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The Rights of Ageing People with Autism

AUTISM-EUROPE POSITION PAPER ON AGEING PERSONS WITH AUTISM

1 - Autism and Ageing – Towards a better quality of life

In the last decade several conferences and seminars have been devoted to the problems of ageing persons but few have approached the problem of ageing persons who also happen to be disabled for different reasons than those resulting from ageing.

Persons with disabilities have:

- Problems resulting from ageing
- Problems resulting from their disabilities.

The International Association Autism-Europe is developing a campaign using an holistic approach to raise awareness in the importance of studying the **common problems** these two populations face as well as the **specific problems of persons with autism**.

Autism-Europe invites persons with autism, their families and all those who are directly or indirectly involved in the subject to raise questions and to demand solutions.

BACKGROUND

- **Ageing people with disabilities in Europe and in the world**

People are living longer and in better health conditions in both developed and developing countries. By 2050 the ratio of older people in society will have doubled from 1 in 10 to 1 in 5. These figures are also true of persons with intellectual disabilities. According to the WHO (World Health Organisation) the social and medical factors leading to this increase in longevity have also increased the life span of people with intellectual disabilities.

Europe has been one of the first regions in the world to be confronted with the problem of ageing people. According to the documentation produced by the European Union the number of ageing people in Europe has increased so dramatically since 1950 that measures have had to be taken at a level of economic, political, social and employment legislation and directives.

At the same time the European Union has become aware of a reality often forgotten. Nowadays there is an increasing ratio of 1 disabled citizen to 10 other European citizens. Dependency and disability are directly linked with ageing. Europe must improve the quality of life of disabled and ageing people.

The fight against the exclusion of older people with disabilities implies that laws and directives must be put into practice. At the employment level, for instance, jobs must be adapted to ageing persons; at the social and economic level, retirement pensions have to be raised; quality health services must be implemented and/or extended; transportation and communication systems must be adequate for their users; housing facilities must be provided.

- **Ageing people with autism and other complex dependency needs**

Autism was first referred to scientifically in the '40s (Leo Kanner in 1943, Asperger in 1944) and the first children studied at that time are now adults and many of them are in their sixties. The world is faced with the ageing process of persons with autism.

Statistics on ageing people with autism are not available. We may infer that they are similar to those of other people with intellectual disabilities. Empirical data show that persons with autism die of the conditions associated with autism, mostly epilepsy. There are also deaths caused by accident and in the case of high functioning persons there are reports of suicide. However we have reason to believe that persons with autism are also living longer. In the last 30 years, according to incidental reports, fewer people with autism have died before the age of 50 years than was previously the case.

Within the group of ageing persons with disabilities (“double vulnerability”), persons with autism and other persons with high complex dependency needs are the most excluded and the most difficult to include in society. This is a fact recognised by the European Disability Forum in the reference document “Excluded among the Excluded” (2000).

When a person has autism, the whole family is being discriminated.

This statement brings us to “*associated discrimination*” as defined in a conference recently organised by the Danish Presidency in 2002. The fight against discrimination should include the discrimination a person experiences through his or her association with another person who is discriminated against.

Ageing persons with autism have older parents who are also in a situation of vulnerability

- **Specific problems of ageing people with autism**

The needs of ageing people with autism are the same as those of other ageing people: economic, social, residential and affective, but aggravated by the neurological, physiological and psychological factors linked to their specific condition.

Moreover they face additional problems like:

- **Health problems** due to associated diseases, secondary effects of medical drugs;
- **Communication and interaction problems** that can lead to isolation;
- **Behaviour problems** that may arise or be aggravated by communication and interaction problems.
- **Residential problems:**
 - Living at home** – no longer possible without a carer because of the ageing parents of persons with autism.
 - Staying in the same day centres or workshops** – ageing persons with autism must sometimes leave their day centres and go to inadequate places such as hospitals or ordinary residences for older people not specifically adapted to people with autism.
- **Lack of a lifelong learning environment** - Persons with autism have considerable learning disabilities and in most cases are very slow learners. Often they must leave their usual structured learning environment, therefore losing the visual cues they need.

- **Lack of trained staff** for ageing persons with autism or with complex dependency needs
- **Lack of realistic and appropriate financial support in most European countries**

THE RIGHTS OF AGEING PEOPLE WITH AUTISM - PLAN FOR ACTION

Persons with autism, their families or representatives, organisations and governments must establish a plan for action based on European laws and directives.

The right to an independent life and self determination

Persons with autism and other complex dependency needs or their representatives have the right to decide their future and to ask for the implementation of the principles stated in the Madrid Declaration and in the Charter of Rights for Persons with Autism. Principles are also present in the treaties and directives issued by the European Union on the rights of ageing persons and persons with disabilities, in particular those with complex dependency needs.

The right to maintain or improve the quality of health

- Prevention of health problems related with ageing
- Accurate diagnosis and accurate information on their specific health condition
- Prevention of problems related to specific health conditions
- Treatment of specific health conditions

The right to maintain and improve communication and social interaction

Access to alternative means of communication, visual information

If possible, foster inter-generational dialogue by:

- Involving young people through their participation in cultural events and other games or sports activities with persons with autism in the community
- Facilitate contacts between schools, youth organisations and institutions.

The right to appropriate intervention

Multidisciplinary assessment and co-ordination of interventions while taking into account:

- The functional abilities of the person.
- The interests and wishes of the person and his/her family

Design and put into practice an individualised support plan with the main objective of:

- Improving and maintaining autonomy skills in the home or residence
- Improving and maintaining social skills in community activities

The right to have services to provide a good quality of life

Services should be the result of a dialogue. Diversity of choice of accredited services must be available.

This will enable family and staff members to identify the individual needs of the person with disabilities. It will also be a way of reducing the risk of isolation and consequently exclusion.

The right to education and lifelong learning

Services must provide a learning environment and education facilities

The right to employment for persons with disabilities and their families

Employment must be adapted to persons with autism and their families so they will not risk exclusion. Professional training must be provided.

The right to housing facilities

Persons with autism must remain in their own homes as long as they can, like other ageing people, or go to places where they were used to living before retiring from "active life". Preparation for the changes in placement and ways of living must be carefully planned. New environments must be adapted to the specific needs of the persons with autism.

- **Living at home**
Provision of special help (medical, technical resources, house keeping, adaptation of the environment, etc)
Support for the ageing members of the family.
- **Living in small apartments** with the permanent assistance of carers.
- **Living in institutions:** keep people with autism in the same institutions they are used to living in with no age limit. Or place them in a nearby structure.
Provide complementary medical and health support: nurses, other support staff, hospital care, technical aids, accessibility, etc
- **Living in an institution while maintaining family contacts** with their ageing relatives:
Staff can take an active role in preserving relationships by enabling persons with autism to visit their parents at home or by making arrangements for the parents to visit residences.
- **Living in a special structure for ageing people with disabilities**
New types of special residences with medical care for ageing persons with disabilities, complex dependency needs and serious need of medical care.
- **Training of professional staff**
On taking into account research results, comparing experiences in developed countries and considering the needs of Northern, Southern and East European countries, it is urgent to implement:
 - Staff training, co-ordinated and prepared according to a systematic plan and with an holistic approach.
 - Programmes for home assistance for ageing persons with autism and their families
- **The right to realistic and adequate financial support**
Persons with autism and other populations with complex dependency needs should be able to live independently in the country of Europe where they were born or reside and have the same rights to realistic and appropriate funding:
 - To have access to a good quality of life in terms of physical, emotional, social and material wellbeing
 - To have an environment that fosters communication and is adapted to the problems of behaviour faced by persons with autism
 - To live a healthy and inclusive life in the community
 - To choose a way of living either at home or in a residential setting with adequate support from health and education services.