

# Online Awareness Raising Event - Challenges and Good Practice Supporting Older PWD

## *Report*

10th December 2021

11.00-13.30 CET, Online

### **EPR presentation of challenges and good practice on services to older persons with disabilities**

After having introduced the goals of the European Platform for Rehabilitation (EPR), Alicia Gómez Campos, EPR Senior Public Affairs and Community Officer, explained that EPR members collected challenges and good practices of services delivered to older people with disabilities. The results of the research are included in the *EPR 2018 Analytical paper on Long-Term Care: Older People & Disability*. Some of the identified issues are still relevant in 2021/2022:

- Deinstitutionalisation in long-term care promotes the well-being of those in need of care and may present lower expenditure for healthcare systems;
- People who live in the community suffer less depression than the ones in long term care facilities
- Healthcare systems are low funded

### **EPR Members presentations: challenges and suggestions to better deliver services supporting older persons with disabilities. AFID Diferença Foundation (Portugal), Aura Foundation (Spain), E.G.N.Y.A (Greece), Fundacion INTRAS (Spain), Panagia Eleousa (Greece)**

EPR Members learned that they face similar challenges to provide services to older people with disabilities:

- Absence of suitable social pensions;
- Lack of suitable legislations;
- Ageing is not seen from a service perspective (lack of proactive planning);
- Loss of skills (ageing symptoms start at a young age, as dementia);
- More needs means increasing costs;
- Shortage of specialised staff and burn out of the current staff;
- Need of resources on services and family level;
- Absence of continuous funding;
- People in rural areas experience more challenges in accessing social services than people living in urban areas

EPR Members also shared good practices that they are implementing:

- Margarida Barros Amaral explained that AFID staff have been trained to respect decisions and routine changes clients wish to have. AFID works on predicting the new needs for delivering services for older people with disabilities, e.g. new requirements for transportation services;
- Roser Fernandez reported that AURA is conducting ageing research programmes and physical and mental health programmes for older people with disabilities;
- Periklis Vavourakis showed that E.G.N.Y.A is promoting a person centred approach in its services and training its staff on the new challenges that come with ageing . The Greek organisation is leading also community based services in cooperation and co-production with other services;
- Mina Kyziridi explained that Panagia Elousa Foundation built more assisted living facilities to offer lifelong services to ageing people with disabilities as their family members are becoming older as well;
- Pablo Sanchez spoke about Fundacion Intras project “Proximity Services. New Opportunities in ageing of dependent people in the rural areas”. The aim is to maintain people with disabilities in the home where they want to stay thanks to the new technology.

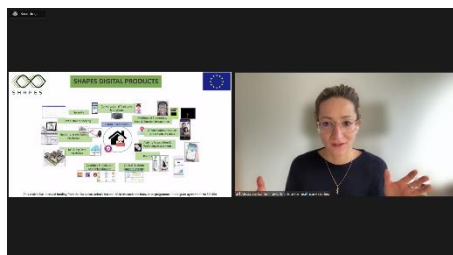
### “Ageing with a disability: Institutionalization or Personal Assistance?”



Dr Adolf Ratzka, Founding Director Emeritus of the Independent Living Institute, Sweden, reported that public and private community-based services are not sufficient for ageing people with disabilities due to high staff turnover and absenteeism. In addition, assistance is limited to one’s home and to the basics. Countries that do not doubt the institutionalization of older persons have ratified the UN

Convention on the Rights of Persons with Disabilities. Article 19 of the Convention expresses the right to “living independently and being included in the community, with choices equal to others”. Institutionalization violates the Convention. Many people with impairments could have rich, interesting and fulfilling lives if they had personal assistance services. Unlike community-based services or residential institutions, personal assistance services entail a one-to-one relationship between the assistant and the person. It is the user - not the staff supervisor - who decides who works as a personal assistant and how the work must be done. Control over the service’s organization and content gives users the means of optimizing service quality, of achieving something in their lives. Dr Adolf Ratzka receives a monthly amount from the Swedish Social Insurance Fund that enables him to purchase 18 hours a day of personal assistance services. Personal assistance provides a decent chance to a rich and fulfilling life as enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities.

## “Improving In-Home and Community-based Care in a rural area in Germany” - a Pilot Theme of the SHAPES Pan-European Pilot Campaign.

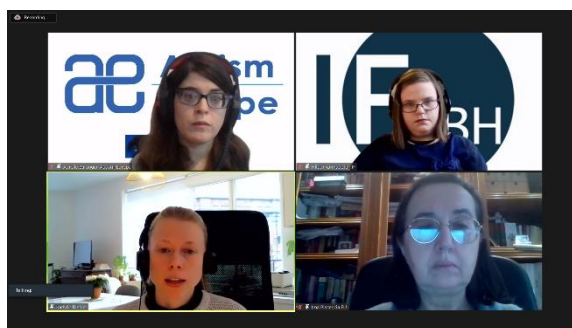


Dr Alexia Zurkuhlen, Head of gewi-Institut for healthcare studies, Cologne (Germany), presented the project SHAPES: “Smart and Healthy Ageing through People Engaging in supportive Systems”. gewi regards older people living at home and in care homes in need of continuous care. By stimulating their cognitive and physical activity with tech-based offers and technical

devices, gewi strives to enable older individuals to stay in their own home-environment fitter and for longer. gewi will lead the socio-economic sustainability study and the SHAPES collaborative governance model, in addition to its active engagement in the pilot campaign.

### Panel Discussion

- **Aurelie Baranger**, Director of Autism Europe, mentioned the difficulties emerging in the sector of ageing people with autism: limited research on the needs of older people with autism, overmedication and high rates of undiagnosed autism, loneliness, existing policies on autism are mainly directed to children with autism, high dependency on families due to the lack of services and staff. Some good practices have been identified in France that is bringing older people from psychiatric hospitals to community based centres, Sweden is supporting people living in their houses, and Denmark is conducting a person centred approach.
- **Hildur Önnudóttir**, Policy Officer at International Federation of Spina Bifida and Hydrocephalus (IF) encouraged the development of personalised and holistic model of care for the older adult with SBH and sustainable and well informed workforce. She highlighted that services should be delivered according to a person centred strategy. In addition, legislation on accelerating ageing should be brought to the table. Besides, further research on ageing people should be supported. Hildur Önnudóttir emphasized that disability issues should be integrated into EU policies in a coherent way.
- **Inmaculada Placencia**, Deputy Head of Unit for Rights of Persons with Disabilities within the Directorate General for Justice European Commission, gave an overview of the Strategy for the Rights of Persons with Disabilities 2021-2030. She explained that the Strategy is covered by the UN Convention on the Rights of Persons with Disabilities. The Strategy addresses the matter that the majority of the elderly has a disability and takes into account the diversification of disabilities. In the Independent Living section, it is stressed that support services should be accessible to everyone,



also in the rural areas. In conclusion, the Strategy recognises mental health issues and domestic violence against people with disabilities.

- **Kathrin Riedler**, Policy Officer for Long-term care at European Commission, took part in the panel discussion introducing the Social Care Strategy. She explained that the strategy was announced in the letter of intent accompanying the Commission President's 2021 State of the Union, Ursula von der Leyen. Moreover, it should contribute to implementing the European Pillar of Social Rights. The European Care Strategy aims to support carers in their work and ensure that those receiving care or needing support are best provided for. Principle 18 of the European Pillar of Social Rights enshrines that "Everyone has the right to affordable long-term care services of good quality, in particular, home-care and community-based services". Kathrin Riedler pointed out that Member States confront similar limitations in offering long-term care, such as affordability to access care services, poor quality, low job attractiveness, gender gap, and an increasing number of the ageing population. The strategy's key elements consist of a communication plan to outline challenges and describe the actions to address them, the revision of the Barcelona targets, and Council's recommendations on long-term care also addressing Member States. Finally, stakeholders are invited to give their input to the strategy.

## Recommendations

- Members States are called to produce suitable legislations to support ageing persons with disabilities by taking into account accelerating ageing;
- Older persons with disabilities are subject to a greater extent to loss of power, denial of autonomy, marginalization, social isolation, exclusion, poverty and abuse. Policies on inclusive living/ deinstitutionalization are needed to overcome these issues;
- Demand for care services is expected to increase in an ageing society, while the lack of quality standards in care and gaps in access to quality services, including in rural areas, are a serious concern in many Member States;
- To provide quality in services, it is important to have permanent funding from government (or any other source). Part of the budget should be used to provide more and specialised staff. This is crucial to guarantee the staff working life balance and avoid the burnout;

Participants were asked to rate the overall event from 1 (poor quality) to 5 (excellent). The average rating of the event was a 4.2 out of 5.