



## European Council of Autistic People

### **Written contribution to the discussion on the General Comment on the right of persons with disabilities to work and employment**

The European Council of Autistic People (EUCAP) is an umbrella organisation of sixteen European NGOs led and run by autistic people, with autistic people forming the majority of their membership. We thank the UN Committee on the Rights of Persons with Disabilities for this opportunity to participate in the General Discussion. We would like to offer the following comments as our contribution to the development of the General Comment on Article 27.

We defend the right to appropriate employment for the members of our community, calling for neurodiversity and the qualities and strengths of autistic people to be valued and respected. Furthermore, we call for a truly inclusive society where this group, as citizens with full rights, has access to active participation and can contribute successfully to society.

#### **Overview of issues specific to autism**

Studies and surveys from several countries suggest that autistic people's employment levels are significantly lower than those of disabled people in general, and that among those who are employed, part-time work, low income and dependence on social benefits are common, including people with vocational or higher education qualifications (1,2) Our observations and local surveys (3) of the autistic members of EUCAP's member organisations agree with these studies. The situation persists despite numerous campaigns and projects that have specifically targeted this population over the past decades.

In addition, as has been observed in a Belgian study (4), there is hardly any “manageable work” available for people with a work related disability. People with a work related disability are more vulnerable to stress, emotional difficulties, lack of task variety and lack of autonomy. They are also bullied twice as much as people without such disability (5).

Many autistic people are not fully recognised as disabled by our states or local authorities and, as a result, do not receive appropriate support, services or reasonable accommodations at levels comparable to other groups of disabled people. Another consequence of this lack of recognition is failure to systematically collect data about our situations, including employment levels, which makes it impossible to monitor any potential improvements with regard to disability rights.

Our disabilities are often difficult to perceive and assess within the state and local service systems we encounter. We do not match stereotypical expectations of how disability should appear, and assessing our needs can require some expertise. In the workplace, we often find that management, supervisors and coworkers suffer from a general lack of knowledge about autism, and accommodations are not fully respected. Similarly, occupational health and human resources departments and professionals have insufficient knowledge, and may base their decisions on stereotypes that should have been abandoned decades ago, equating autism in a simplistic way with self-isolation and intellectual disability.

For many autistic people, differences in communication constitute a severe barrier to suitable employment. Irritations or “peculiarities” are commonly regarded as rudeness or weakness of character or alike; instead of as a different - and often unexpected - way of communicating. On the other hand, communication has become more and more important in working life over the last decades, emphasized even when there is no need for certain communication skills in a particular job.

Research shows that conditions such as depression and anxiety are very common among autistic people (6,7), as well as adverse reactions to ordinary sensory stimuli, leading to stress and fatigue (8), and specific difficulties with initiating activity or switching from one activity to another, known as inertia (9). Other people are known to form negative impressions and avoid interacting with autistic people on the basis of differences in voice, expression and gesture (10, 11). Many of us have individual combinations of subtle differences in perception and cognitive function which can cause impairments in navigating physical environments, language processing, short term memory and directing or maintaining attention. It is known that autistic people in general have lower life expectancy than normal, connected to factors such as co-occurring physical conditions, high incidence of suicide, and facing obstacles in the use of health care services (12, 13, 14). Despite efforts to inform and educate, this type of knowledge does not easily translate into the understanding that an autistic person can be significantly disabled even without a general learning disability or visible co-occurring physical condition. The impairment may not show as any simple outward sign or complete inability to perform any individual task or function, but as a need to expend more time, effort and energy than non-disabled people on various tasks throughout the day, resulting in heightened tendency to stress, fatigue and related health problems.

The overall picture is further complicated by psychological trauma acquired later in life (15). Many autistic people have grown up, studied and started a family and/or a career without knowing they were autistic. They did not know that the problems they often faced were connected to autism. Burnout and other work-related problems often lead to a diagnosis. The consequences of a mental breakdown or burnout often have greater negative impact on the person than the primary autistic characteristics as such.

**To comply with Article 27**, states should fully recognise disabilities associated with complex developmental conditions that have neurological, cognitive, sensory, physical and psychosocial dimensions. These conditions are not adequately covered by any common term under which disabilities are currently grouped. We accept that in the terminology used by the UN CRPD,

autism falls under psychosocial disabilities, but we wish to point out that attempts at simple categorisation can be misleading and sometimes counterproductive to the realization of human rights.

Access to appropriate assessment of functioning is a crucial prerequisite to ensuring the rights of autistic people and other similar groups. In the context of work and employment in particular, it is vitally important that assessment of autism covers all key areas, instead of being limited to psychosocial and learning disability aspects only. Assessment must also take into account the overall stress and strain resulting from the combination of work, family and daily life, instead of assessing disability with regard to individual functions in isolation, which leads to underestimation of support needs. Also, symptoms or impairments observed in everyday situations and real-life tasks should be taken as sufficient reason to provide assessment, rather than requiring a diagnosis.

#### Example: Spain and disability quotas

In countries such as Spain, national law allocates 2% of jobs in companies with more than 50 employees for people with disabilities. However, many companies rarely fulfil this quota, preferring to be fined for non-compliance rather than hire disabled workers.

Furthermore, there are additional barriers for autistic people when applying for employment in public institutions, since the selection procedures only recognize physical, sensory or intellectual disabilities. Most autistic people who wish to gain access to these positions are not recognized as falling within these categories. On the other hand, disabilities are not recognised on the basis of diagnosis. Instead, autistic people must pass a second evaluation of their disability, and most of them do not fit into any of the disability categories. Consequently, the autistic community must try to navigate working life on their own, without any help, support, or reasonable accommodations.

#### Example: Italy and disability quotas

In Italy, the law states that companies with more than 15 employees have an obligation to hire disabled people, but this obligation is often ignored. Companies prefer to pay an administrative fine rather than employ disabled people.

The law is generic for people with disabilities and does not give specific indications in relation to any impairments. Autism is included among the psychiatric conditions and in particular among the psychoses that represent the conditions on which the stigma weighs the most in relation to disabilities.

The placement of autistic people, but more generally for disabled people, through what is defined as "targeted placement" is extremely difficult.

#### Example : France and disability quotas

In countries such as France, national law allocates 5% of jobs in companies with more than 20 employees for people with disabilities. This obligation is often ignored, as companies prefer to pay an administrative fine rather than employ disabled people.

However, the French system allocates the fines to national funds for accommodations: a private fund for private companies and a public fund for public administration (State civil servants, Research Institutes, Schools and similar). These funds decrease if the disability quota rises. In addition, reasonable accommodations (the definition of UN CRPD) is not in the law in France, it is not known. The right to support for disability is recognized, but this support can have various forms, and since the right to reasonable accommodations does not exist as a written rule, employers are not aware of it. Autism has been recognized as a disability since 1996, but it is included in categories such as mental disabilities or psychiatric disabilities, or it is completely unknown in some contexts. The rate of autism diagnoses has been very low in France, and those who are diagnosed are considered to be people with high support needs and minimal employment prospects.

### **The concept of *capacity to work***

While we recognise the right to employment for all as a positive and necessary principle, there is some concern among our members that this can be interpreted as an obligation, generating pressure to pursue employment even when it is clearly unattainable. It can also be taken as signalling that life without employment is a life of less value. In our communities, we have experience of many autistic people trying to conform to social pressure, seeking ordinary employment, and paying the price in the form of traumatic experiences, burnout and long-term mental health issues. Many of them clearly state that they have had to choose between employment and participation in family life, or that they can only be employed while their lives outside the workday are reduced to nothing but basic functions such as eating and sleeping (3). Being pressured to overexertion, or to sacrificing fundamental parts of our lives to ideals of productivity, is a real threat to our rights.

We respect the judgement and choices of those autistic people who have sought disability pension, we value their lives and contributions, and we consider it a serious human rights issue that all who genuinely need this option do not have appropriate access to it. We fear that if the term and concept of *capacity to work* were removed from use, it could become more difficult to advocate for people in such circumstances.

We urge the Committee to exercise caution in recommendations regarding terminology to be used in legislation and guidelines. Instead of being removed from use, *incapacity to work* could be defined similarly to the concept of *disability* itself, in accordance with the Social Model. We suggest that as an official term, incapacity to work should be understood as inability to engage in sustained paid employment, referring to the person's factual circumstances and experienced reality in their current environment, with the understanding that such (in)capacity is not a characteristic of the individual, but an expression of the relationship between individual and society. In this sense, a person could be described as *incapacitated* just as they can be described as *disabled*.

### **On section 2 (vii.) of the Outline (Interpretation of article 27 (d))**

It is stated in the Outline that “*Inclusive education and inclusive vocation training should aim to develop learners’ capacities and confidence and provide learners with reasonable accommodation [ ]*”. The provision of reasonable accommodations in education is a complex matter, requiring negotiation with educational institutions that do not automatically have sufficient understanding of disabilities. In another section of the Outline, *assistance in the implementation of reasonable accommodations to all stakeholders* is recommended, including employers and disabled people. We would like to point out that institutions for vocational and higher education, and the authorities that regulate them, as well as those that grant student benefits, are stakeholders in this matter. Any assistance with reasonable accommodations that employers and employees may need is likely to be necessary for these institutions, as well.

A form of reasonable accommodation that is particularly relevant to autistic students and others with comparable neurological conditions is the extension of study time, allowing for some extra months or even 1-2 years to attain qualifications, coupled with a corresponding extension of crucial student benefits to allow financial survival. In many countries, this kind of accommodation is simply denied. The disabilities that lead to slow progress, or where slowness is the main outward manifestation of impairment (not to be confused with general learning disability), are not well understood or accepted. Authorities refuse to accept that students cannot predict their rate of progress years in advance, but need to find the limits of their capacity, and the support forms that work for them, through extended trial and error. As a result of the refusal to accommodate, many disabled students are left in very difficult situations, with partially completed studies and no resources to continue to improve their employability.

### **On section 2 (x.) of the Outline (Interpretation of article 27 (h))**

EUCAP welcomes the suggestion of programmes that target intellectual and psychosocial disabilities. However, we would like to point out that private entities or NGOs with sufficient resources to run such programmes do not exist in all countries, or for all types of disabilities, and that the results of many programmes of this type have been disappointing. States and international bodies, for example the European Union, should both fund these programmes and monitor their effectiveness. It is important that the scale of the programmes is broad enough. Such programmes should be designed to reach large numbers of people, including those who have difficulty accessing diagnostic services and appropriate needs assessment, and to collect disaggregated data about employment, financial status and quality of life over long periods, exceeding the duration of projects typically run by local NGOs. This is necessary in order to generate a solid evidence base and to identify which groups of people benefit and which do not. The running of numerous local small-scale projects that invent and reinvent employment service models is wasteful and inefficient, disrupts the lives of disabled people who need predictability and reliability from their services, and typically provides no real information about the ability of the new models to bring about significant and lasting change.

Acceptance training has been shown to have positive effects on negative perceptions and bias concerning autism (16). Similar results could probably be attained with many disability groups when stigma and negative perceptions are major factors leading to exclusion from employment.

In order to reduce the barrier resulting from communication differences for those who experience it, awareness of these differences should be increased. People who make recruitment decisions should be trained on this issue.

EUCAP recommends close involvement of NGOs in programmes for people with intellectual and psychosocial disabilities, at all stages, from planning, funding decisions and implementation to assessment and dissemination of results. Such programmes lack credibility if they fail to lead by example. Positive models are provided for example by the Czech POST and PARTA projects (17,18), where autistic people are engaged in supporter and employee roles, providing services to others in the target group.

Example: Italian organisation with relevant knowledge and views regarding programmes

The Italian organisation NeuroPeculiar APS has surveyed 150 autistic people and identified issues that could be targeted in programmes that promote and support employment. For example, the majority of survey respondents who had jobs preferred not to communicate their diagnosis for fear of being discriminated against. The majority also had at least one experience of suffering discrimination or bullying. Most had obtained their jobs without accessing the benefits mentioned in disability legislation. In the companies where they worked, there were no specific inclusion programs for autistic people, and no cultural training courses dedicated to employees and managers. In most companies, there were no environmental adaptations to meet the specific needs of autistic people (for example: noise reduction, lights adaptation, room to relax, etc).

Neuropeculiar APS recommends establishing mandatory training courses within companies in order to change the cultural climate and encourage the acceptance and inclusion of differences. The training must be conceived, planned and carried out with the active contribution of disabled people (therefore autistic people in the case of specific training on autism).

### **On section 3 (b)(ii) of the Outline (Provision of reasonable accommodation)**

For autistic people, as well as many others classified as having psychosocial disabilities, it is important that secondary mental health issues and burnout should be prevented. This can be accomplished by making workplaces more accessible. Furthermore, there is a lot of variation between autistic people. Consequently, they have different needs and requirements, which vary depending on time, place and context, calling for flexibility in the working environment and working conditions. Therefore, the present-day paternalistic perspective on autism is no longer valid. The acceptance of individual needs and requirements is necessary, and employers, as well as society in general, need to realize that autistic employees often have to invest more to obtain the same goals and standards as non-autistic colleagues.

The Covid-19 pandemic has taught us some useful lessons. The confinement measures impacted our work/school related stress. An ongoing study (19) assesses the effects of the Covid-19 measures on both autistic and non-autistic people. The first results show that autistic

people report more impact of the Covid-19 measures, both positive and negative, on their work/school than non-autistic people. The possibility to work from home is one of the reported elements related to positive effects. This can be taken as an indication that more flexibility in the work environment for autistic people can create more integration for them in working life.

A better image of autism can lead to more acceptance and diversity in the workplace. Through this, a workplace can be established where the needs of both employers and autistic employees can be addressed, with better understanding and communication between the parties involved.

#### Example: Inflexible rules and structures

In the German system, inflexibility shows as strict rules governing part-time work, requiring for example that a person works three hours a day on five days per week, instead of longer days on two days per week, even if the latter is the best solution for their individual needs.

In Denmark, there are schemes to support disabled people into IT jobs, cleaning or grocery store work, but there is little available for those with other types of skills.

The Outline mentions that the Committee has recognized that reasonable accommodation must be negotiated with the applicant(s). In this matter, autistic people and many others with intellectual and psychosocial disabilities are not in strong positions to negotiate. When a disability is not recognised, its effects are misunderstood and underestimated, or the disabled person's judgement is incorrectly perceived as impaired, reasonable requests are seen as unreasonable. This is further complicated by impairments that affect a person's ability to describe their needs in a clear and convincing manner. In our experience, employment services and employers lack knowledge of what reasonable accommodation can mean, and are suspicious of autistic people's suggestions.

We welcome the suggestion to provide assistance in the implementation of reasonable accommodations to all stakeholders, including employers and disabled people. This is a matter where full inclusion and active involvement of disabled people is necessary, and especially important to those whose needs are not well understood. Codes of good practice can be part of the solution, but they have limitations. The interpretation of such codes in real-life situations would still require in-depth knowledge of many different types of disabilities. We recommend extensive and permanent integration of experience-based expertise into employment services. This could be accomplished through close cooperation with NGOs and by employing disabled people to work within national and regional employment service systems.

### **Examples of good practice at national level**

#### ***Autisme Ambassade, the Netherlands***

The cooperation of Dutch ministries and public service organisations with the *Autisme Ambassade* network (20) is an example of using resources in a positive way, involving disabled

people in long-term active roles where their experience-based expertise benefits both jobseekers and companies, and changing people's perceptions of a stigmatized group.

### ***Nederlands Autisme Register, the Netherlands***

The Dutch Autism Register is an example of the kind of long-term data collection that is needed as a basis for effective programmes. It allows analysis of the needs and wishes of the target group, which supports the design of new programmes, and it allows independent monitoring of the effects of programmes at the national level.

### ***De Vlaamse Werkbaarheidsmonitor, Belgium***

*De Vlaamse Werkbaarheidsmonitor* is a resource provided by SERV, Sociaal Economische Raad voor Vlaanderen, the advisory board concerning all social-economic matters for the Flemish government and Flemish parliament (21-24)

Four bottlenecks have been defined in the Flemish monitor: psychological fatigue, problems with well-being at work, problematic learning opportunities and imbalance in the work-life balance. Six characteristics of the work situation were examined as workability risk: workload, emotional burden, task variation, autonomy, support for direct management and physical working conditions. The analysis is done in relation to relevant background characteristics (gender, age, family situation, scope of work, profession, type of contract, business dimension) and using the technique of logistic regression. This method makes it possible to estimate the pure risk effect of a specific characteristic of the work situation.

### ***Disability rights in the Belgian constitution***

On March 11 2021, an article about equal rights for people with disabilities was added to the Belgian constitution (25).

The text speaks of "inclusion" and not "integration," with the assumption that it is not the person with a disability that has to adapt, but society itself. The article provides a constitutional basis for affirmative action in favor of persons with disabilities. For example, imposing quotas on the government or companies to recruit a minimum number of people with disabilities is not undisputed legally. "Reasonable accommodations" can no longer be considered contrary to the constitutional principle of equality, because the constitution is read as a whole.

### **A more general remark on the rights to work of disabled people**

As this is a contribution to a General Comment on an article of the CRPD that concerns the rights to work of people with all types of disabilities in all countries of the world, one point that is of importance not only to people with autism but to all disabled people needs to be emphasized (again):

That wherever possible disabled people should fully participate and be consulted on all matters: policies, programs, accommodations and measures, etc., that concern them and their rights to

work, whether directly and individually in the workplace, or at the level of organizations and institutions, states and regions through organizations that represent them.

This is particularly important for people with autism as the nature of their disability and specific needs and competences is not always well understood, and it often falls to them to educate people on it.

This is important also because, although the principles of this participation and inclusion are enshrined in articles 4 (3) and 33 (3) of the Convention, this idea of involving disabled people in measures concerning them gets no mention in the draft Outline for the general comment, except for brief remarks about individualizing "reasonable accommodation" and ensuring involvement of organizations of persons with disabilities in social dialogue concerning labour market legislation and policies.

General Comment 7 (2018) to the CRPD indeed underlines this gap between the principle of inclusion and its implementation, due to "the absence of meaningful consultation with and involvement of persons with disabilities".

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