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## **Autism and Employment**

### ***A POSITION PAPER ON DISCRIMINATION IN EMPLOYMENT OF PERSONS SUFFERING FROM AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY***

Autism-Europe supports the measures launched by the European Union in the field of the fight against discrimination and in particular the Directive in favour of “Equal Treatment in Employment and Occupation” adopted by the Council in November 2000.

However, Autism-Europe believes that, at this point in time, the general framework defined by this Directive does not sufficiently take into account the needs of persons with autism or a complex dependency needs disability and their families.

The particularly complex situation of persons with autism or a complex dependency needs disability and their families and the discrimination that they suffer from in terms of accessing or remaining in the labour market calls for the following recommendations:

#### **A - Persons suffering from autism or another complex dependency needs disability**

1. The severity of their disability means that they require life-long training, adapted to their specific needs in the fields of:
  - education, to develop not only work competencies, but also the social and personal skills needed to access professional training and a job, albeit a protected one.
  - professional training,
  - continuous teaching.

Those that are lucky enough to enjoy adapted training are subsequently able to work. Conversely, the absence of early, individualised and continuous training has irreparable consequences on the development of the person and their ability to gain employment at an adult age.

2. Adequate support at the workplace (adaptation of the environment, supervision by professionals, tasks appropriate to their disability...) is an essential condition for people with autism or a complex dependency needs disability to benefit from the services that do exist for people with disabilities, such as sheltered workshops.

The lack of training and of adapted support, explains to a large extent why people with autism or a complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term. This is independent of their ability or otherwise to work, even though the discrimination that they suffer from, as people with disabilities and through lack of support, should be fought against by the Directive 2000/78/CE.

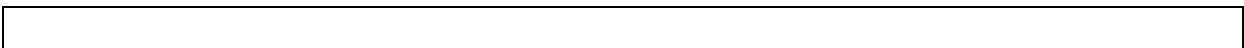
### **B - Families of persons with autism or another complex dependency needs disability**

1. families need measures aimed at preventing them from being forced to modify their professional situation and/or ambition in order to assure the care of their child, even when this child has reached adult age. The lack of care services adapted to the needs of their child, hours of care services incompatible with a job and the unavailability of facilities during the school holidays mean that, in the vast majority of cases, one or other of the parents, very often the mother, is driven to give up his/her job indefinitely. An indirect consequence of this can then be that the partner is forced to increase their working hours to make up for this loss of income or to meet the extra financial costs incurred.
2. families need to be supported and informed of the existing provisions that can help them, notably in terms of flexible working hours, from the moment their child receives its diagnosis.

For these reasons, Autism-Europe is calling for complementary measures to the Directive in favour of "Equal Treatment in Employment and Occupation" and to EU policy in terms of employment and social protection to be taken, in order to fight against the barriers to the employment of people with complex dependency needs disabilities and their families.

Autism-Europe notably recommends the development of the following measures:

- Reinforcing life-long training of persons with autism or a complex dependency needs disability, notably professional training
- Strengthening and adapting support at the workplace to the needs of persons with autism or a complex dependency needs disability
- Putting in place quality care services for all dependent persons (children, the elderly, people with disabilities)
- Improving the existing indicators on the care of children in order to be able to measure the proportion of children with disabilities benefiting from these services
- Developing flexible working hours whilst maintaining the social rights of the families (parental leave, career breaks....)
- Systematically informing families on the legislation and provisions already in place which allow the reconciliation of family and professional life.



DISCRIMINATION IN EMPLOYMENT OF PERSONS SUFFERING FROM AUTISM  
OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY

**ANNEX:**  
**THE INVESTIGATION ON THE ACCESS TO WORK OF PERSONS WITH  
AUTISM OR ANOTHER COMPLEX DEPENDENCY NEEDS DISABILITY AND OF  
THEIR FAMILIES**

During the course of the year 2001-2, Autism Europe launched a survey<sup>1</sup> amongst its members and any interested European organisations via the European Disability Forum and the Platform of European Social NGOs. A questionnaire, prepared in dialogue with the Council of Administration of Autism-Europe, and treating the question of the situation of persons with autism of working age and that of their families, was circulated throughout the network of our member associations across Europe. The questionnaire, translated into 8 European languages, was also accessible on the Web page of Autism-Europe. We received more than 400 replies from 19 different countries (of which 11 EU member states) within two months.

The survey was made up of two parts, one concerning the employment of the persons with autism themselves and with the difficulties that they meet, the second part concerning the employment of the families of people with autism (mainly their parents), whose professional situation is very often affected by the presence of the person with autism.

Although this investigation does not pretend to be scientific<sup>2</sup>, given the limited means at our disposal, the analysis of these replies highlighted, at least on a qualitative level, the key elements of the situation of the group of people that we represent. The main ideas of the results of this investigation are set out below:

#### **A - Persons suffering from autism or another complex dependency needs disability**

The first important element that comes out of this study is that, in the vast majority of cases, persons with autism or another complex dependency needs disability **do not want to or cannot work** (61.5% of cases).

Directly linked to this result, we notice that these people **only rarely receive professional and/or continuous training** (37%), which can probably explain, at least partially, the impossibility or non-willingness to work.

Finally, their **participation in social life remains difficult, if not non-existent** in the majority of cases (57%). Unfortunately, barriers to this participation are still numerous, mainly due to a failure to adapt the environment (36%), lack of adequate services (24%) or negative attitudes from the general public (18,3%). Although out of the area of this investigation, it can be pointed out that the lack of educational services in the childhood, not allowing a preparation for social life, is an aggravating factor of the disability.

These two factors combined, lack of training and of adapted support, explain to a large extent why people with autism or a complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term.

<sup>1</sup> The full results of the investigation are available at the secretariat of Autism Europe.

<sup>2</sup> The percentages indicated represent only the responses received in the sample. It can not be extrapolated to the total population of the persons concerned.

**B - Families of persons with autism or another complex dependency needs disability:**

With regard to the families who have a person with autism or another complex dependency needs disability to look after, it is noticed that their employment situation changes significantly after the arrival of their disabled child. The main elements that come out of the report are: **a total cessation of work, a reduction in hours worked or conversely an increase in the hours worked**. Only a minority have not been led to change their employment situation (26%).

But, what is doubtless particular to the sector that we represent is that these **changes have been brought about through necessity** (54%) much more than through choice (36%).

Another important point is that there is a lack of information on the existing measures at national level in favour of families of people with disabilities. A vast majority of the people that replied to the questionnaire think that there are none (46%) or do not know if there are any (22%).

Finally, concerning the support of families of persons with autism or a complex dependency needs disability, the replies show that care services outside of the home only provide **partial, occasional or even no aid** (50% of the people during the school year and 63.5% of the people during school holidays have partial, occasional or no access to care services outside of the home.) and that help within the home is very rarely provided by a social service but rather through family solidarity.

The families almost inevitably have to change their professional situation and/or ambition in order to be able to ensure the care of their child, even when this child has reached adulthood. The lack of care services adapted to the needs of their child, hours of care services incompatible with a job and the unavailability of facilities during the school holidays mean that, in the vast majority of cases, one or other of the parents, very often the mother, is driven to give up his/her job indefinitely. An indirect consequence of this can then be that the partner is forced to increase their working hours to make up for this loss of income or to meet the extra financial costs incurred.

**Observations**

In the light of these different results, one cannot help but notice that the area covered by the current Directive is still not sufficient to respond to the needs of persons with autism or a complex dependency needs disability and their families. The different elements of this study back up the recommendations that the members of Autism-Europe have been making for many years.

The issue here is not their ability or otherwise to work, but the discrimination that, through lack of support, persons with autism or another complex dependency needs disability suffer from as people with disabilities, a form of discrimination nevertheless fought against by the Directive 2000/78/CE.

These elements highlight the particularly complex situation of the families of people with autism or a complex dependency needs disability and the discrimination that they suffer from in terms of accessing or remaining in the labour market.

Autism-Europe hopes to have contributed to a better understanding of the situation of persons with autism or a complex dependency needs disability and their families at the European level, thanks to the contributions of its members, and in so doing, to have participated in the fight against the discrimination of the most vulnerable groups, for a Europe that is more just for all its citizens.

AUTISM-EUROPE is a European network regrouping nearly 80 associations of parents of persons with autism in 31 countries, of which 14 EU member states. Its principal objective is to promote and defend the rights of people with autism

and their families and to improve their quality of life. Autism-Europe is a founding member of the Platform of European Social NGOs and of the European Disability Forum.