

## Response of EASPD to the

## Commission's Green Paper "Confronting demographic changes: a new solidarity between generations" COM(2005)94 final

The European Association of Service Providers for Persons with Disabilities (EASPD) promotes the **equalisation of opportunities for people with disabilities**, from all age classes, through effective and **high quality service systems in Europe**. As a network we believe in inter-generational solidarity as well as in a good social system to support the people in need.

Our objectives are achieved through:

- **1. Service provision to members (Information):** networking/offer exchange possibilities to members at European, national/regional and local level;
- 2. Policy-influencing (Impact): offering service providers a voice in Europe;
- **3. Research and Development (Innovation)** as basis for innovation and improvement of service provision.

The principles of EASPD are aiming at high quality of services facilitating full participation and inclusion in society in an appropriate way of persons with a disability. To achieve this EASPD is committed to:

- User participation in the development and delivery of services
- The implementation of governance principles
- Active life long learning opportunities for staff
- Focus on Accessibility, availability and affordability of services

Service Providers in Europe respond to the needs of over 50 million people with a disability in the EU. The sector employs over 4 million directly and another 4 million people indirectly. EASPD represents more than 7000 service provider organisations in 24 European countries and is the mouthpiece for the sector in Europe. As such, our input on this Green paper is of great value

We welcome the Commission's initiative to launch a debate on the topic of an ageing population in Europe and would like to further deepen the debate from a **disability provider's perspective**.

### 1. Effect of Ageing on persons with disabilities

Indeed, a disability perspective is necessary in this Green paper, as an ever growing ageing population is inevitably linked with an increase of the disabled population, that is people in need of more care and specialised services (point 1. challenges of European demography). In the next two decades over 15 million people in the EU 25 (in addition to todays figures) will be confronted with severe functional limitations and disabeling conditions and thus will need appropriate support, as a direct effect of ageing alone.

Furthermore, thanks to the medical care and health support, the average age of people with a disability increases too. Nore the disability sector or the sector providing services for ageing people is prepared for this.

Age	% Functional limitation	% Severe Functional limitation
15-24 years	6,3 %	2 %
35-44 years	13,4 %	3 %
55-64 years	34,2 %	12 %
65-69 years	45,4 %	18,5 %
70-74 years	55,3 %	22 %
75+ years	72,5 %	41 %

(© 2001 Trace R&D Center, University of Wisconsin)

Figure 1: Percentage Increase of functional limitation in an ageing perspective

As one can see from the table, ageing people become disabled, more and more vulnerable and an increased support system becomes inevitable. One will, therefore, need to develop an adequate care system which is nowadays still insured by the families and especially women. Services will have to originate, which will have to be available and accessible for all and meet high quality standards, especially in the training of qualified personnel. For this, a major investment is needed.

#### EASPD's request:

- 1. Disability perspective
- 2. New services and support systems for 15 million ageing people
- 3. Capacity building in the disability sector for persons already disabled at this stage

## 2. Feedback on the Commission Green Paper

The Green paper does not **take into consideration the ageing disabled population** as well as other groups exposed to discrimination, like women, migrants, ethnic minorities... This goes against the current EU policies of social protection, gender equality, immigration, employment and youth. Therefore, it is necessary to link both aspects, in order for the debate to be more realistic and efficient.

First of all, the sectors age and disability are one and the same looked at as two different ones. In the future it will be necessary to achieve a more holistic approach. Indeed, it creates unnecessary duplications in services, as they are so similar.

- Accessibility of society, like transport, is a problem for both groups
- Availability of services: there are still not enough services focusing on those two groups. Especially in this trend of demographic ageing, these services will need to be developed considerably
- **Affordability** of these services: retired people have reduced incomes, as it is the case with disabled people, because most of them don't work. The services should be available for all and not be reserved for a wealthy minority

It is necessary, that the Commission creates and **organises a forum for stakeholder dialogue** (ageing and disability sector), for example in order to discuss these overlapping services (retiring homes and services for disabled people offer similar care) and to join hands in creating one effective service system for all.

Furthermore, a falling and an ever-ageing population also bring about a reduction of the active population. The Green paper does, however, not include the **disabled people as a source of active population**. The disabled group can be a massive input in labour force that is too often forgotten and not acknowledged.

<sup>&</sup>lt;sup>1</sup> Commissioner Vladimir Spidla, Ministerial Conference on the Green Paper, Brussels 11-12 July 2005

Hence, persons with a disability are, at this stage, still **excluded to a large extent from the labour market**. For example 75% of the severe and complex disabled are unemployed today. It is necessary today to change the mentality of all, especially of companies, that they can also benefit from disabled people, that they are a valuable and accessible source of labour force.

Life long learning is mentioned as a possible solution for an ageing population to reduce the employment problem. This **life long learning** should also be available for ageing disabled persons.

## Person Centred Services and Community Based Settings:

Since the 1970s both society and the social care sector in general have witnessed and encouraged fundamental developments in the way services are provided to people with disabilities.

Today, services for people with a disability are very different. They are based on a close cooperation with the involvement of all stakeholders and of course with the direct involvement of the person with a disability and his/her family and friendship /support networks. These services aim for social inclusion, and are designed around the needs of each individual.

The ultimate aim of the disability service providers sector is to support and empower people with a disability to live a full, active and contributing role in their community, whether as employee, family member, friend, consumer or in other ways. Service providers aim to empower and create awareness amongst other society members about the value and contribution each disabled person can make. **Full participation in the community as a respected individual** is the overall aim of the service provider in 2005.

This full participation of persons with a disability should become a reality especially in this everageing population demographic trend. A deeper focus, mainstreaming, in all age categories as well as on diversity in abilities (disabled and not disabled population) is necessary in all fields: gender equality, employment, education and training, social protection, social inclusion, anti-discrimination, immigration, integration, health, and social and health services.

Services for ageing people should be built around the same principles of stakeholder involvement, full participation in society and empowerment of persons in need. Services will have to be accessible, available and affordable for all.

- 3. Answers to the questions asked by the green paper
- > Do you take the view that the discussion of demographic trends and managing their impact should take place at European level?

  And if so, what should be the objectives, and which policy areas are concerned?

The objectives should be

- The implementation of a **positive approach of ageing** and longevity (available know-how, expertise, ...)
- The **empowerment of ageing people:** self-steering and stakeholder involvement
- The building of an ageing friendly and accessible environment
- How can the availability of child care and elderly care structures be improved by the public and private sector? (1.1)

Integrate a disability perspective and a strategic plan on building a public environment for all (accessibility of services for all).



➤ How could Community instruments, in particular the legislative framework to combat discrimination, the structural funds and the Employment Strategy, contribute? (1.2)

It could help to activate the jobless population with a disability to tackle the employment problem. Special attention on this topic should be part of the NAPs.

How can the organisation of work be modernised, to take into account the specific needs of each age group? How can young couples' integration in working life be facilitated and how can we help them to find a balance between flexibility and security to bring up their children, to train and update their skills to meet the demands of the labour market? How can we enable older people to work more?

It is necessary to find a solution for the benefit traps by focusing on it in the national action plans.

How do we arrive at a balanced distribution of care for the very old between families, social services and institutions? What can be done to help families? What can be done to support local care networks?

More **Community Based and Person Centred services** are needed. This sector should be particularly emphasised on in the future and the necessary means put at the disposal of the sector to increase the number and variety of services.

- > Conclusion: what should the European Union's role be?
  - I. Create a platform for stakeholder dialogue (in this case the disability and ageing sector)
  - II. Focus on the benefit trap in the European Employment strategy and in the National Action Plans
  - III. Research and comparable data is needed across Europe. These will then be used to develop policies
  - IV. Benchmarking, exchange of models of good practice, in service delivery and activation of ageing and disabled people.
    - 4. Conclusion

We welcome the Commission for their initiative to address the demographic changes and the related consequences of an ageing population in relation to employment, migration, health systems, ...

However, we would like to give this paper a more human perspective by adding minorities that are also confronted directly with this phenomenon. In our case we focused more on the disabled population by stressing two major points:

- Ageing people become disabled
- Disabled people are ageing

We hope this reality will be looked into more deeply, as they go hand in hand.



#### Annex

# The Verona 2001 Declaration on Ageing and People with Disabilities (4th and 5th of October 2001, Italy)

Like all other citizens of the European Union, people with disabilities are living longer. However, if they are to enjoy this extra lifespan, they will need a great deal of support to safeguard their basic right to inclusion and to have a proper Quality of Life.

How to achieve this was the theme of the 2001 EASPD conference of Verona. It was clear to the participants, who came from 22 European countries, that – despite policy declaration (e.g. UN Standard Rules on the Equalisation of Opportunities and the global policy of the World Health Organisation) – many of the basic rights and quality of life dimensions for people with disability remain to be implemented.

The conference ended with the Verona Declaration. The declaration is mindful of the rich and economic diversity of the Union. It calls on:

- 1. Service providers who organise support for people with disabilities and their families.
- 2. Researchers in the field of disabilities, particularly ageing.
- 3. European, regional and national policy makers to ensure that practice, research and policy are based on the following principles.

## Principles:

- 1. Getting old is not an illness. Older people with disability should be respected and treated as wise people who are knowledgeable of the family and the service system in which they live.
- 2. People with disabilities are individuals. Services should be the result of a dialogue. It will enable family and staff members to identify their individual needs. This helps to make a difference between a good life and the risk of being isolated.
- 3. Starting early with appropriate support will ensure that people with disabilities learn to live with responsibilities, opportunities, risks, choice and control.
- 4. Parents, brothers, sisters and friends need to get support for they play a critical role. They are the link to the wider community.
- 5. Staff training programmes should draw on sources of research data to shape new models and approaches of service delivery. Staff should obtain the competence and knowledge necessary to realise a person centred support process. A combination of theory and practice should help professionals to become "reflective practitioners".
- 6. People with disabilities themselves, their family and the general public should have access to training and information on living, working and support, to enable them to take up their responsibilities with dignity and achieve a good quality of life.
- 7. A variety of systems must be available; to ensure people with disabilities can make individual choices and live the life they want to live. Accessible information on social policy and support systems should enable families and professional carers to learn about alternatives and make conscious choices.
- 8. Realistic and appropriate funding is a key requisite in the provision of support. This funding should be used to achieve the long-term objectives of a healthy and inclusive life for people with disabilities. Their right to be active citizens must be reflected by an adequate income, access to all new



technologies, enhanced communication adapted to their individual needs, (physical) accessibility and transport.

- 9. There is an urgent need for outcome based evaluation of generic and specialised services to enhance the quality of life dimensions (material, emotional and physical well-being, rights, self-determination, interpersonal relationships, social inclusion and personal development) in existing and future services.
- 10. It is essential to gather comparative data (statistical and narrative) on people with disabilities across the European Countries in order to address demographic challenges at national and local levels and to form a basis for action.

EASPD will disseminate this document to policy makers on all levels, researchers and service providers to promote the implementation of these principles in the support for ageing people with disabilities.



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