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## **REVIEW OF PORTUGAL: NEGLECT OF COMMITMENTS AND AUTISTIC PERSONS**

Autistic Minority International is a Geneva-based NGO. It is the first and only autism self-advocacy organization – run by and for autistic persons – active at the global political level. We aim to combat bias and prejudice and advance the interests of an estimated seventy million autistics, one percent of the world's population, at and through the United Nations, World Health Organization (WHO), human rights treaty bodies, and other international organizations. Autistic Minority International is an associate member of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO), a member of UNICEF's Global Partnership on Children with Disabilities (GPCwd), and a partner in the WHO's Mental Health Gap Action Programme (mhGAP).

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### *Introduction and executive summary:*

Disability in Portugal is addressed by a voluntary charitable approach, instead of being viewed as a mandatory human rights commitment. There are as many rules and laws concerning disability as there are different interpretations and practices. The rights of autistic persons are considered even more subjectively in daily living. Consequently, autistic persons' rights are constantly neglected. Autism is either understood as a cognitive intellectual disability or as an emotional disturbance, but rarely as a lifelong and equally valid neurological difference. Therefore, supports put in place tend to rely on the medical paradigm of disability, which is totally inappropriate to support autistic persons' needs. Legislation has been adopted to stop discrimination, but the culture of prejudice is ingrained in practices and customs. Persons with disabilities are often disregarded from public concerns and this reinforces stigma and exclusion, jeopardizing the possibility for many autistic persons to have a free and independent life in Portugal. Not enough data is collected to fully characterize the living conditions of this population, and autistic voices aren't heard in fundamental matters, such as health care, inclusive education, employment, independent living, and participation in public and political life. Autism is included in the major disability scenario, which however lacks recognition of autistic persons' specific needs and challenges. Similarly to other groups of persons with disabilities in Portugal, autism is often addressed with the promotion of outdated practices, instead of the implementation of mechanisms to assure that all clauses of the Convention on the Rights of Persons with Disabilities (CRPD) are respected and fulfilled.

*Article 24 – Education:*

Article 24 of the CRPD affirms the right of persons with disabilities to quality education in an inclusive system, directed to the full development of human potential and sense of dignity and self-worth. Unfortunately, this is far from being common practice in Portugal. Despite the approval of legislation that foresees accommodations for students with special needs, the lack of human resources in schools – both specialized teachers and daily activities assistants – and the broad culture rooted in the educational system of low expectations and presumption of incompetence towards disabled students represent serious barriers to the development of personal skills and academic knowledge.

The general unfamiliarity with the state of the art regarding autism and autistic persons' perspectives and the stereotypes that still persist around this neurological condition make it harder for autistic students and their families to get the supports they need in order to have successful educational experiences.

Furthermore, parents are often pressured to agree to "specific individual curricula" for autistic students which prevent them from studying subjects that are considered the bottom line for the rest of the school age population. The "schools of reference" network established in Portugal, with special units dedicated to autism, instead of promoting the inclusion of autistic students in regular classes and activities, may create segregated places inside the school.

This set of circumstances ends up excluding autistic children and teenagers from regular classrooms and many school activities, doesn't allow them to develop age-appropriate social skills and intellectual abilities, and deprives them of being involved and actively participating in the nourishment of a diverse school culture.

When confronted with contexts of discrimination and segregation, autistic children lack interpretative and argumentative abilities to properly address situations, because they weren't taught to critically analyze and react to abuse, nor to associate lack of power and privilege with the status of disability. Instead, many grow up being constantly put aside, in special settings, with special curricula, attending special events. They are taught what is needed to become institutionalized.

To prevent this educational deficit, it would be highly recommended that schools strictly follow "least restrictive environment" policies, ensuring that autistic students learn amongst same-age disabled and non-disabled peers and follow the national curriculum, with the necessary accommodations and supports.

"Least dangerous assumptions" should also be put into practice, meaning that decisions on autistic children's education should be based on premises that provide least restrictions to future independent functioning. Rather than anticipating problems and difficulties, even before a student arrives at school, the general culture of low expectations towards autistic persons needs to be challenged and changed.

Parents' recommendations must be seriously considered by school administrations and the right of autistic children and teenagers to be heard and participate in the decision-making process concerning their future must be respected. Mechanisms need to be put

in place in order for national recommendations and guidelines, as well as article 3 of Decree-Law 3/2008, to be implemented, respected, and monitored.

Difficulties escalate in the transition to high school, when autistic teenagers are often directed to the vocational training available, regardless of their motivation and personal goals. The lack of proper special education supports in mainstream environments makes it impossible for many to pursue their inner interests and complete formal education.

In fact, most teachers in high school never had and don't expect to have autistic students in their classes and are very reluctant to accept them and provide the educational accommodations dictated by law. Family complaints are often dismissed and parents ignored and discredited.

It is important to consider that the great majority of students who don't follow the regular curriculum in Portugal aren't subjected to national exams and evaluations. Therefore, devising alternative curricula for pupils with lower grades, special needs, and autism may become an appealing practice, both for teachers who decrease their range of responsibility and for school directors that can artificially improve the school's status in the national ranking.

#### *Article 25 – Health:*

Implementation of the health provisions outlined in article 25 of the CRPD is hindered by the fact that there isn't an articulated national plan to address autistic persons' health needs. The national plan for mental health (2007-2016) is very generic, and neurological differences such as autism require a specific approach. Information about and understanding of autism in medical settings is insufficient and many professionals – general practice and hospital doctors, dentists, nurses, assistants, administrative staff, and so on – lack essential knowledge of autistic children and adults' particularities and challenges.

Autistic persons don't get the specialized services and supports they require, for example with regard to frequent co-morbidities such as anxiety and depression. There aren't enough psychiatrists, psychologists, and therapists in the public health system to meet the demand. Waiting lists exist to obtain an autism diagnosis, and the general perception is that getting a diagnosis is even more difficult for girls and women. Access to private health services covered by the government is full of bureaucratic hurdles and administrative procedures that may be particularly hard to navigate for autistic adults without proper support.

When parents aren't proactive, resilient, and informed, autistic children miss basic medical assistance. The same when autistic children become autistic adults and don't have the skills to self-advocate. Hence, there is a lot of negligence towards autistic persons' health concerns. The situation can get even worse for those who do not speak and have difficulties expressing symptoms, aches, and pains. Augmentative and alternative communication faces prejudice and isn't commonly used. Medical professionals and facilities clearly aren't prepared to properly serve this population.

*Article 27 – Work and employment:*

The provisions of article 27 of the CRPD concerning work and employment also aren't fulfilled. Despite financial aids and incentives granted to companies to employ persons with disabilities, managers are very reluctant to use the mechanisms in place. Public authorities should act as role models in this area and include autistic persons in their workforce.

It would also be important to closely monitor and evaluate the results of vocational training courses for persons with disabilities, which should aim to reduce unemployment rates among this population, promote effective job opportunities, and not only assume the form of a recurrent occupational activity. Autistic persons' vocational training should not represent just another form of income for disability-related associations and institutions. It must have a real impact on the long-term employment of the autistic population, about which no reliable data is being collected in Portugal.

Individualized reasonable accommodations in the workplace should be promoted and encouraged as a regular practice and baseline in any developed organizational culture and not only regarded as an inconvenience employers have to endure. A paradigm shift needs to happen, so that autistic persons are perceived as a valid human resource, able to make an effective and valuable contribution to any business and sector of the economy.

*Article 28 – Adequate standard of living and social protection:*

It is very questionable whether the majority of autistic persons in Portugal enjoys an adequate standard of living and efficient social protection, as required by article 28 of the CRPD. The "lifetime monthly benefit", meant to support the livelihood of persons with disabilities that can't provide for themselves, currently stands at €176.76. In 2005, this benefit represented 41.5% of the national minimum wage, while in 2015 it only equalled 35%. This is clearly not enough to ensure a life with dignity, being way below the poverty line.

*Article 29 – Participation in political and public life:*

The essential basis for the participation of autistic persons in political and public life, following article 29 of the CRPD, does not exist in Portugal. There are no autistic self-advocacy organizations, run by and for autistic persons, and there is a lack of autistic representatives in organizations and initiatives which address autism and disability, public and private alike. Without a platform of independent self-advocates, discussion and inner knowledge of the specific issues this population faces, there will be neither effective participation nor real inclusion. A national platform of self-representatives with intellectual disabilities is being established in Portugal, but it's important to highlight that it is managed and coordinated by disability-related institutions and doesn't apply basic principles upheld by autistic self-advocacy groups worldwide.

To pave the way for autistic persons' representation in civil society and politics, it should be recommended that the Portuguese national administration appoint autistic persons to participate in all initiatives and projects concerned with disability affairs. The staff of

entities like the "National Institute for Rehabilitation" (INR) and juries of national competitions like "School Alert" should be diverse and include persons with different kinds of abilities and perspectives, including autistic persons. That would ensure that a wide range of needs and assets are taken into account in the national framework.

Autistic persons should also have a place on the boards of autism and disability organizations and be encouraged to organize independent autistic groups, outside the realm of parents, therapists, medical establishment, and current associations.

*Article 30 – Participation in cultural life, recreation, leisure and sport:*

Despite article 30 of the CRPD regarding participation in cultural life, recreation, leisure, and sport, there are frequent informal reports by parents of autistic children who are denied the right to participate in one or another activity in the community. Whether it is music lessons or sports, religious instruction or cultural events, the refusal to accept registrations or the demand to evaluate autistic children prior to admission are so common that they are taken for granted.

*Article 5 – Equality and non-discrimination:*

The legislation forbids discriminatory practices, but contrary to article 5 of the CRPD, which demands equality and non-discrimination and effective legal redress, the judicial procedures discourage complaints. The legislation is not respected, and the mechanisms to enforce its application are slow and ineffective. The general feeling is that the rights of persons with disabilities can be ignored completely, even as it concerns persons with physical disabilities, where everything can be proved and understood more easily. It becomes much more subjective and difficult for autistic persons to claim their rights. Going to court is a nightmare, and when parents of autistic children and autistic adults have so many daily battles, the last thing they want is to waste time, energy, and money on a lost cause.

*Article 8 – Awareness-raising:*

In this context, there is little point in requesting more demanding anti-discrimination legislation. Instead, in line with article 8 of the CRPD on awareness-raising, public campaigns should be launched to change people's mindset and reinforce the rights of disabled persons to full and equal participation and involvement in life in the community. There is also the need to empower the autistic population through specific initiatives that highlight human rights and to implement procedures that turn those into effective daily practices.

*Article 12 – Equal recognition before the law:*

The provisions of article 12 of the CRPD enshrining equal recognition before the law and guaranteeing persons with disabilities legal capacity aren't properly addressed in the Portuguese legislation. People with a "mental anomaly" (autism can easily fall into this category), deafness, or blindness can have their legal capacity taken away, at the request of parents, spouses, other family members, or even the "Public Ministry".

Autistic persons are particularly vulnerable to this kind of abuse and particularly ill equipped to defend themselves against it, due to difficulties in communication and lack of support to participate in legal processes.

*Article 14 – Liberty and security of the person:*

Institutionalization of autistic children, teenagers, and adults is a matter of concern, when it comes to the deprivation of liberty and security of the person confronted by article 14 of the CRPD. There is no reliable available data, and autism can certainly go undetected, while autistic persons are misdiagnosed with some other psychiatric condition and/or an intellectual disability. In 2013, 20% of all children who were institutionalized in Portugal had a disability. It would be important to know how many of those are autistic and need proper care and most of all if appropriate supports are in place.

*Article 19 – Living independently and being included in the community:*

Specifically regarding article 19 of the CRPD, it should be considered that persons with disabilities living independently and being included in the community is making its first steps in Portugal, and it would be of the utmost importance that this philosophy could spread all over the country and be available to persons with all kinds of disabilities, including autism.

All organizations that are committed to the goal of independent living in Portugal should be consulted, in order for the process to have solid roots from the beginning. It is highly recommended that not only physical disabilities are taken into account, but also intellectual and invisible ones.

Financial funds need to be allocated to make independent living a reality. Autistic persons could benefit a lot from this concept, and with proper support, community living could be successfully achieved by many of those who nowadays face exclusion and lack of perspectives for the future.

*Conclusion:*

In summary, Portugal has a long way to go with regard to respect and implementation of disability rights. Social constructs regarding autism and autistic persons are ingrained with ableism and prejudice which represents a huge barrier to autistic persons' enjoyment of fundamental standards set by the CRPD.

Thank you for your consideration.

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Autistic Minority International