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## Questionnaire for a consultation in view of a possible designation of 2012 as European Year for Active Ageing and Intergenerational Solidarity

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**Should this contribution be published anonymously? No**

### 1. IDENTITY OF THE RESPONDENT

*Please identify yourself and the organisation on behalf of which you are replying to this consultation*

Name	Autisme-Europe
Organisation (including a short description of its mission and membership)	<p>Autism-Europe (AE) ensures effective liaison among more than 80 member associations of parents of persons with autism in 30 European countries, including 20 Member States of the European Union, governments and European and international institutions. It cooperates with other EU networks striving to promote anti-discrimination.</p> <p>AE strives to allow people with autism to enjoy the same rights than the rest of the European population. These rights should be enhanced and protected. They are anchored in the declaration for the rights of People with autism spectrum disorders (ASD) presented during the 4th AE Congress in 1992 and adopted as a written declaration on 9th May 1996 by the European Parliament. AE also fully endorses the UN Convention for the Rights of Persons with Disabilities ratified in 2007 and has been involved in its preparation.</p> <p>Its main activities include:</p>

	<p>1. Represent persons with ASD towards all EU institutions</p> <p>2. Promote the rights and dignity of persons with ASD</p> <p>3. Promote awareness on the appropriate care, education, and well-being of persons with ASD</p> <p>4. Liaise with other Non-Governmental Organizations sharing similar objectives</p> <p>5. Promote the exchange of information, good practices and experience</p> <p>AE is one of the key EU network in the field of disability supported by the Programme PROGRESS of DG EMPL to fight against discrimination.</p>
Expertise (please precise the area)	<p>Disability rights/ Specific needs of persons with Autism.</p> <p>Expertise regarding positive actions needed in order to allow persons with ASD to have access to proper services and facilities ensuring early, life-long, effective education, vocational training, and habilitation programmes.</p>
Contact details (notably e-mail address)	<p>Aurélie Baranger - Director</p> <p>Autism-Europe</p> <p>Rue Montoyer, 39 – bte 11</p> <p>1000 Bruxelles</p> <p>Tel : +32 2 675 75 05 - Fax : +32 2 675 72 70</p> <p>secretariat@autismeurope.org</p> <p>www.autismeurope.org</p>

## 2. THREATS AND OPPORTUNITIES OF AGEING IN RELATION TO INTERGENERATIONAL SOLIDARITY

*Please explain briefly how your organisation perceives the challenges and opportunities in relation to intergenerational solidarity in a context of accelerating demographic ageing.*

Autism-Europe would like to stress the fact that not all the population is living longer and healthier lives. Studies have shown that life expectancy of people with mental disabilities is significantly shorter than the rest of the population.

Nevertheless, ageing of general population affects people with ASD also, and implies the need to provide a proper support after their families' death or breakdown. Most provision for adults with ASD comes from families, as a matter of fact, but when family care is not available any more an alternative support must be provided. The provisions for elderly

persons with ASD should not be simply a “parking”, but ensure them to be respected citizens and participate in community activities as anyone else.

ASD features do not necessarily improve with age, mainly if they did not have access to proper education and habilitation programmes. On the contrary, elderly persons with ASD can show more complex needs in terms of health care and support. As a consequence, ageing of persons with ASD implies not only the need for a life-long qualified support, but also enhanced intensity of the care in their elderly age.

In contrast, many elderly persons with ASD or other complex dependency needs disabilities are placed in large, segregating institutions, as well as young adults with ASD or other complex dependency needs disabilities, whose families are not likely to be able to ensure fundamental rights to life-long, effective education, habilitation and inclusion. To their detriment, neither the community nor the policy makers in many cases are ready to accept to support adequately long-term dependency and to provide the financial and professional resources needed. The issue of ageing of persons with ASD open therefore a wider debate on the de-institutionalisation process and its meaning for persons with ASD.

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.

Additional problems they face are the following:

- 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

### **3. POLICY MEASURES REQUIRED TO AVERT SUCH THREATS OR EXPLOIT THE OPPORTUNITIES AND HENCE PROMOTE INTERGENERATIONAL SOLIDARITY**

*What policy measures would your organisation recommend to preserve or promote intergenerational solidarity? What obstacles need to be overcome to implement such policies; in particular, is there a lack of awareness and resistance to change?*

In order to promote intergenerational solidarity and tackle the specific needs of persons with ASD, the following rights should be enforced, notably through the implementation of the UN Convention on the rights of persons with disability:

-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 rights stated in the UN Convention on the rights of persons with disabilities

- 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

Closing institutions is easy if one has little concern for what happens to residents. The challenge is to build good community care services, respecting human rights and ensuring quality of life by meeting the individual needs of the users. The great deal of support needed by people with ASD in community based living services is not always available. However, in a good care system, the costs of supporting dependent people are usually high, wherever those people live. Policy makers must not expect costs to be low in community settings, even if the institutional services they are intended to replace appear to be inexpensive. Low-cost institutional services are almost always delivering low-quality care.

\* 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 residential services: keep people with autism in the same residential services 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 must be built.

- 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 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
  - Facilitating 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 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.

- 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.

#### **4. ROLE OF THE EU IN PROMOTING THE RIGHT POLICY RESPONSES**

*Is there a specific role for the EU in relation to intergenerational solidarity? What measures could be taken at the level of the EU in addition to the existing EU policies? In particular, is a European Year an appropriate instrument?*

The EU can play a significant role in raising awareness of the specific issues faced by persons with ASD and with other kind of complex needs disabilities requiring a high level of support when getting older.

The EU should promote the existence of adapted services for the ageing population within the community, in order to enhance intergenerational solidarity.

It would also be important to encourage and promote initiatives that foster intergenerational contacts.

## **5. TOPICS AND ACTIVITIES FOR A EUROPEAN YEAR**

*Given the limited resources available for a European Year, what topics and types of intervention should it focus on? How could it achieve the greatest possible mobilisation of stakeholders at all levels (EU, national, regional, local, company, sector) and thus maximise the impact of the European Year?*

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

Ageing parents who act as carers for their children are also very much concerned by the issue of active ageing and face a lot of difficulties and anxiety as regard the future of their children.

These particular topics should also be considered during the European Year.

## **6. YOUR ORGANISATION'S CONTRIBUTION TO A EUROPEAN YEAR**

*How could your organisation contribute to the success of a European Year? What activities could it develop?*

Autism-Europe could contribute through an awareness raising campaign on the situation and needs of elderly persons with ASD.

On the occasion of the European Day of Autism 2012, AE conference could focus on the needs of ageing people with ASD. It would be an opportunity to exchange views and best practices between various stakeholders (representatives of persons with ASD, services providers, public authorities) at the EU level.

AE could also encourage its members to hold seminars at national/local level on this issue, as well as to develop activities fostering inter-generational contacts (as already done by some of them.)

A compendium of best practices to allow for a better quality of life of persons with ASD could be published. It could be done through encouraging our network of members to reflect on this issue and share experiences.

**7. WHAT SUPPORT WOULD YOUR ORGANISATION REQUIRE TO PLAY A MAJOR PART IN A EUROPEAN YEAR?**

*Please explain what support your organisation would require from public authorities to make a significant contribution to the success of a European Year.*

We would need financial support to organise a EU-level conference and publish a compendium of best practices.