| Information& Communication | 12 | 37,5 |
| Health, Habilitation and Rehabilitation | 12 | 37,5 |
| Privacy and Family Life | 10 | 31,3 |
| Education | 7 | 21,9 |
| Access to Justice | 0 | 0,0 |

On the other hand, there were few experiences reported in the field of education (7 interviews, or 22%). This can be explained by the sample's characteristics and particularly by the small number of persons in the youngest age group, probably closest to school age, and the predominance of interviewees with paid occupations. The interviews described the support and obstacles experienced by persons with disabilities at different moments in their daily lives and their implications on their human rights. In all the fields analysed, the interviewees described more barriers than support in the exercise of their human rights especially in the areas of social participation, economic security and support services and work, which were identified as the most problematic and cause for concern.

The accounts given in the different fields in question reflect the deprivation or exercise of human rights that these persons experience in their daily lives. The highest incidence in many stories was of negative experiences of violations or denial of rights with multiple disadvantages and harmful effects on the quality of life and wellbeing of persons with disabilities in Portugal (see Table 3).

According to the data in Table 3, exclusion and disrespect for difference are the most common forms of violation of human rights, while lack or limitation of personal autonomy was that mentioned least. Among the positive experiences, inclusion and accessibility and respect for difference were the main principles, as opposed to dignity, which was mentioned by only a few interviewees. The results are shown in more detail below and the reports are analysed on the basis of each of the five principles of human rights: respect for difference; non-discrimination and equality; participation, inclusion and accessibility; dignity; and autonomy.

Table 3 Reports of the principles of human rights

| Table 3 Reports of the principles of numan rights | | | | | |
|---------------------------------------------------|-------------------------------------|-------------------|------------|--|--|
| Principles of Hu | | | | | |
| | | Number of persons | Percentage | | |
| Dignity | Dignity | 2 | 6,3 | | |
| | Lack Of Dignity | 26 | 81,3 | | |
| Autonomy | Self-Determination | 4 | 12,5 | | |
| | Lack of Autonomy | 14 | 43,8 | | |
| Participation, Inclusion & | Inclusion and Accessibility | 22 | 68,8 | | |
| Accessibility | Exclusion and Lack of Accessibility | 30 | 93,8 | | |
| Non-discrimination & Equality | Non-discrimination and Equality | 6 | 18,8 | | |
| | Discrimination and Inequality | 27 | 84,4 | | |
| Respect for Difference | Respect for difference | 12 | 37,5 | | |
| | Disrespect for difference | 31 | 96,9 | | |

Respect for difference

"There's not a disabled person on the face of the earth who hasn't been labelled at some time or other. Look at the cripple, the blind man or the poor soul." (Man, 53)

In this research, from a human rights point of view, respect for difference involved recognition and acceptance of persons with disabilities as an integral part of human diversity. Stereotyping or labelling of persons on the basis of their disability was therefore considered disrespect for difference, as was lack of appropriate attention to the needs arising from the interviewees' physical and sensory disabilities.

According to the reports, preconceptions and stereotypes regarding persons with disabilities occurred in all the fields analysed, thought they were more predominant in the areas of *social participation* and *economic security and social support*, as shown in Table 4.

The existence of pejorative social representations of disability was one of the main factors limiting opportunities for inclusion and social participation for persons with disabilities. Although the most references in terms of social participation were to situations of *respect for difference*, there were three times more negative than positive reports.

Table 4 Human rights principles - respect for difference

| RESPECT FOR DIFFERENCE | | | | | |
|-----------------------------------------|------------------------|------------|---------------------------|------------|--|
| Domain of Life | Respect for Difference | | Disrespect for Difference | | |
| Domain of Life | Number of persons | Percentage | Number of persons | Percentage | |
| Privacy and Family Life | 0 | 0,0 | 3 | 9,4 | |
| Education | 0 | 0,0 | 5 | 15,6 | |
| Work | 2 | 6,3 | 10 | 31,3 | |
| Social Participation | 8 | 25,0 | 25 | 78,1 | |
| Information&Communication | 1 | 3,1 | 4 | 12,5 | |
| Income Security and Support Services | 3 | 9,4 | 14 | 43,8 | |
| Health, Habilitation and Rehabilitation | 1 | 3,1 | 10 | 31,3 | |

Negative, derogatory images of disability also arise in access to and progression in employment of persons with disabilities, as one of the interviewees told us:

"I was invited for an interview. When they asked for my medical report, the man read it and sent me away very kindly. I think there's a very clear label associated with cerebral palsy." (Woman, 26)

Violation of the principle of respect for difference was also demonstrated by the failure of goods and services to respond appropriately to the needs of persons with disabilities. This situation is particularly blatant in home support services, which are currently based on the stereotyped assumption that persons with disabilities have no productive activity and have no work schedules or responsibilities. This does not correspond to the daily lives of many persons with disabilities, who study, work and are involved in many outside activities. The gap between the support needs for an independent life and the response capacity of existing services therefore constitutes disrespect for difference, as illustrated by the following excerpt:

"My daily personal hygiene takes a while and the service only starts at 8 a.m., that is exceptionally, as it usually begins at 9. They made an exception in my case, but even so sometimes I only get to work at 11 and often even at 11.30, which is very inconvenient. On the other hand, I don't use the service at bedtime because they often finish the service when I'm still at work. They sometimes finish at 6 and put persons to bed at 6, 7, 8." (Man, age unknown)

As this case shows, when disability-related needs are not appropriately met, the disabled are prevented from participating on an equal footing with others. Their unequal participation is regarded as natural and attributed to the characteristics of their disability. This reinforces the stereotypes of dependency and incapacity still associated with the disabled. On the contrary, the respect for difference that the Convention sets out as the guiding principle

of disability policies and actions requires appropriate support to guarantee true equality of opportunities.

Non-discrimination and equality

"They say, 'It's not discrimination; it's not because you're deaf.' But I feel that it is."

(Man, age unknown)

Discrimination occurs when persons with disabilities experience any kind of disability-based distinction or restriction that denies them the recognition or exercise of their human rights and fundamental freedoms based on equality with others.

Negative, prejudiced attitudes to disability are often the basis of discriminatory behaviour towards the disabled in Portuguese society. In more than half the interviews there was strong evidence of differential, discriminatory treatment based on disability. This figure far exceeds the reports of assertion of the right to equality, as shown in Table 5.

Once again, it is in the labour market that discrimination is often felt. Ignoring or underestimating the skills and potential contributions of the disabled, employers and supervisors regard them only in light of their physical or sensory disabilities.

In other cases, however, discrimination is systemic and rooted in existing legislation and policies that urgently need to be changed. For example, discrimination in blind persons's exercise of the right to vote persists, as reported by an interviewee:

"We come up against certain situations that upset us, such as the way elections are organised, how we vote. We are obliged to bring a person that we trust completely or we run the risk of being betrayed. This is an issue that bothers me and I think that a way should be found to overcome this." (Woman, age unknown)

Table 5 Human rights principles – non-discrimination and equality

| NON-DISCRIMINATION & EQUALITY | | | | | |
|-----------------------------------------|---------------------------------|------------|-------------------------------|------------|--|
| Domain | Non-discrimination and Equality | | Discrimination and Inequality | | |
| Domain | Number of persons | Percentage | Number of persons | Percentage | |
| Privacy and Family Life | 0 | 0,0 | 3 | 9,4 | |
| Education | 0 | 0,0 | 6 | 18,8 | |
| Work | 1 | 3,1 | 15 | 46,9 | |
| Social Participation | 3 | 9,4 | 18 | 56,3 | |
| Information& Communication | 1 | 3,1 | 2 | 6,3 | |
| Income Security and Support Services | 1 | 3,1 | 12 | 37,5 | |
| Health, Habilitation and Rehabilitation | 1 | 3,1 | 2 | 6,3 | |

Whether it takes the form of individual attitudes and behaviour or institutional policies and practices, discrimination is a serious violation of human rights that has highly negative impacts on quality of life, opportunities and the exercise of citizenship. The Convention expressly forbids all forms of disability discrimination. In Portugal, this goal is still a distant target, however.

Participation, inclusion and accessibility

"I don't think the world is 100% adapted to deaf persons. I feel the lack of a lot of things." (Man, age unknown)

An analysis of denial of the principle of *participation, inclusion and accessibility* considers experiences of disability-based segregation and isolation, including lack of accessibility. In fact, in order to take part in social, economic and cultural life, persons with disabilities need accessible environments. Nonetheless, this is a principle that is often denied them, because buildings, transports and information and communication systems have been designed without their needs in mind and are therefore inaccessible, as the following report shows:

"The health centre was built very recently and for a long time there were no accesses to the planning clinic. The disabled have no access to the health centre and so they can't do the regular tests. The tax office has no access. One side has access but from another parish. The other side has no access." (Woman, 28)

It is communication barriers that constitute the main obstacle to social participation for persons with sensory disabilities: no information in Braille or other accessible formats and inadequate sign language interpretation or teletext services. In spite of changes made in recent years, this is an area that contributes considerably to this group's isolation and social exclusion. A deaf interviewee said:

"Television for example. What are they saying? I don't know what they're saying. I just watch. RTP has subtitles but it sometimes says 'temporary faults' and there are words missing. They're very rare on the news and they don't keep up with what is being said." (Man, age unknown)

Persons with disabilities are also denied opportunities to participate fully in society due to inadequate support and assistance for their needs, as shown in Table 6.

At the same time, the lack of support to offset the added costs of disability place persons with disabilities and their families at a disadvantage in relation to their peers. In Portugal, the cost of living with a disability, which is compounded by lack of accessibility, is between 6,000 and 27,000 euros a year (Portugal, coord., 2010), resulting in a huge social and economic disadvantage for the disabled, illustrated by the following account:

"If I want to go up to the café or somewhere, my wife has to come with me. If I want to go to Lisbon someone has to go with me and that involves costs at several levels. There are availability costs, as someone has to be willing to put up with me and come with me. There are transport costs because I always have to buy two tickets. If I go to the café I always have to pay for two coffees or if I go to Lisbon I have to buy my companion lunch. All this means added difficulty that is not taken into account. Nobody thinks about it, do they?" (Man, 62)

Table 6 Human rights principles – participation, inclusion and accessibility

| PARTICIPATION, INCLUSION AND ACCESSIBILITY | | | | | | |
|--------------------------------------------|-----------------------------|------------|--------------------------------------------|------------|--|--|
| Domain | Inclusion and Accessibility | | Exclusion and Lack of Accessibility | | | |
| Domain | Number of persons | Percentage | Number of persons | Percentage | | |
| Privacy and Family Life | 3 | 9,4 | 6 | 18,8 | | |
| Education | 0 | 0,0 | 3 | 9,4 | | |
| Work | 5 | 15,6 | 15 | 46,9 | | |
| Social Participation | 16 | 50,0 | 24 | 75,0 | | |
| Information& Communication | 2 | 6,3 | 7 | 21,9 | | |
| Income Security and Support Services | 5 | 15,6 | 19 | 59,4 | | |
| Health, Habilitation and Rehabilitation | 5 | 15,6 | 6 | 18,8 | | |

A society founded on human rights is necessarily an inclusive society. Just like everyone else, persons with disabilities want to participate as equals in the social, economic and cultural life of their communities. Dispensing with their contribution by denying them the right conditions for effective participation is more than an error; it is violation of their citizenship rights.

Dignity

"The last time I was in hospital, they tied me to the bed. My hands and feet were tied.

I didn't like it." (Woman, 37)

The human dignity of persons with disabilities is asserted when they feel that their experiences and opinions are valued and they do not suffer any physical, psychological or emotional damage in the way they are treated by others.

Valuation and social recognition are not found very often in the lives of persons with disabilities in Portugal. In fact, appreciation for their human dignity was the positive principle mentioned the least in the interviewees' accounts, as shown in Table 7.

As with the other principles, the data suggest that violations of *dignity* occur most in work contexts and in participation in social life. Accounts of violations of the principle of human *dignity* also often appear in the fields of *health*, *treatment and rehabilitation* (at mental health services or in hospital are in general) and in *economic security and support services*. One interviewee recounted the following episode:

"At a public department (...) I went to deal with some paperwork and they said, 'We can't do it! You can't come on your own. You have to bring someone. Your mother has to come with you.' 'What? What do

you mean I can't?! I have to bring my mother? Am I some kind of child?' 'You have to bring your mother. You have to bring your mother.' 'I'm sorry but my mother doesn't live with me. I'm independent!' 'But you have to bring her; otherwise I won't give you the information!' 'What? I can't believe it! I want the complaint book!' 'It's not possible' 'Sorry, but it's my right. Give me the complaint book! It's my right.' 'I can't do that! I can't do that!' I was really annoyed!" (Man, age unknown)

The irony of this situation is that it took place in a context that, because of its mission as a public social security service, should have particularly inclusive premises that promote everyone's human rights. If this happens in this department, we have to ask what it must be like in the rest of the country.

Table 7 Human rights principles – dignity

| DIGNITY | | | | | | |
|-----------------------------|-------------------|------------|-------------------|------------|--|--|
| Domain | Dignity | | Lack of Dignity | | | |
| Domain | Number of persons | Percentage | Number of persons | Percentage | | |
| Privacy and Family Life | 0 | 0,0 | 2 | 6,3 | | |
| Education | 0 | 0,0 | 3 | 9,4 | | |
| Work | 2 | 6,3 | 9 | 28,1 | | |
| Social Participation | 0 | 0,0 | 12 | 37,5 | | |
| Information& Communication | 0 | 0,0 | 3 | 9,4 | | |
| Income Security and Support | | | | | | |
| Services | 0 | 0,0 | 6 | 18,8 | | |
| Health, Habilitation and | | | | | | |
| Rehabilitation | 0 | 0,0 | 6 | 18,8 | | |

Autonomy

"I should have done several things in that department that they never let me do..."

(Woman, 34)

Autonomy is every human being's basic right to make free, informed choices on matters related to their lives. In the past and today, disability has been an (il)legitimate cause for limiting this right based on the assumption that disabled persons cannot or do not want to make decisions for themselves.

In view of the high percentage of workers in the sample, the data in this study reveal countless barriers to independent choice experienced in the workplace by persons with disabilities, as recounted by this interviewee:

"I've got a degree in Social Psychology and I have an employment contract as a psychologist. But the truth is that I was told that it was not advisable to work directly with a target population because I have a slight [speech impediment]". (Woman, 34)

On the basis of this alleged disability, and against her will, this woman was prevented by her supervisor from performing the work for which she was qualified and was placed in a "more secluded" position with no direct contact with the public. She was also pressured not to report the case under threat of reprisals. The emotion with which she recounted this episode clearly shows the impact that it has had on her life. Once again, prejudices are behind decisions that deny persons with disabilities fundamental freedoms that other citizens can take for granted.

As shown in Table 8, denial of autonomy is also demonstrated by limitations on individual expression and decision making resulting from inappropriate treatment by professionals (such as the above-mentioned case in a social security office) and from overprotective families. In both cases, although for different reasons, it is the image of the disabled as being unable to look after

themselves that prevails and creates situations of inequality and injustice that are real violations of their human rights.

Table 8 Human rights principles – autonomy

| AUTONOMY | | | | |
|-----------------------------------------|--------------------|------------|-----------------------|------------|
| Domain | Self-determination | | Lack of Autonomy | |
| Domain | Number of persons | Percentage | age Number of persons | Percentage |
| Privacy and Family Life | 0 | 0,0 | 2 | 6,3 |
| Education | 0 | 0,0 | 1 | 3,1 |
| Work | 1 | 3,1 | 3 | 9,4 |
| Social Participation | 2 | 6,3 | 3 | 9,4 |
| Information& Communication | 1 | 3,1 | 2 | 6,3 |
| Income Security and Support Services | 1 | 3,1 | 7 | 21,9 |
| Health, Habilitation and Rehabilitation | 1 | 3,1 | 1 | 3,1 |

Incorrect representations of persons with disabilities on the part of professionals at care facilities also prevent them from making decisions on matters such as housing, privacy and independent life. A young interviewee with learning difficulties living in an institution spoke about this:

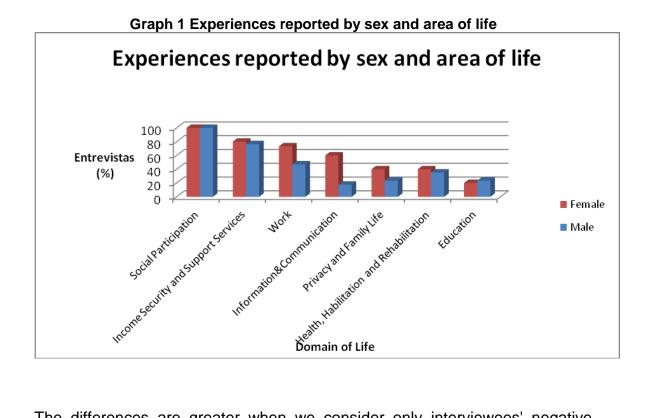
"I should probably have my own place and be allowed to choose what I want in life (...) I don't know. I've been put on the shelf. I should be the one deciding about my life and I should have my own opinions and choose what I want. As the oldest person at home, I should have the right to choose." (Woman, 20)

2.2 Intersectional analysis

This study also analysed possible associations between some sociodemographic characteristics and the life experiences of persons with disabilities. Below, we describe our analysis of two identity factors: sex and age.

a. The impact of gender

Although there were fewer women than men in the sample, there were more accounts from women than men in practically all areas of life with the exception of *education*, in which there were more from men (see Graph 1).



The differences are greater when we consider only interviewees' negative experiences, showing that women with disabilities may be at a disadvantage in relation to men with disabilities in many contexts. According to the study, gender-based differences arise most in the fields of employment, access to information and communication and family life, though they also occur in access to support services, as shown in Graph 2.



Graph 2 Denial or violation of human rights by sex and area of life

The scenarios of widespread discrimination described in the literature (see for example Correia 2010, Pinto 2011), which limit opportunities and place women with disabilities in a situation of greater vulnerability and social isolation, were echoed in the accounts of the interviewees in this study.

When analysed from the point of view of the principles of human rights, the experiences of the men and women with disabilities were different, as shown in Table 9. Although both sexes often mentioned violations of the principle of respect for difference, the men also referred to denial of the principle of participation and inclusion just as much, while the women's accounts suggested more violation of the principle of equality and non-discrimination.

Table 9 Experience of human rights principles by sex

| Principles of Human Rights | | Female | Male |
|----------------------------|-------------------------------------|--------|------|
| Dignity | Dignity | 1 | 1 |
| Dignity | Lack Of Dignity | 11 | 15 |
| Autonomy | Self-Determination | 3 | 1 |
| Autonomy | Lack of Autonomy | 8 | 6 |
| Participation, Inclusion & | Inclusion and Accessibility | 11 | 11 |
| Accessibility | Exclusion and Lack of Accessibility | 13 | 17 |
| Non-discrimination & | Non-discrimination and Equality | 3 | 3 |
| Equality | Discrimination and Inequality | 14 | 13 |
| Respect for Difference | Respect for Difference | 7 | 5 |
| | Disrespect of Difference | 14 | 17 |
| | TOTAL | 15 | 17 |

a. The impact of age

There were also differences between experiences of denial or exercise of human rights on the basis of the interviewees' age, as age mainly determines persons's life contexts. For example, occurrences in education were the most relevant field for the youngest age group. In contrast, experiences in the area of *work* were found more in the 26-40 age group, as this was the group with the most interviewees in paid occupations and therefore those most prone to violation or denial of the principles of human rights in a work context.

Table 10 Experience of human rights by age group

| · | Age Group | | | |
|-----------------------------------------|-----------|-------|-------|-------|
| Domain of Life | 18-25 | 26-40 | 41-55 | 56-70 |
| Privacy and Family Life | 1 | 4 | 3 | 2 |
| Education | 3 | 3 | 0 | 1 |
| Work | 0 | 10 | 4 | 3 |
| Social Participation | 3 | 13 | 9 | 5 |
| Information& Communication | 1 | 7 | 2 | 1 |
| Income Security and Support Services | 2 | 10 | 7 | 5 |
| Health, Habilitation and Rehabilitation | 0 | 7 | 4 | 1 |
| TOTAL | 3 | 13 | 9 | 5 |

It is important to note that age was not a factor of differentiation in situations of deprivation or support in the exercise of rights in the fields of participation and economic security and support services, as all the age groups addressed them equally (see Table 10). This finding demonstrates the relevance of these fields in the lives of persons with disabilities, regardless of the diversity of their life contexts and personal characteristics.

2.3 Responses to abuse and discrimination

"No, I had no response, but I'm not giving up!" (Man, 31)

When faced with denial or violation of their human rights, the interviewees had many different reactions, ranging from reports or formal complaints to resistance to returning to the situation, as shown in Table 11.

Table 11 Response to abuse and discrimination

| RESPONSE TO ABUSE AND DISCRIMINATION | | | |
|--------------------------------------|-------------------|------------|--|
| Response | Number of persons | Percentage | |
| Distancing | 5 | 15,6 | |
| Resisting | 2 | 6,3 | |
| Report/Legal Action | 6 | 18,8 | |
| Other | 1 | 3,1 | |
| TOTAL | 11 | 34,4 | |

According to the interviewees, use of a complaint book or formal reports sent to entities responsible for denial or violation of rights are the most common responses to abuse and discrimination among persons with disabilities. One interviewee said:

"My constant struggle is with architectural barriers. I've written lots of complaints. I've lost count of the complaint books: bathrooms, shops that I

can't access even in shopping centres. It's disgraceful but true! I never let these things drop." (Woman, 37)

Only six of the 32 interviewees lodged a complaint after suffering discrimination, while most of the cases were not reported for fear of possible retaliation or lack of trust or unease at having to explain negative aspects of their lives in public, which is typical of Portuguese culture and not exclusive to persons with disabilities, as shown in Table 12.

Table 12 Reasons for not reporting

| RESONS FOR NOT REPORTING | | | | |
|-------------------------------|-------------------|------------|--|--|
| Response | Number of persons | Percentage | | |
| "NOTHING WOULD HAVE HAPPENED" | 4 | 12,5 | | |
| LACK OF ACCESS | 3 | 9,4 | | |
| FEAR | 5 | 15,6 | | |
| LACK OF FINANCIAL MEANS | 0 | 0,0 | | |
| CORRUPTION | 2 | 6,3 | | |
| SELF-BLAME | 3 | 9,4 | | |
| OTHER | 5 | 15,6 | | |
| Avoiding conflict/exposure | 4 | 12,5 | | |
| Other | 1 | 3,1 | | |
| TOTAL | 18 | 56,3 | | |

Lack of access to the system, including ignorance of disability rights and ways of achieving them on the part of the disabled and agents in the judicial system and persistent feelings of shame and inferiority are also reasons for not making a formal complaint. The account below is a good example of these:

"I didn't do anything, although it made me sad. I don't think it's worth it because nobody would take any notice of me." (Woman, age unknown)

A common reaction on the part of persons with disabilities is to distance themselves from the contexts in which they experienced abuse or discrimination, in order to avoid embarrassment and emotionally painful experiences, as shown in the following passage:

"My colleague wanted to do something. He wanted to talk to the bar manager, but the customers were looking at us and I was feeling uncomfortable with the situation, so I chose to do nothing. Now I can say that I have never been back to that bar; I've never placed myself in a situation like that again. I try to avoid them because I know that they make me feel very uncomfortable." (Woman, 26)

2.4 Perception of causes of discrimination

The interviews were also used to find out the subjects' perceptions on the causes of discrimination against them. According to the data obtained, we can say that, from interviewees' point of view, situations of discrimination are the result of ongoing pejorative representations of disability that are still strong in Portuguese society and are reflected in social practices often hostile to the inclusion and participation of persons with disabilities. The persistence of this type of mentality is regarded by persons with disabilities as a cause of discrimination, as shown in the following excerpt:

"The fact that I'm disabled means to many persons that I'm useless, an inconvenience. I didn't want go as far as that, but in some situations it's true. We're regarded as an inconvenience. We're often thought of as persons who have nothing to offer ... 'Why are they here getting in the way?'". (Woman, 37)

Thus, fuelled by incorrect assumptions on persons with disabilities that are sustained by gaps in information and education, continuing stigmas pose social barriers to the exercise of human rights in many social fields. The interviewees identified the lack of information and awareness on the part of the Portuguese population as a social barrier, as shown in this account:

"It has to do with ingrained rules, what persons learn, what they are taught. Because probably, if you put children, let's imagine, children in different schools with no type of discrimination, persons will get used to them. We see children who have dealt with the issue of disability since they were little but then there is the other side, the children who say, 'Oh that's horrible. I hate being anywhere near disabled persons.'" (Woman, 32)

According to the data, the media as highly influential information and communication channels are considered mechanisms for spreading negative views of disability, as illustrated by the following quotation:

"The media play a role in this issue and it's not always a good one. Often, and I know that it's good to show on TV the positive things that persons with disabilities can do, but not as if it was an extraordinary, historic feat (...) It's highly appreciated when a person with a disability works, makes a living and is independent. Yes, persons appreciate that at lot, but they still see the disabled person rather than the actual person." (Woman, 36)

The respondents felt that discrimination sometimes also arose as a result of practices by institutions providing services to persons with disabilities, which provided assistance inappropriate to the situation and their needs. One of the interviewees made the following comments on the home support that he received:

"At the weekend, I get up early to go and do things. I have to wait for them to come and sometimes it's midday by the time I'm ready and I don't have any time left for anything. It can be very inconvenient. For example, when I have to (...) go somewhere or deal with some matters and I'm unable to be there, I have to reschedule or do it some other time because I've been waiting for them to come and help me. This is not occasional, it happens all the time." (Man, 44)

Political factors, such as laws and programmes are also systemic causes of discrimination, as we can see in Graph 3.

Shortcomings in programmes or policies and the existence of laws that do not respect human diversity were sometimes mentioned as causing inequality and constituted factors of discrimination experienced by the subjects in the sample.

Systemic roots of discrimination

Interviews

Interviews

Systemic Social Legislative

Systemic roots of discrimination

Legislative

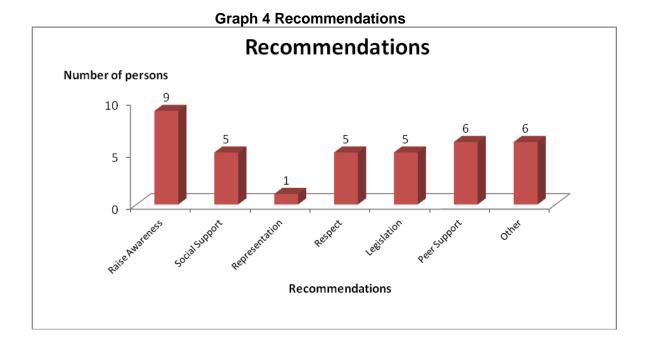
Finally, some of the ways in which economic activities are organised and made available were also mentioned as originating discrimination against persons with disabilities in Portugal. The aim of maximising profit typical of business organisations leads to the devaluation of persons with disabilities, which prevents recognition of their social and economic potential and also means that their needs are ignored or neglected. This is particularly evident in the labour market, as illustrated by this account:

"They send a letter saying that the person can only give 80%, which is not in the company's interest. They do this. The job centre sends a letter saying that employee x applying for vacancy y can only give 80%, because of her problems. You work a three-day trial period and after that they say persons have been admitted or something ..." (Woman, 69)

2.5 Recommendations

On the basis of personal experience and recognition of the existence of limitations on their human rights in Portuguese society, the interviewees made

some suggestions as to how to promote their human rights and improve their lives. The table below quantifies their recommendations.



Persisting labels and stereotypes associated with disability also identified as causing discrimination show the need to foster greater acceptance of difference and an understanding of disability as a feature of human plurality. The persons with disabilities interviewed in this study suggested raising public awareness in order to demystify prejudices and change attitudes that are undesirable in a society that respects human rights.

There should be education and information for the general public and professionals in the area, especially via the direct influence of enforcing the human rights of persons with disabilities. This is what happened when a person was admitted to a psychiatric hospital:

"It's a question of education; they have to have the training so that they don't manhandle persons like that without their permission. A person is tied down and they're not going to touch me without my consent." (Woman, 37)

Awareness also involves inclusion of the subject of disability in official school syllabuses so that young persons participate in the construction of an inclusive society as potential agents of change.

Persons with disabilities must help build the foundations of this inclusive society by participating directly in matters that concern them, as shown in the following opinion:

"I think it would be extremely important to have a number of persons with disabilities in this project for eliminating architectural barriers because we often get the feeling that persons do the work and spend the money but get things wrong. We still have the barrier, as they've sloped the pavement but not properly or the slope is wrong or the height is wrong or it's not in the best place." (Man, 44)

Persons with disabilities can also participate by demanding their rights politically (demonstrations, protests, etc) or taking part in artistic (theatre, etc) or social activities:

"It has a lot do with us; it depends on us. If we don't go, if we don't insist, if we don't ... Although persons stare at us because we go to the cinema, because we go to the football, we have to keep going. Only if we keep it up, will we be able to change mentalities." (Woman, 36)

Social support and technical resources were also requested by the persons with disabilities so that they could lead an independent life and participate fully. As the results showed, the lack of support and services is an important limitation on the exercise of human rights by persons with disabilities. Some interviewees pointed to the need for more services and support, including this respondent:

"More transports, longer hours. There should be at least one vehicle to every place that we can go, even if there was an adapted bus and another ordinary one, but there should be timetables ..." (Man, 31)

It is not enough to draft legislation. It must be effectively implemented in the

field, as one interviewee explained in the following excerpt:

"The legislation has to be passed and enforced and persons with disabilities must be consulted so that persons know what their needs are and then they can make laws. But they must be enforced! This is always a problem that's not raised. The legislation often exists. I'm thinking of the law on physical barriers, which is not always enforced." (Woman, 36)

These were the main ideas gathered from the interviewees, who suggested changes to be made in compliance with disability rights. We complete this analysis in the next chapter with a detailed examination of the relevant legal and political instruments in the area of disability to achieve an overview of the constraints on and support for the human rights of persons with disabilities in Portuguese society.

3. Summary

Our analysis of the interviews enabled us to identify a number of obstacles and constraints limiting the exercise of the human rights of persons with disabilities in Portugal. The following were the most important:

- Inaccessibility of buildings, transports, information and communication resulting in discrimination, marginalisation and social isolation
- Persisting prejudice and negative stereotypes of persons with disabilities that seriously limit their job and career progression opportunities and inclusion and social recognition in general
- Insufficient support for leading an independent life, such as personalised services thereby perpetuating serious social and economic disadvantages for persons with disabilities and their families

Faced with discrimination and violations of human rights, few persons with disabilities take a proactive attitude and report them or make formal complaints. In most cases, they accept them passively **due to lack of confidence or access to the system** (including their own ignorance of disability rights and ways of exercising them or that of agents in the judicial system), fear of reprisals or unease at publicly exposing negative aspects of their personal lives. There is still a lot work to be done in empowering persons with disabilities on their human rights and ways of monitoring them.

Enforcement of the human rights of persons with disabilities means change at all levels of the system: political structures, supports, programmes, services, society and the persons with disabilities themselves. An inclusive society is not only one that accepts and respects differences, it is also one that is included by everyone, where everyone wants and is able to participate.

II. Systemic monitoring – policies and legal framework for disability in Portugal in light of the Convention on the Rights of Persons with Disabilities

This chapter reviews the main political and legislative instruments on disability in Portugal and compares them to the commitments made by Portugal when ratifying the Convention on the Rights of Persons with Disabilities (CRPD) and Optional Protocol. As mentioned above, this analysis was based on a report commissioned by the ANED - Academic Network of European Experts on Disability, to which the DRPI-Portugal team belongs and which it represents in Portugal. The chapter follows the structure of the Convention. This analysis was completed in December 2011 and so does not include any updates or amendments made in Portuguese laws or policies after that.

1. UN Convention status

1.1 Ratification or conclusion of the UN Convention

The President of the Portuguese Republic ratified the UNCRPD on the 15 July 2009 through Decree 71/2009 published in the official journal on 30 July 2009. The ratification followed approval by the Portuguese Parliament, through Resolution 56/2009 of 7 May, also published in the official journal on 30 July 2009. The ratification deed was deposited by the Secretary General of the UN on 23 September 2009 and therefore, in accordance with Art. 45(2), the Convention entered into force in Portugal on the 23 October 2009.

1.2 Ratification or accession to the Optional Protocol

The President of the Portuguese Republic ratified the Optional Protocol on 15 July 2009 through Decree 72/2009 published in the official journal on 30 July 2009. The ratification followed approval by the Portuguese Parliament, through Resolution 57/2009 of 7 May, also published in the official journal on 30 July 2009. The ratification deed was deposited by the Secretary General of the UN on 23 September 2009 and therefore, in accordance with Art. 13(2), the Optional Protocol entered into force in Portugal on the 23 October 2009.

1.3 Declarations, Reservations and Objections

Portugal has not presented any declarations, reservations or objections in relation to the UNCRPD and Optional Protocol.

1.4 Comprehensive review

No comprehensive review of existing legislation has been conducted by the Portuguese government in preparation to the implementation of the Convention.

1.5 Focal point

The National Institute for Rehabilitation (INR, I.P.), whose mission is to ensure the design, implementation and coordination of national policies aimed at promoting the rights of persons with disabilities is the focal point for the implementation of the Convention. The INR, I.P. is a public body located under the authority of the Ministry of Solidarity and Social Affairs.

1.6 Coordination mechanism

The National Institute for Rehabilitation is the body that coordinates national policies aimed at promoting the rights of persons with disabilities. In addition, the Directorate-General of Foreign Policy (within the Ministry of Foreign Affairs) and the Office of Strategy and Planning (within the Ministry of Solidarity and Social Security) have been designated as governmental coordination mechanisms to facilitate action within government on the implementation and monitoring of the Convention. By Decree-Law 126/2011, of 29 December the former Council for the Rehabilitation and Integration of Persons with disabilities is extinct and the new National Council for the Policies of Solidarity, Charity, Family, Rehabilitation and Social Security is created as a broad consultative body of the Ministry of Solidarity and Social Affairs that also addresses disability issues. However the composition, tasks and functioning of this new advisory body have not yet been regulated.

1.7 Independent mechanism

According to the Initial Report of Portugal on the Implementation of the Convention on the Rights of Persons with Disabilities, the structure of the independent mechanism to monitor the CRPD is in its final stage of definition.

1.8 Official reporting

Portugal was due to submit its first report on December 2011 and it has just fulfilled that obligation on August 2012. A Working Group of the National Human Rights Committee has prepared the Portuguese official report for the UN Committee on the Rights of Persons with Disabilities and the Committee held a consultation meeting with civil society on 29 February 2012, which

included the participation of Organisations of Persons with Disability. Comments and inputs from civil society were gathered at that meeting.

1.9 Shadow reporting

A shadow report is under preparation by civil society organisations, drawing on the work developed by Disability Rights Promotion International Portugal and the annual reports prepared for ANED. The preparation of the shadow report is involving the participation of a large number of DPOs and is being coordinated by researchers from the Centre for Administration and Public Policy of the School of Social and Political Sciences, Technical University of Lisbon, in partnership with the Portuguese Association of Disabled People (APD).

2. General legal framework

2.1 Anti-discrimination legislation

The right to non-discrimination is established for all citizens in the 1976 Constitution (and subsequent revisions including the most recent one in 2005). Although Article 13 of the Constitution does not specifically mention disability as a ground for discrimination, the list of grounds presented is not meant to be exhaustive and therefore the clause is usually interpreted as also including disability. Prohibition of discrimination on the basis of disability has been more recently re-enacted in two key legal documents: the 2004 Disability Act (Law 38/2004 of 18 August) and the 2006 Anti-discrimination Law (Law 46/2006 of 28 August). Both pieces of legislation prohibit direct and indirect forms of disability-based discrimination and put forward the principle of affirmative action or positive discrimination, as a way to compensate for structural inequalities facing persons with disabilities. The Anti-discrimination law defines what constitutes "discriminatory practices"; (Art. 4). These include, among

others, the denial or imposition of limitations in the provision of goods and services, including in access to credit and insurance, to the built environment, to sign language, to education, healthcare and information technologies. The law dedicates a whole Article (Art. 5) to discrimination in the workplace, restricting the principle of 'reasonable accommodation' to situations occurring in this realm. Moreover, as defined in the law, the burden of proof remains with the plaintiff, who needs to substantiate his/her complaint. Individual persons, or disability organisations on their behalf, may submit complaints. The specific rights and particular vulnerabilities of disabled women and children with disabilities are not mentioned in any of these laws, nor is it anywhere recognised that they might be subject to multiple discrimination. Hence, no specific measures are envisioned for them.

2.2 Recognition of legal capacity

Legal capacity is defined in the Portuguese law as the ability to enter a legal relationship (Civil Code, Art. 67). The majority of Portuguese citizens acquire legal capacity when they reach 18 years of age (Civil Code Art. 130). The Civil Code, however, defines two ways in which legal capacity can be limited or suppressed; they are the regimes of inabilitation (inabilitação) and interdiction (interdição). The regime of interdiction implies a severe containment in the exercise of rights. Regardless of age, persons who are subjected to this regime remain in the status of minors, for instance they cannot exercise the right to vote, and if interdiction is ascribed on the basis of a "mental anomaly"; they are prevented from exercising paternity and testifying in court, and although they can marry, the marriage can be declared null. According to the law, persons with "mental anomalies, deaf-muteness and blindness, who show inability to govern their lives"; can be assigned the status of interdiction (art 138(1)). The Court assigns the status of interdiction on the basis of a legal request (by a parent, the spouse, a child, the curator or the public attorney), a medical assessment of the individual, and statements of family members,

friends, neighbours and others close to the person. Once the status of interdiction is assigned, a Tutor is designated. The Tutor is usually a family member (e.g. parent, spouse, eldest child) but if a family is lacking, a professional (e.g. the director of a service provider organisation) may also be designated as a Tutor. A Pro-Tutor is further designated to supervise the Tutor. The Tutor should act as a "good parent"; and provide for the well-being, health and education of the person who is under his/her guard. Tutors are obliged to request permission from the Court in order to perform certain acts (e.g. buy and sell property, accept inheritances, submit claims). The regime of inabilitation, in turn, implies the suppression of the right to manage one's own property. It is also assigned by a Court, on the basis of a legal request and a medical assessment. Persons whose 'mental anomalies, deaf-muteness and blindness are not so severe to justify their interdiction, as well as persons who systematically incur in "unjustified and ruinous expenses"; or are addicted to alcohol and other drugs may be assigned the status of inabilitation (Art. 152). A Curator is then designated to assist the person in all acts related to property, or even to act on his/her behalf. In this latter case, a Family Council (composed of family members, neighbours, friends and others) is set in place, and a representative is nominated to supervise the acts of the Curator.

2.3 Accessibility of voting and elections

According to the Portuguese Constitution (article 49(1)), all citizens of 18 years old and over who are properly registered are entitled to vote in Portugal, except for people who have the incapacities laid down in the general law. Article 2 of the Electoral Law (Law 14/79) Portuguese specifies that citizens who have been assigned the status of interdiction, or those who are deemed "demented"; and are institutionalised, are not allowed to vote. The law further states that the act of voting is always 'direct and secret' however, in Article 97, it entitles "persons with visible physical disabilities or illnesses"; to bring an assistant of their own choice to the voting booth, in order to assist or vote for

them. Citizens whose disabilities or illnesses are not visible, and yet require assistance to vote, need to present an official medical note to justify their need (Art 97). Hence, by not allowing alternative ways of expressing the vote (e.g. electronic vote) the Portuguese electoral law discriminates against persons with disabilities, and prevents them from exercising with autonomy, the right to vote. As a result of a complaint lodged by the Portuguese Association of Disabled (APD), the National Elections Commission (CNE) issued in 2009 a recommendation on accessibility in which it calls upon the responsibility of Municipalities to ensure physical accessibility to the voting sites.

2.4 Official recognition of sign language

Sign language is recognised in the Portuguese legislation in several ways. Article 74.h of the Constitution states that, in pursuing an education policy, the State must, "protect and value the Portuguese sign language, as a means of cultural expression and a tool to access education and equality of opportunities";. Sign language is also mentioned in the Anti-discrimination Law; according to Article 4(d) the denial of access to or dissemination of sign language is considered a "discriminatory practice";. Article 43 of the Disability Act requires the State and other private and public stakeholders to provide information in accessible formats to persons with disabilities, including information in sign language. Law 27/2007 of 30 July (amended by Law 8/2011 of 11 April) which regulates television operators, states in Article 34 that it is up to the media regulatory body to define a multiannual plan for gradual implementation of the rules that enable access for persons with special needs to broadcast TV, "notably through the use of captioning, sign language interpretation, audio-description and other adequate techniques";. The plan will be developed in consultation with TV operators and will take into consideration "the market conditions and the technology available in each moment";. The use of sign language interpreters is also allowed during the training and the practical exam to obtain a driving permit.

3. Accessibility

3.1 Transport accessibility

Denying and limiting access to public transportation is expressly prohibited by the Portuguese Anti-discrimination Law (Law 46/2006 of 28 August). Decree-Law 58/2004 of 19 March defines the accessibility standards for newly acquired public buses (transposition of the European Parliament and Council Directive 2001/85/EC). New trains must ensure the accessibility standards defined in the COST 335 norms (COST 335 - Passengers' accessibility of heavy rail systems, final report, November 1999). In addition, Decree-Law 252/98 of 11 August provides for the licensing of accessible taxis. The Accessibility Law (Decree-Law 163/2006 of 8 August) further requires that railway stations, subway stations, bus central stations and bus stops, ferry piers, airports, petrol stations and service areas in motorways are made accessible to disabled persons. Deadlines for the implementation of the accessibility standards vary according to the construction year of the facilities. Thus, there are three possible situations: adaptations to facilities built before 22th August 1997 should be concluded within a period of 10 years; adaptations to facilities built after 22th August 1997 should be concluded within a period of five years; Adaptations to facilities built in accordance with the previous accessibility law (Decree Law 123/97 of 22 May) are exempt from the new standards. After these deadlines, non-compliance with the accessibility standards will be sanctioned as follows: individual person 250 to 3,740,98 Euros and collective persons 500 to 44,891,81 Euros. Exceptions are also previewed in the law. The implementation of the accessibility standards is not required when: the elimination of architectural barriers is disproportionately difficult; it requires economic and financial means that are disproportionate or not available; the implementation of accessibility standards would affect significantly the cultural and historical heritage, whose morphological, architectural and environmental preservation is intended. However, this law is

currently under revision - a new project-law has been issued and is open to public consultation in the website of INR, I.P. Further to the law, the National Plan for the Promotion of Accessibility 2007/2015 (Resolution of the Ministers Council 9/2007) establishes a set of actions to remove transport barriers. The plan considers two phases: 2007- 2010 and 2011-2015. Examples of measures to promote accessibility in transportation during the first phase include: easing the allocation of parking badges for disabled people; promoting accessibility in all underground stations; promoting accessibility at railway stations, including accessibility in circulation areas, at service counters, ticket vending machines and installing adapted toilet facilities for use by persons with disabilities; and progressively replacing the fleet of buses, with special priority for those operating in urban areas. At the end of the first phase an evaluation process was due to take place and new measures were to be developed accordingly. An evaluation report has been issued in 2011 and the new measures for the second phase (now 2012-2020) are currently available to public consultation, so they have not yet been established. Finally, the National Disability Strategy, 2011-2013 (Resolution of the Ministers Council 97/2010) also includes measures to remove obstacles and promote accessibility in public transportation.

3.2 Built environment accessibility

The Portuguese Anti-discrimination Act (Law 46/2006 of 28 August) requires that public buildings and public-use facilities are made accessible to disabled persons. Decree-Law 163/2006 of 8 August defines the accessibility standards for buildings, public spaces, public facilities, and housing. These standards apply both to old and new buildings. Deadlines for the implementation of the accessibility standards vary according to the construction year of the facilities. Thus, there are three possible situations: adaptations to facilities built before 22th August 1997 should be concluded within a period of 10 years; adaptations to facilities built after 22th August 1997 should be concluded

within a period of five years; adaptations to facilities built in accordance with the previous accessibility law (Decree Law 123/97 of 22 May) are exempt from the new standards. After these deadlines, non-compliance with the accessibility standards will be sanctioned as follows: individual person 250 to 3,740,98 Euros and collective persons 500 to 44,891,81 Euros. Exceptions are also previewed in the law. The implementation of the accessibility standards is not required when: the elimination of architectural barriers is disproportionately difficult; it requires economic and financial means that are disproportionate or not available; the implementation of accessibility standards would affect significantly the cultural and historical heritage, whose morphological, architectural and environmental preservation is intended. However, this law is currently under revision - a new project-law has been issued and is open to public consultation in the website of INR, I.P. Through Resolution of the Council of Ministers 9/2007, the government adopted the National Plan for the Promotion of Accessibility 2007/2015 (PNAP). The Plan identifies three main goals: (1) to raise awareness; (2) to provide information; and (3) to provide training on accessibility issues, and establish a set of measures to remove barriers to accessibility in transportation and the built environment, in workplaces, housing and ICT. The measures cover the period 2007-2010, after which they are to be evaluated and redefined accordingly. Some of these measures include promoting accessibility in public buildings, supporting the adaptation of housing and raising awareness in society about the need to improve accessibility. An evaluation report has been issued in 2011 and the new measures for the second phase (now 2012-2020) are currently available to public consultation, so they have not yet been established. The National Strategy for Disability 2011-2013 (Resolution of the Ministers Council 97/2010) also includes measures to remove obstacles and barriers in the built environment, especially in public buildings, health facilities and the services of the National Institute for Rehabilitation. Finally, the RAMPA program (Accessibility Support Regime for Municipalities), includes measures to

support accessibility assessments, awareness-raising and training activities, as well as the development of accessibility plans for public spaces.

3.3 ICT and Web accessibility

ICT and website accessibility are required by the Action Plan for Information Society adopted through Resolution of the Council of Ministers 107/2003 of 12 August. ICT and website accessibility are promoted in the National Programme for the Participation of Citizens with Special Needs in the Information Society (Resolution of the Council of Ministers 110/2003 of 12 August). Some of the measures proposed include the promotion of accessibility on public television channels and training on Internet usage for persons with disabilities. In this context, the programme Digital Inclusion was created through Regulation 1354/2004 and funds were made available to support projects aiming to train and improve access to ICT by persons with disabilities and older persons. The ACCESS Programme, created by the UMIC-Agency for the Knowledge Society, is another initiative in this domain. It developing, providing disseminating information aims and communication technology tools to improve the quality of life of citizens with special needs, as well as supporting the widespread use of ICT by persons with disabilities and the professionals who work with them. One of the components of the programme is the Solidarity Network which provides internet access, web hosting and e-mail management for disability organisations. In 2004, 240 non-profit organizations in the disability field were part of this network. Moreover, the National Strategy on Disability 2011-2013 defines, under headings four 'Accessibility and Design for All' and five 'Administrative Modernisation and Information System' measures to promote access to information and electronic services such as developing a pilot customer service project for the deaf and improving the accessibility of websites and information technologies. UMIC-Agency for the Knowledge Society has translated into Portuguese and makes available on the internet

the WCAG 2.0 Web Content Accessibility Guidelines of the W3C World Wide Web Consortium and has created a certification system to assess accessibility on the web.

4. Independent living

4.1 Choice of living arrangements

Article 65 of the Portuguese Constitution states that, 'all citizens have the right to adequate housing that preserves personal intimacy and family privacy. Furthermore, Article 32 of the Disability Act (Law 38/2004) calls upon the State to take the necessary measures to ensure the right to housing for persons with disabilities, notably by eliminating barriers and promoting universal design in housing building and renovation. Nevertheless, according to the norms that rule the implementation and operation of residential facilities for persons with disabilities (Order 28/2006), persons with disabilities aged 16 years old or over may be forced to live in a residential facility. This may happen when: they are attending educational and training programmes or other programmes in a region different from their home; when their families cannot accommodate them; when their families need temporary breaks (e.g. in duly justified cases of illness or respite). According to the same Order, youngsters with disabilities under 16 years of age may also be temporarily institutionalised whenever the family context so recommends, and all other possibilities of referral to more adequate options have failed. Persons with severe mental health conditions may also be limited on their choice of living arrangement and forced to institutionalisation. The Mental Health Law (Law 36/98 of 24 July) establishes the principles of the mental health policy and regulates compulsory institutionalisation of persons with "psychiatric anomalies". According to the Law, the court will determine compulsory institutionalisation when a person with a severe psychiatric anomaly puts at risk valuable personal or patrimonial assets and refuses to get adequate treatment, as well as when the person is

not able to understand the meaning of consent and the lack of treatment significantly deteriorates her health status (Art.12).

4.2 De-institutionalisation

According to the 2001 Census, 94.5% of persons with disabilities live in households. In fact, except in the case of persons with psychosocial disabilities, institutionalisation has never been a very common pattern among persons with disabilities in Portugal. Instead, historically, families have been the primary support systems for persons with physical, sensorial or intellectual disabilities. This has raised important issues of autonomy and selfdetermination for disabled people. Hence, the National Disability Strategy 2011-2013 (which followed the First National Action Plan for the Integration of Persons with Disabilities and Impairments: PAIPDI 2006-2009) recognises this reality and selects "Autonomy and quality of life" as one of the key areas for policy development. Measures included under this heading, targeted to support community living are: to pilot a Personal Assistance Service; to increase the number of Group Homes; to increase the number of Home Assistance Services and to create a loans programme for home renovations related to improving accessibility. Data from the 2009 Evaluation Report of the PAIPDI further indicate that Home Assistance Services for persons with disabilities increased by 21% in four years (from 607 places in 2004 to 734 in 2008). Life in the community for persons with disabilities is further encouraged through housing policies. With Decree-Law 308/2007 of 3 September the Portuguese Government created the Door 65-Youth Programme. This programme aims at supporting youth (18-30 years old) living in urban rented housing. It grants a monthly allowance for a maximum of two years and is based on a principle of positive discrimination towards youth with disabilities and young people with lower income with children. Positive discrimination in favour of persons with disabilities of all ages is also in place in the application process to access social housing throughout the country (as per Decree 50/77

of 1 August). Institutionalisation has been more prevalent among persons with psychosocial disabilities. However, following international recommendations, the National Mental Health Plan 2007-2016 established the goal of deinstitutionalisation and determined the gradual closure of psychiatric hospitals. Decree-Law 8/2010 (amended by Decree-Law 22/2011 of 10 February) creates a new typology of units and multidisciplinary teams to provide integrated continuous care at local level. These include: residential units, socio-occupational units and home support care teams. Through Order 149/2011 these community services were extended to children and adolescents and the coordination of the network was established, involving at regional and local levels both health and social care services.

4.3 Quality of social services

The majority of the community-based social services providers in Portugal are non-profit organisations. These organisations establish memorandums of agreement with the Institute for Social Security, the public body that funds and supervises their operation (as of Decree-Law 64/2007 of 14 March). In addition, many non-profits are voluntarily undertaking quality control processes through international systems such as EQUASS or the ISO 9001:1200 norms. The non-profits can apply for funds from the European Social Fund and the national QREN/POPH programme to initiate the certification process under EQUASS. The Portuguese Association of Quality is the independent inspection and certification body in Portugal for this system. The organisations that show conformity with the nine principles of quality of EQUASS; leadership, rights, ethics, partnerships, participation, orientation towards the client, scope, orientation towards results, and Continuous improvement, are certified for a period of two years in either level I (EQUASS Assurance), Level II, (EQUASS Excellence) or Level III, (EQUASS Award).

4.4 Provision of assistive devices at home

The Disability Act (Law 38/2004 of 18 August) states, in Article 31, that 'it is up to the State to provide, adapt, maintain and renew the appropriate means of compensation to ensure greater autonomy and adequate integration of persons with disabilities'. The National System for the Ascription of Assistive Devices (SAPA), established by Decree-Law 93/2009, of 16 April and Decree-Law 42/2011, of 23 March, gives expression to this norm. SAPA was created to compensate for impairments and reduce their impact in the daily life of persons with disabilities. It is a public and universal system and covers the areas of health, vocational training and employment and independent living. A medical prescription is always required. Funding is provided by the Institute of Vocational Training and Employment (IEFP) for all assistive devices required for accessing vocational training or for accessing, maintaining or progressing in a job, including access to transportation. Assistive devices prescribed by a health or a rehabilitation centre are funded by the Institute for Social Security and the Ministry of Health. In addition to SAPA, education-related assistive devices are provided by the Ministry of Education to students with disabilities attending compulsory education. No similar system, however, exists for students with disabilities attending university. Persons with disabilities are also entitled to reduced taxes when purchasing an adapted car (Law 22-A/2007 of 29 June 29; Decree-Law 43/76 of 20 January; Decree-Law 352/2007 of 23 October).

4.5 Availability of personal assistance schemes

In Portugal there is no legal recognition of the position of Personal Assistant, and families remain the main care providers for persons with disabilities. Nevertheless, the Portuguese state provides the following options to support personal care: an allowance for Personal Assistance (in the amount of 88.37 Euros per month) which is provided to persons with disabilities of all ages who

are not working and who need someone to assist them with their basic needs for a minimum of 6h per day; Home Care Support, available only when the family is not able to provide assistance but the disabled person is still able to remain in her home. This service can include meal preparation, house cleaning and laundry as well as personal care. According to the 2009 Report of the PAIPDI there were 734 places for Home Care support in Portugal in 2008.

4.6 Income maintenance

In Portugal, disability-related income maintenance benefits include a disability pension (for workers who retire due to disability), a disability allowance (for adults with disability who never worked and are considered unable to do so), and a means-tested supplement to family allowances (for parents of children with disabilities) as well as a special education cash benefit for parents of children with special education needs .In the context of the implementation of austerity and fiscal consolidation measures in Portugal, the government changed in 2010 the conditions for entitlement to all cash benefits within the national social security system (Decree-law 70/2010 of 16 June). These conditions became more stringent with the new and enlarged concept of household that started to be used to calculate the "household income" and determine the "level of need" of the applicants. The new concept of household now includes 'relatives in the straight line and in the collateral line to the third degree, who live in common with the applicant', that is, it may include parents, in-laws, stepfather, stepmother, children, stepchildren, son, daughter, grandparents, grandchildren, siblings, in-laws, uncles, nephews, greatgrandparents and/or great-grandchildren, provided that they live with the applicant. On the other hand, the household income continues to consider all annual income obtained from employment, business and professional services, capital and estate, pensions, etc, but now also includes social supports that compensate for the loss or lack of income, such as subsidies due to sickness, unemployment, etc, with the exception cash benefits for disability and dependence. Since 2011, however, all cash benefits, including disability-related benefits, have been frozen. The only exception were minimum pensions which increased by 3% (Order 320-B/2011 of 30 December). The freeze is expected to continue through, at least, the end of 2013, so these cash benefits are no longer indexed to the cost of living. In all situations described above, marriage constitutes a legal condition to cease entitlement to Social invalidity pension, if the couple has an income over 50% of the Minimum wage; Survival Pension and Disability Allowance. Currently, the income maintenance benefits for persons with disabilities in Portugal provide the following supports:

Disability Pension: an amount variable according to the contributory career of applicant

Disability Allowance - € 176,76 per month

Disability Supplement to Family Allowances: Varies between €59,64 and 139,15 euro (depending on household income and whether it is or not a single-parent family)

Special Education Allowance - Up to €293,45 per month during the school year

4.7 Additional costs

The allowance for assistance by third-person (for children and adults with disabilities who require hygiene and other self-care) and the complement for dependence allowance (for recipients of disability and work pensions) are the two cash benefits available to persons with disabilities in Portugal to help meet care costs. The amounts currently provided are as follows:

Allowance for Assistance by Third Person - € 88,37 per month;

Complement for Dependence Allowance - €97,70 EUR (for 'bed-bound' disabled people) and €87,93 for others.

4.8 Retirement income

Persons with disabilities above retirement age are entitled to the same social security provisions available for younger disabled persons. However, the Extraordinary Complement of Solidarity (an allowance that complements the Disability Allowance as well as the Disability Pension) is double for those aged 70 - 34; 63 Euros (amount not changed since 2009).

5. Education

5.1 Special schools

Decree-Law 3/2008 of 7th January establishes the legal framework for special education. As amended by Law 21/2008 of 12th May, it states that special education in Portugal is organised around a 'diversity of models of integration', providing every child with 'the least restrictive environment' as long as 'from the modality of integration does not result segregation or exclusion of the child or youth with special needs' (Article 4(6)). The same Article further states that in situations where the implementation of special education measures is insufficient, "given the type and degree of the student's disability", those who participate in the referral and assessment of the child (including parents) 'may suggest the attendance of a special school (Art. 4(7)). Attendance at a special school is therefore regarded in the law as the last resort, when inclusion in the mainstream school fails, given the degree of need of the student and the lack of adequate supports provided by mainstream schools. Decree-Law 3/2008 entitles parents to contest placement in a special school as well as any other decision regarding the provision of educational supports to their children. When parents do not agree with the measures proposed by the school,

including the decision to place the child in a special school, they may appeal the decision by submitting a written file to the Ministry of Education. No reference is made in the legislation, however, to the ability of children or youth to contest decisions made in relation to their own education.

5.2 Mainstream schools

Special Education in Portugal is guided by the principles enshrined in the legislation, particularly the Education Act, Law 46/86 of 14 October, Decree-Law 35/90 of 25 January and Decree-Law 3/2008 of 7 January. Decree-Law 3/2008 is particularly relevant, establishing the legal framework for special education. According to Article 2(2) of this Decree-Law, public schools and private schools that are directly or indirectly funded by the Ministry of Education are subject to the principle of non-discrimination on the grounds of disability. Therefore, they cannot deny registration to children or youth on the basis of their disabilities. Furthermore, schools must recognise the unique needs of these students and provide an education that is adequate to their needs. Once a child or youth with special needs is referred to a school, an assessment of the student is done by the department of special education and the psychology department of the school. This assessment should determine whether the child has, or has not got "significant limitations at the level of activity and participation in one or various domains of life, resulting from functional or structural permanent impairments" (Art. 1). While other tools may also be used, the International Classification of Functioning, Disability and Health (ICF) provides the reference for the students' assessment. Parents are entitled to actively participate in the evaluation process of their children, but no reference is made in the law as to the participation or voice of the child/youth. The outcome of the assessment is a technical-pedagogical report that becomes the basis for the elaboration of the students' individual education plans or IEPs (DL 3/2008, Art. 6). An IEP establishes the specific education and evaluation strategies that will be put in place for the student, the school

subjects that will be covered, the general and specific goals that will be achieved, and the human and technical resources that will be needed, including special equipment and materials. Parents should sign the IEP as a means of expressing their agreement (Art. 9). At the end of every school year a report is produced stating the student's achievements in relation to the Plan. This report must be signed by all participants in the education process, including the parents (Art.13). When the school does not have the human resources needed to implement the IEP, particularly if specialised professionals such as speech therapists, occupational therapists, psychologists, sign language interpreters and others are required, schools are entitled by law to hire them, 'under the regular legal and procedural terms' (Art.29). Schools are also encouraged to establish partnerships with private non-profit organizations and specialised resource centres in order to get these supports. Education is free for all students up until grade 9 so it is up to the Ministry of Education to provide the human and technical resources and materials necessary to guarantee the education of children, regardless of their disabilities.

5.3 Sign language and Braille in school

According to Decree-Law 3/2008, children have the opportunity to learn Braille and sign language from pre-school to the end of compulsory education in specially designated mainstream schools; so-called 'reference schools' for deaf and/or blind or low vision students. Reference schools are public mainstream schools, attended by regular students, but which differ from other schools in the sense that they concentrate human and technical resources for the bilingual education of deaf students and the education of blind/low vision students (Art.18). Deaf and blind/low vision students thus attend the closest reference school, whether or not it is located in their neighbourhood (Art. 19).

5.4 Vocational training

Vocational education and training providers are not subject to specific nondiscrimination laws in relation to disability. However, as a general rule, Article 6 of Law 38/2004 states that 'a person shall not be discriminated against, either directly or indirectly, by act or omission, on the basis of his/her disability...'. Students who have permanent special educational needs that prevent them from achieving the skills and knowledge established in the general curriculum, are provided with an Individual Transition Plan two years before they complete compulsory education. The Plan includes an identification of the student's aspirations and skills, an assessment of the job market opportunities, and an outline of training opportunities or real work experiences available in the student's community. The National Institute for Vocational Training and Employment (IEFP) is the national public body responsible for promoting the vocational training and rehabilitation of persons with disabilities. The IEFP funds private non-profit organisations and cooperatives that provide vocational training services to persons with disabilities through the Programme for the Qualification of Persons with Disabilities and Impairments. Services funded under this Programme may include initial and continuous vocational training activities aimed at developing the professional skills and employability of persons with disabilities. The areas and specific training activities provided to persons with disabilities should gradually be organised following the guidelines, contents and standards of the National Qualifications Catalogue (CNQ), which includes all training programmes available in the country for the general population, and should be implemented in close liaison with the job market (including through in-job training schemes). In 2011, for instance, it is expected that at least 55% of the training offered for persons with disabilities in Portugal complies with these standards. Initial vocational training programmes last between 1200 and 2900 hours, while continuous training programmes must not exceed 400 hours. During the training, trainees are entitled to a small stipend.

5.5 Higher education

Universities are not subject to specific non-discrimination laws in relation to disability. However, as a general rule, Article 6 of Law 38/2004 states that 'a person shall not be discriminated against, either directly or indirectly, by act or omission, on the basis of his/her disability...'. Moreover, each year, under the legislation that regulates the higher education national application process, a special quota (usually 2% of vacancies) is reserved for students with physical and sensorial disabilities. In order to benefit from this quota, disabled students must fulfil all the requirements of a regular applicant. In addition, they are required to fill out a special form and submit detailed clinical evidence about their impairments to prove their disability. Reports discussing the students' educational process, as well as the type and degree of success of the adjustments and adaptations that have been developed in previous school years are also required. A decision on whether the student is entitled to benefit from the quota is made on the basis of a paper analysis complemented, if deemed necessary, with interviews conducted by an evaluation committee (appointed by the Minister, on a joint proposal of the Directors of the Departments of Secondary and Higher Education). Whether or not a student with disabilities enters university through the special quota, the support he/she will be provided with will depend on what is available in each institution. Some universities have developed guidelines for professors and staff, set up Disabled Students Support Offices and/or provided accessible materials and equipments. Others however, have no support available at all.

6. Employment

6.1 Non-discrimination in employment

The principle of non-discrimination in occupation and employment for people with disabilities is mostly promoted and enforced in Portugal through the Labour Code. The Labour Code, approved by Law 7/2009 of 12 February in 2012 as amended by Laws 105/2009 of 14 September, 53/2011 of 14 October and 23/2012 of 25 June, provides to any employee or job candidate the right to not be directly or indirectly discriminated against, based on several personal characteristics, including disability, reduced working capacity or chronic disease (Article 24(1)). This right applies to: a) recruitment, selection and hiring processes; b) access to vocational guidance, training and retraining; c) payment and other reward systems as well as career development or dismissal; and d) participation in collective bargaining structures (Article 24 (2)). Employers are also required to post in the workplace, a list with the rights and duties related to equality and non-discrimination (Article 24 (4)). Positive discrimination, in the form of timely limited legislative measures to benefit a discriminated group and correct a situation of inequality, is also allowed under Article 27. Besides these more general rules, in a specific section dedicated to 'workers with disabilities or chronic diseases', the law states that these workers have the same rights and duties as all other "regular" workers, and affirms the duty of the State to stimulate and support employers in their hiring and professional rehabilitation (Article 85). Employers must take all adequate measures to guarantee that these workers have the rights of getting access to a job and to be able to advance in a career, unless the costs involved are considered disproportionate (Article 86(1)). Considering that the State must support the employer within this process (Article 86(2)), the situation of disproportionate costs is not considered a plausible excuse whenever there is State aid available (Article 86(3)). Furthermore, workers with disabilities or chronic diseases are excused from providing work in specially organised working schedules or during the night whenever this may be harmful for their

work health or safety (Article 87), and they may also be exempted from the obligation to provide overtime work (Article 88). In the subsection related to 'workers with reduced working capacity' the law states that employers must enable working conditions to these workers, namely by providing workplace adjustments, payment and by promoting adequate vocational training and professional development (Article 84(1)). These accommodations must be supported by the State (Article 84(2)). According to the law, workers with reduced working capacity may get a salary below the national minimum wage. Finally, the Labour Law also states that collective bargaining regulations must facilitate access to part-time jobs for specific groups of workers, including workers with disabilities, chronic diseases and reduced working capacities (Article 152(1)). In order to promote the professional integration of people with disabilities within Public Administration, Decree-Law 29/2001 of 3 February established a mandatory quota for public service external admissions: 5% of places should be reserved for persons with disabilities when the application process involves ten or more places; one place when it involves between three and nine places; and preference should be given to the candidate with disabilities before an equal ranking situation when application involves one or two places.

6.2 Public employment services

Through Decree-Law 290/2009 of 12 October, the government created the so-called Programme to Support the Vocational Training and Employment of Persons with Disabilities and Impairments, determining that employment advice and support services must be provided by the public agency Institute for Employment and Vocational Training (IEFP), or some other entities designated by the IEFP. Support to labour market integration, maintenance and reintegration of people with disabilities is promoted by Job Centres (the local structures of the IEFP) or by Resources Centres (entities that, given their expertise in working with people with disabilities, are accredited by IEFP as

support structures) and entails five sub-measures, namely: (1) information, assessment and guidance to qualification and employment, that is guidance on decisions about a vocational path and the means and supports which may be necessary given the person's needs (for a maximum period of four months); (2) support provision in the job (which includes support to help people create their own jobs), information to employers about the benefits of hiring employees with disabilities, and mediation between employers and employees in workplace adjustment and accessibility (for a maximum of six months); (3) after-placement follow-up, to ensure employee adjustment to job tasks and workplace and workplace accessibility (for a maximum of 12 months or 24 months in exceptional situations, namely when related to people with intellectual disabilities); (4) workplace adjustments and removal of architectural barriers; and (5) exemption and reduction of contributions for Social Security. Supported employment aims at enabling people with disabilities to develop personal and professional skills that ease their transition to a "regular work regime" The "supported employment" regime entails the following measures: (1) nine month-long Insertion Traineeships which aim at providing practical vocational training;(2) Employment-Insertion Contracts which foster, for a maximum of 12 months, the development of socially useful activities in order to reinforce relational and personal skills; (3) Sheltered Employment Centres either with public or private organisations; (4) Supported Employment Contract, which implies the creation of an enclave inside an organisation for a group of workers who develop their professional activity within a "regular" working environment but under special conditions. The Merit Award aims to honour and reward especially successful cases of people with disabilities who have created their own jobs, as well as employers who have excelled in the professional integration of people with disabilities.

6.3 Workplace adaptations

The Labour Code establishes the duty of 'reasonable accommodation' by stating in its article 84 that employers 'should take appropriate measures to ensure access to employment and a career path to persons with disability and chronic disease, except if those measures impose a disproportionate burden'. To help with those costs, the government provides some funding through the Support Programme for Employment and Vocational Training of People with Disabilities and Incapacities, under certain conditions and to a maximum amount (articles 32 and 34). Funding however, will not be available for cases in which the need for workplace adjustments results from a work accident or an occupational disease (article 33 (2)).

6.4 Financial incentives

There are no direct financial wage subsidies for employers to hire disabled people in the open labour market, although some assistance is available with reasonable accommodations. However, given the high rate of unemployment across the country, in consequence of the current economic and fiscal crisis, the government has recently created the new Programme *Incentivo Jovem*. This scheme offers deductions of social security contributions to employers who hire long-term unemployed youth, 18-30 years old, including youth with disabilities. Financial incentives are also available to Sheltered Employment Centres, including subsidies to co-fund expenses of construction, installation and equipment, and expenses with wages and social security contributions.

7. Statistics and data collection

7.1 Official research

The National Institute for Rehabilitation (INR) is the official body responsible for research on disability equality and for the collection of data and statistics

on disability (Decree-Law 217/2007 of 29 May and Order 641/2007 of 30 May). The INR is a public body that operates under the tutelage of the Ministry of Solidarity and Social Security. The INR worked with the national statistics agency to develop the questions about activity limitation that were included in the 2011 Census. In addition, occasionally the INR commissions independent research on disability issues. The most recent studies have been a research on the costs of disability and a study on the discrimination of women with disabilities. Findings reports are published from these studies.

7.2 Census data

The Portuguese Census is carried out every 10 years by the National Institute for Statistics (INE). The 2001 Census included for the first time questions about disability. The data collected through these questions is available for public use on the site of the Institute for National Statistics and was also discussed in a specific paper published in the journal of the INE, Demografia. In the 2011 census, a new set of questions was developed to address disability. The new questions are based on the Washington Group on Disability Statistics methodology. Respondents were asked to indicate the degree of difficulty they experience in everyday life 'as an outcome of their health status or aging'. The following questions were asked: Do you have difficulty seeing, even if using glasses or contact lenses?; Do you have difficulty hearing, even if using a hearing aid?; Do you have difficulty walking or climbing stairs?; Do you have difficulty remembering or concentrating?; Do you have difficulty bathing or dressing yourself?; Do you have difficulty understanding others or making yourself understood? For each question, the following options were presented: A. No difficulty or just a little; B. A lot of difficulty; C. Cannot do at all. The Census took place between February and April 2011. Although some preliminary data from this round is already available that does not include data on persons with activity limitations.

7.3 Labour Force Survey

The Labour Force Survey is carried out every three months by the National Institute of Statistics (INE). Persons with disabilities are usually not identified in the survey but in 2002 they were included in a special module. This happened again in the module that accompanied the application of the LFS in the second trimester of 2011. The module Employment of Persons with Disabilities 2011 (EPD 2011) targeted persons with disabilities aged 15-64, living in Portugal. The module aimed at providing information about the situation of persons with disabilities in the labour market, compared with that of persons without disabilities. Persons living in collective accommodation such as hotels, pensions and institutions, and individuals living in mobile homes were excluded from this survey. The EPD 2011 module included 11 indicators to describe the main long-term health problems, the main activity limitations and the limitations and special needs that result from them: four indicators to identify the two major health problems and the two major difficulties in daily life activities (19 questions); three indicators to evaluate the association between health problems and difficulties in daily life activities and limitations in the work schedule, the work tasks and transportation to and from work (12 questions); three indicators to determine needs for assistance with health problems or with daily life activities (three questions); and one indicator to identify the main causes of limitations in work abilities (10 questions). Data from this module is not yet publicly available.

7.4 Disability equality indicators

The National Institute for Rehabilitation (INR, I.P.) is the official body responsible for developing disability equality indicators. However, to date those indicators have not yet been developed.

8. Awareness and external action

8.1 Awareness raising programs

According to Decree-Law 217/2007 of 29 May, the National Institute of Rehabilitation is the public body responsible for promoting and raising disability awareness activities. The National Disability Strategy, ENDEF 2011-2013 (Resolution of the Ministers Council No. 97/2010) identifies five key areas for policy development. Under the first heading, 'Disability and multidiscrimination', a number of measures to fight multiple inequalities and discrimination are listed, including measures to promote and raise public awareness and train professionals. Some examples are: launching awareness raising campaigns at schools and in workplaces; launching an awareness raising campaign on the topic of disability and employment; raising awareness about accessible tourism among tourism agents and implement training programs for staff; implementing disability awareness programs for journalists and other professionals working in cultural facilities, health care services, as well as to front-desk civil servants from various departments; producing the weekly TV show Consigo (a magazine dedicated to disability issues) in partnership with the public channel RTP. However, as stated in the 2012 Monitoring Report of the ENDEF, given the current fiscal crisis of the State, with the exception of the magazine Consigo, most of the measures included have been suspended or delayed. Every year the INR provides funding to support disabled people's organisations including to organise awareness raising activities.

8.2 Training for teachers

Disability awareness/equality issues are not a compulsory part of initial teacher training programs in Portugal. However, over the last decade, and particularly since Decree-Law 3/2008 on Inclusive Education was issued, a number of training programmes started to become available for teachers in

this area. Therefore, currently the following options are available: optional units about special education in some initial teacher training programmes; Postgraduate Diplomas, Master's and PhDs programs and specialised programmes in special education and early intervention as well as the possibility of developing research, theses and academic work on the topic of special education. There is no requirement for the involvement of disability organisations in these teacher training programmes and although some schools promote it, it remains quite an infrequent practice. The National Institute for Rehabilitation (INR) offers every year a number of short training programmes on disability awareness and equality issues that are available to professionals in all areas of work, including teachers. The involvement of disability organisations as trainers in this training is not a current practice.

8.3 Training for lawyers

Disability awareness/equality issues are not a compulsory part of initial professional training programmes for lawyers in Portugal. However, the subject of the human rights of persons with disabilities is addressed in Human Rights Courses in some schools (e.g. the School for Social and Political Sciences of Technical University of Lisbon). The only initiative that we are aware of in this domain has been the post-graduate diploma on the topic of Law and the Rights of Persons with Disabilities, launched by the Law School of the University of Lisbon in 2009/2010. This specialised training programme was undertaken in collaboration with a disability organisation; LIGA Foundation. The National Institute for Rehabilitation (INR) offers every year a number of short training programmes on disability awareness and equality issues that are available to professionals in all areas of work, including lawyers. The involvement of disability organisations as trainers in this training is not a current practice.

8.4 Training for doctors

Disability awareness/equality issues are not a compulsory part of initial medical training programs for doctors in Portugal. The National Institute for Rehabilitation (INR) offers every year a number of short training programmes on disability awareness and equality issues that are available to professionals in all areas of work, including doctors. The involvement of disability organisations as trainers in this training is not a current practice.

8.5 Training for engineers

Disability awareness/equality issues are not a compulsory part of initial training programmes for Engineers in Portugal. However, the University of Trás-os-Montes e Alto Douro has created a bachelor degree in Rehabilitation Engineering and Human Accessibility. The National Institute for Rehabilitation regularly offers short training courses on accessibility for engineers, architects, designers, etc. The involvement of disability organisations as trainers in these training courses is not a current practice. However, a disability organisation, the LIGA Foundation, has offered some training for these professionals, notably the Postgraduate Diploma on Design for Diversity, in 2007, in partnership with Technical University of Lisbon and. LIGA is also launching, in September 2011, two new programmes: a Postgraduate Diploma on Accessibility Advisory (with Fernando Pessoa University) and another one on Inclusive Projects (in partnership with ISCTE-IU).

8.6 International development aid

Disability is a topic identified in the bilateral agreements that the Portuguese government has signed with the following states: Spain, Algeria and Cape Verde. These agreements focus on cooperation and exchange of information on a diversity of themes, including that of disability. The Community of

Portuguese-speaking Countries (CPLP) is also starting to address disability. In the 16th Ordinary Meeting of the Council of Ministers of the CPLP, which took place in July 22nd, 2011 in Luanda, Angola, disability was recognised as a human rights issue and a topic of exchange and international aid among partner countries.

Summary

This review of legal and political instruments relevant to disability in Portugal conducted in light of the Convention pinpointed a number of gaps and inconsistencies that must be remedied. The following needs are particularly important⁵:

- Appoint an independent body to monitor the Convention and ensure the participation of civil and particularly disability organisations in the monitoring process
- Change the electoral law to include electronic voting to ensure equality in the exercise of this right for voters with and without disabilities
- Obey, enforce and supervise compliance with the accessibility law and continue actions set out in the PNA and ENDEF concerning buildings and transports
- Enforce the ENDEF, particularly with regard to support for an independent life and its goal of implementing a pilot personal assistance service
- Review legislation on legal capacity and incompetence so that it complies with Article 12 of the Convention.
- Intensify efforts to raise awareness and educate professionals and society as a whole on disability from the perspective of human rights;
- Collect statistics on the situation of persons with disabilities in Portugal and systematically monitor their life conditions and human rights

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⁵ This analysis was completed in December 2011 and so does not contain the changes made to laws and policies in Portugal after that.

Review legislation on the education of persons with disabilities, such as
the criteria for use of the CIF when assessing special education needs
and guarantee human and technical conditions in the field for inclusive
education and support for disabled students in higher education.

Conclusion

This study monitored the human rights of persons with disabilities in Portugal by collecting and analysing personal accounts and conducting a critical appreciation of current disability policies and legislation. The research used the method and instruments developed for the Disability Rights Promotion International project and used the Convention on the Rights of Persons with Disabilities as a reference. Thirty-two in-depth interviews were conducted with adults of both sexes with a wide range of disabilities living in different parts of the country. This sample, which was not intended to be statistically representative of the disabled population in Portugal, was diversified enough to identify issues and problems that reflect the experience of many persons with disabilities in Portugal. In the last part of the report, we have endeavoured to use their experiences to identify the gaps and tensions in current legislation and policies that need to be eliminated and corrected as soon as possible.

Our analysis of these personal histories revealed countless examples of discrimination, which are reflected in experiences of denial or violation of human rights in many areas of life, but particularly in the fields of social participation, access to support services and participation in the labour market.

Where social participation was concerned, the experiences of segregation and isolation identified were due essentially to lack of access to buildings, transports and communication systems. Although Portugal has laws on accessibility to means of information and communication (Decree-Law 163/2006 of 8 August, Council of Ministers Resolution 107/2003 of 12 August, Council of Ministers Resolution 97/2010 of 14 December and Decree-Law 58/2004 of 19 March), persons with disabilities often experience discrimination and marginalisation due to lack of accessibility. This expressive result points to the urgent need to step up the efficacy of supervision of enforcement of this legislation, as indicated in previous studies (see Teixeira, 2010, for example).

At present, the guarantee of accessibility is still compromised by the austerity measures introduced to deal with the crisis in Portugal, such as budgetary restrictions on public transport companies. The purchase of accessible vehicles has been postponed and no alternative, less costly solutions are being considered for removing barriers in access to transports, such as removable ramps.

Insufficient or inappropriate support for an independent life, such as shortcomings in personalised support services is another significant constraint that was highlighted by this study and seriously inhibits the exercise of human rights by persons with disabilities in Portugal. While the position of personal carer does not figure in Portuguese legislation, thereby perpetuating the dependency of persons with disabilities on their families, it is also true that the options offered by the state are insufficient, due to the tiny subsidy currently available for personal care and the poor, incipient coverage of home care services in the promotion of independence for persons with disabilities. As documented in the literature (Pinto, 2011; Portugal, 2010), this study also found that lack of personal care services places a heavy social and economic burden on persons with disabilities and their families, as they are forced to seek private solutions to achieve independence and participation for them.

This burden is particularly heavy in view of the poverty in which most of the disabled population lives in Portugal, as previous research has shown (Portugal, coord., 2010; Sousa et al, 2007). Even in this study, which was based on a sample mainly comprising educated persons in paid jobs, we found discrimination as a result of inappropriate and insufficient social security policies.

Equally important to the independence and self-determination of persons with disabilities is their access to support technologies. Portugal currently has some solutions, such as the National Support Product Allocation System (SAPA), which was set up by Decree-Law 93/2009 of 16 April and Decree-Law 42/2011 of 23 March. However, as shown by the accounts gathered in this

project, access to assistance devices in Portugal generally involves a very long, difficult, bureaucratic process, which raises serious obstacles to access to an independent life.

The third issue raised in the interviewees' accounts is the continued existence of pejorative social representations of disability in Portuguese society. The lives of persons with disabilities in Portugal are still strongly affected by discrimination resulting from prejudices and negative stereotypes regarding disability. According to the data, this is constitutes a decisive limitation in all areas of life in society, though it is particularly significant in the context of the labour market. In spite of government employment policies, such as the Anti-Discrimination Law, disability-based labelling is a clear obstacle to access to jobs or career progression. It is therefore essential to take measures to combat and prevent society's negative attitudes by educating society and raising its awareness. This entails including disability in the initial training of professionals in education, health, engineering, architecture and design in order to promote the human rights perspective. It is also important to reflect on the efficacy and efficiency of government employment measures, such as the job quota law, which resulted in disabled workers in the civil service totalling less than 1% of all public servants (Anjos and Rando 2009).

Finally, this study shows that many persons with disabilities, even those with high levels of school attainment and economic insertion, are still largely unaware of their rights and how to enforce them, which suggests a need to take action to empower them for active participation in defending their rights.

In addition to these issues that emerged from our analysis of the interviewees' accounts, our review of legislation and policies on disability showed further insufficiencies and shortcomings in Portuguese law when compared to the state's commitment when it ratified the Convention on the Rights of Persons with Disabilities. While it is true that fiscal restrictions resulting from the Memorandum of Understanding signed in May 2011 may prevent the full implementation of the National Disability Strategy, it is important to point out

the main needs identified at this level, in the certainty that many of them do not require more than political will to be met. They are as follows:

- Form a body to monitor the Convention and ensure the participation of civil and particularly disability organisations in the monitoring process
- Change the electoral law to include electronic voting to ensure equality in the exercise of this right for voters with and without disabilities
- Review Portuguese legislation on legal capacity and incompetence so that it complies with Article 12 of the Convention
- Gather statistics on the situation das persons with disabilities in Portugal and systematically monitor their life conditions and exercise of human rights
- Revise the legislation on the education of persons with disabilities, including the criteria for using the CIF when assessing education needs and guarantee the technical and human conditions in the field for inclusive education and support for disabled students in higher education

In short, fighting discrimination and violation of the human rights of persons with disabilities in Portugal means adjusting legislation, policies and mentalities in a general process of social change that can only be achieved if everyone is involved. It requires the state, civil society and especially the active, informed participation of persons with disabilities and their organisations. We hope that this report will be a contribution to this ongoing process.

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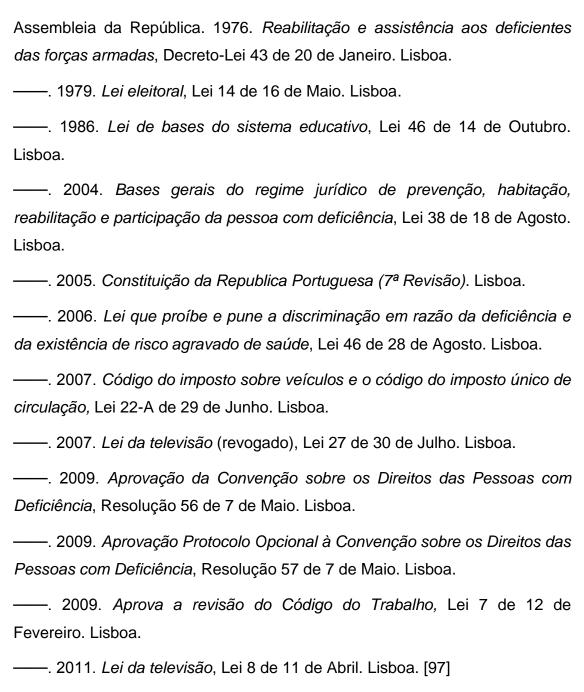
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