

Groupe d'Action qui dénonce le Manque de Places  
pour les personnes handicapées de grande dépendance



# MEMORANDUM 2019 EUROPEAN ELECTIONS

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# INTRODUCTION

**GAMP** is a citizens pressure group that advocates for specialised support and adapted care for disabled people with complex dependency needs in a society that is inclusive of all types of disabilities.

A person is considered to have complex dependency needs when he/she requires the assistance of another person to carry out simple daily tasks. **According to the latest estimates, there are approximately eighty million disabled people in Europe and approximately five million people with autism\*.**

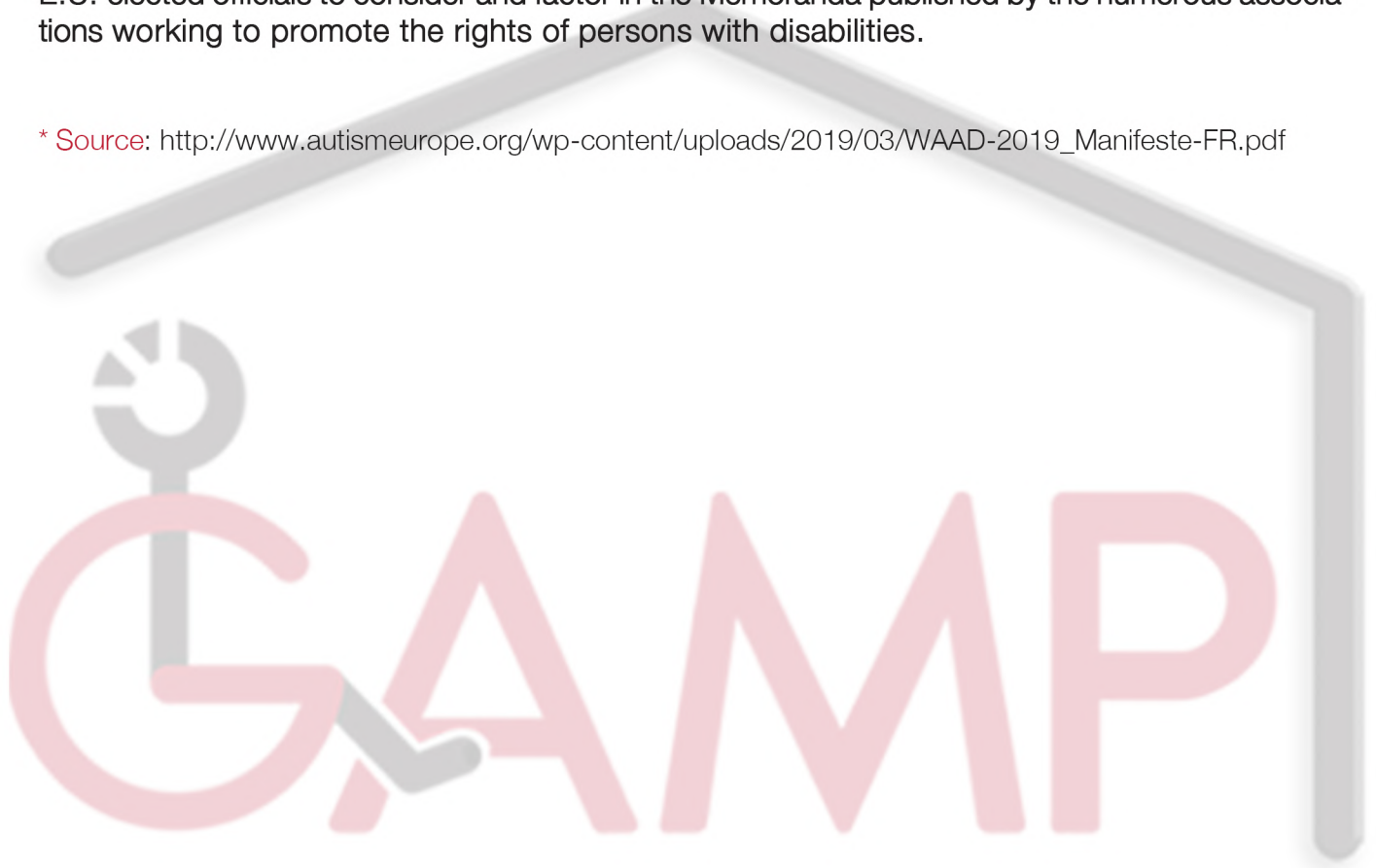
The target audience of GAMP's Memorandum presented hereinafter are the **European candidates in the May 2019 E.U. elections**. Our Memorandum is based on multiple, extensive contacts with disabled persons' families, government officials, politicians and members of associations working in the field of disability.

**We call for the respect of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and request that future E.U. elected officials spare no effort in ensuring the effective E.U.-wide implementation of the Convention.**

By virtue of the principle of subsidiarity, the responsibility for implementing social assistance policies within the E.U. lies with each Member State. E.U. disability policies are therefore not legally binding on Member States. However, by establishing guidelines, **the E.U. can encourage Member States to remove the barriers which countless disabled persons face on a daily basis.**

The Memorandum contained herein is not exhaustive, nor do our demands reflect the full spectrum of disability-related issues. We have chosen to focus on key priority areas. Moreover **we call on E.U. elected officials to consider and factor in the Memoranda published by the numerous associations working to promote the rights of persons with disabilities.**

\* **Source:** [http://www.autismeurope.org/wp-content/uploads/2019/03/WAAD-2019\\_Manifeste-FR.pdf](http://www.autismeurope.org/wp-content/uploads/2019/03/WAAD-2019_Manifeste-FR.pdf)





# THE E.U.'S DISABILITY POLICY: OBSERVATIONS AND CONCERNS

E.U. officials have been decidedly slow to include social issues on their political agendas, but slower still as regards disability: **the extremely slow emergence of the E.U.'s disability policy is indeed striking.**

It is fair to state that the E.U. still has a long way to go before its disability policy is a truly inclusive one.

The 1997 Treaty of Amsterdam explicitly refers to the issue of disability, thus establishing the milestones of the E.U.'s disability policy. This Treaty provides the E.U. with the legal basis to combat all forms of discrimination.

However, the Treaty of Amsterdam is based on non-binding legal rules under which **neither the E.U., nor equal-opportunity-promoting bodies may turn to the European Court of Justice in proven cases of violation** of Article 13 of the Treaty.

By virtue of the principle of subsidiarity, the European Disability Strategy 2010-2020 for persons with disabilities is **not legally binding** either. However, via its Disability Strategy, the E.U. is in a position to set guidelines aimed at reinforcing the effective E.U.-wide implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

**The European Disability Strategy 2010-2020\*** should therefore also, in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), **guarantee that disabled persons and disability-related issues are fully included in all of the E.U.'s spheres of competence.**

\* **Source:** <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM%3A2010%3A0636%3AFIN%3Aen%3APDF>





We deplore, however, the E.U.'s excessively restrictive approach to its own European disability policy.

The European Commission has indeed narrowed its sphere of action to eight priority areas, as defined in its Disability Strategy 2010-2020:

- **Accessibility:** people with disabilities have access, on an equal basis with others, to the physical environment, transportation, information and communications technologies and systems (ICT), and other facilities and services.
- **Participation:** these are rights linked to E.U. citizenship (the right to free movement, to choose where and how to live, and to have full access to cultural, recreational, and sports activities).
- **Equality:** equal treatment of people with disabilities.
- **Employment:** enable many more people with disabilities to earn their living on the open labour market.
- **Education and Training:** promote inclusive education and lifelong learning for pupils and students with disabilities.
- **Social Protection:** promote decent living conditions for people with disabilities.
- **Health:** foster equal access to health services and related facilities for people with disabilities.
- **External Action:** the area of emergency and humanitarian aid.

Additionally, the above policy contains **no provisions whatsoever on the establishment of adapted support services and care facilities for disabled persons with complex disability needs**. And yet in many cases, alternate solutions to mainstream schools are required.

Moreover, people with severe disabilities are not always able to access the labour market. Alternate options have yet to be considered and developed.

While the right to housing is a fundamental right guaranteed by the Universal Declaration of Human Rights, it must be noted that **disabled people with complex disability needs still have difficulty finding housing and a certain level of autonomy** that is essential to their well-being.

Being inclusive of all categories of persons with disabilities is all the more important as **autism is sometimes described as an invisible disability**, which leads to a situation in which the specific needs of autistic people in terms of accessibility and support are often neglected.

Inasmuch as disabilities impact on each and every aspect of community and social life, **the European Union should integrate to a far greater extent the rights and freedoms of disabled people into the totality of its spheres of competence**.

# OUR KEY PRIORITY DEMANDS

Hereinafter are GAMP's **six key demands** in the framework of the May 2019 European elections. Additional demands can be found in the following chapters. We call for:

**1. Including the fundamental rights and freedoms** of persons with disabilities in all European programmes and policies, in accordance with the United Nations Convention on the Rights of Persons with Disabilities.

**2. Improving and providing lifelong care and support for disabled people with complex disability needs on the basis of their specific needs.**

**3. The participation of people with disabilities in political life** at both the national and European levels.

**4. A European employment policy which provides better quality care and support structures** for disabled people via favourable tax mechanisms aimed at facilitating and enhancing the mobility of goods, services, and health professionals across Europe.

**5. The implementation of the Anti-Discrimination Directive: the Goods and Services Directive.** We call for an inclusive definition of disability on the basis of the definition contained in the UN Convention on the Rights of Persons with Disabilities, as well as a favourable tax scheme (see above) in order to increase the mobility of goods, services, and health professionals.

**6. The implementation of a European strategy for autism.** Assessing the number of autistic people and the prevalence of autism in the European Union is crucial. We also request that cross-sectoral national action plans be established in order to respond to the needs of people with autism so that they may fully participate in the life of the community and society as a whole.

# I. DESIGNING AN INCLUSIVE, HOLISTIC APPROACH FOR THE FUTURE EUROPEAN STRATEGY

## We call for the following:

- Improved and enhanced lifelong support and care for disabled people with complex disability needs by better acknowledging and taking into account the specificity of their needs:

### → Early childhood support and care:

Adapted interventions during early childhood are crucial in order to avoid compounding multiple disabilities over the course of a person's life. This is especially true for less visible disabilities such as autism.

Crucially, the European Union must encourage Member States to set up a sufficient number of support and care services and facilities in order to meet current and future needs, and tackle long waiting lists.

### → Teaching and education:

While the inclusion of students with disabilities in mainstream schools is a right that must be respected, such an inclusion may at times not be possible due to the complexity of the special needs of some disabled persons.

In light of the above, we call on and expect the European Union to support the creation of smaller support and care structures that are tailored to the specific needs, age group and type of disability of young persons with disabilities.

### → Lifelong support and care throughout adulthood:

When disabled children become adults and leave school or a specialised centre, they are not all equally capable of finding a job and face a dearth of adapted support and care solutions.

To remedy the above situation, we call on and expect the E.U. to encourage all Member States to develop projects aimed at establishing small residential facilities which will provide daily activity services and day-care centres. Such structures should be based on actual requests/requirements and tailored to the specific needs of individual profiles. We call on and expect the E.U. to make funds available to finance such projects.



- **Effective recognition of the status of carers.**

Across the European Union, countless carers live in poverty after having no other alternative but to abandon their jobs in order to care for a disabled child or relative.

In order to improve carers' living conditions, we call on the European Union to officially recognise the status of family carers in its future employment strategy, and to provide an adequate level of compensation or income to carers.

- **Including the fundamental rights and freedoms of persons with disabilities in all European programmes and policies.**

We call on the European Union to foster the inclusion of disabled people in all aspects of life. Specifically, we request that the European Pillar of Social Rights and related initiatives be implemented.

Working hand in hand with the European Disability Forum and the non-profit Autism-Europe, we advocate for a social protection floor for disabled persons with a view to promoting employment, inclusive workplaces and adequate services to foster the inclusion of persons with disabilities.

- **The participation of persons with disabilities in national and European political life** via a structured, permanent and transverse consultation mechanism covering the full spectrum of the E.U.'s spheres of competence in accordance with the United Nations Convention on the Rights of Persons with Disabilities.

## II. EFFECTIVE ANTI-DISCRIMINATION ACTIONS

The E.U.'s adoption of the Treaty of Amsterdam provided it with the **legal basis to prevent and combat all forms of discrimination**, including discrimination on grounds of disability.

"Without prejudice to the other provisions of this Treaty, and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission, and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation." (Article 13 of the Treaty of Amsterdam)

However, Article 13 above is part of the E.U.'s **non-legally binding** "soft law". Therefore the E.U. has no legal authority to enforce compliance with Article 13 or take punitive action against non-compliant Member States.

In light of the above, on July 2, 2008, the European Commission put forward an anti-discrimination directive, the Goods and Services Directive, **the aim of which is to expand the protection of European citizens against multiple forms of discrimination in the fields of social protection, healthcare, housing and access to goods and services**. However, the text is currently blocked at the level of the European Council and only discrimination in the fields of employment and professional training are currently prohibited under a European Directive.

**We call for the adoption of the Goods and Services Directive** and have aligned ourselves with the European Association of Service Providers for Persons with Disabilities' demands (EASPD).

### WE CALL FOR:

- **the inclusion of provisions granting the right of access to support services** for persons with disabilities.
- **an inclusive definition of disability** in accordance with the definition contained in article 1 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).
- **the inclusion of clear and straightforward clauses on special education needs**, the integration of children with disabilities into the education system, and the opportunity of lifelong learning for all.
- **favorable tax schemes to enhance the mobility of goods, services and health professionals** in order to improve the support and care for persons with disabilities.



### III. A EUROPEAN STRATEGY FOR AUTISM

In September 2015, the European Parliament officially adopted the Written Declaration on Autism which was co-signed by 418 Members of the European Parliament. The Written Declaration on Autism calls on the European Commission and Council to adopt a European strategy for autism.

As is the case for all persons with disabilities, autistic people across Europe also face similar challenges in myriad aspects of their daily lives. It is therefore essential to adopt a robust European strategy for autism which **encourages the exchange of best practices, fosters cooperation and improves the daily lives of people with autism.**

We support the adoption of the European strategy for autism. As the post 2020 European Disability Strategy already provides for, the European strategy for autism should also put forward **measures aimed at including persons with autism in all sectors of society and community life** in accordance with the UNCRPD. The European strategy for autism should therefore **guarantee that the specific needs** of autistic people are factored into the full range of political actions and life.

#### WE CALL FOR :

- **An assessment of the prevalence of autism** in the population of the E.U.
- **Cross-sectoral national** action plans to meet the needs of autistic people and foster their full participation in the life of the community, in accordance with the United Nations Convention on the Rights of Persons with Disabilities
- **Setting up a forum** aimed at coordinating E.U. Member States' individual plans, efforts and approaches to autism
- **Collaboration between Member States** in the field of research and researchers' networks in order to improve the quality of life of persons with autism throughout the E.U.
- **Designing an Erasmus programme** specifically focussed on autism for medical students and future health professionals
- **Access to early testing, diagnosis, support and care for children.** The M-C.H.A.T., for example, is an internationally recognised and validated tool for the early detection of autism for children aged 15 to 22 months.
- **Improving the quality of services supporting the inclusion** of autistic persons across the E.U.
- **The participation of autistic people in the construction of the European strategy for autism** via representative organisations and the consultation of all people concerned, at every stage and throughout the entire process
- **Factoring in the diversity of persons with autism** while also taking into account the roles of families as carers on a daily basis



# THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (UNCRPD)

The Convention on the Rights of Persons with Disabilities (UNCRPD) was unanimously adopted by the United Nations General Assembly on December 13, 2006.

The UNCRPD is the **very first international legal instrument** pertaining specifically to the rights of persons with disabilities. This benchmark Convention, a fundamental instrument which provides for the effective protection of the rights of persons with disabilities, **was signed and ratified by the European Union in 2010** and entered into force in 2011.

This was the first time an international organisation ratified a UN treaty. Pursuant to this ratification, **the European Union is legally obliged to abide by the terms of the UNCRPD and adapt its own legislation accordingly.**

The UNCRPD has created a paradigm shift :

- An inclusive **approach to disabilities**: “Nothing about us without us”.
- The European Union has a legal **obligation to abide by the UNCRPD and adapt its own legislation** to the Convention, notwithstanding the gradual nature of such a process:
  - Direct impact of **anti-discrimination provisions**.
  - The legal obligation to ensure the full and **compliant implementation** of the Convention.
  - The standstill effect: **reducing levels of protection** already granted is forbidden.

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