



Achieving Holistic Person-Centred Care to Leave No One Behind

A contribution to improve the everyday lives
of people living with a rare disease and their families

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Alec, Sanfilippo syndrome, Australia

Making holistic care a reality for people living with a rare disease

Pillar 1

Quality and
adequate social
services and
policies

Pillar 2

Integrated care:
bridging health
and social care

Pillar 3

Equity of rights
and opportunities

1/3 of people living with a rare disease
**have insufficient access to a
social worker**

“ I have had a **full time job of supporting my children in daily tasks**, accessing social educational and leisure activities, training them for many independent living tasks etc. ”

Female carer, United Kingdom



Commission Expert Group on Rare Diseases

Recommends:

**Specificities of rare diseases
to be incorporated into
mainstream social services**

Our recommendations to achieve holistic care for people living with a rare disease and their families, by 2030:



1. Making full use of EU instruments and European networks
2. Creating a supportive political environment at national level
3. Gathering and disseminating knowledge and good practices
4. Implementing specific mechanisms that ensure integrated care
5. Meaningful engagement in design and implementation of policies/services
- 6. Ensure access to adequate social services and social protection**
7. Ensuring the recognition and compensation of disabilities
8. Creating conditions for access to adapted and sustainable employment
9. Implementing specific mechanisms for empowerment
10. Eliminating all types of discrimination

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Brian and Swen, congenital melanocytic nevus, The Netherlands

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65% of people living with a rare disease
have to visit different health,
social and local services in a
short period of time

“ Inter-professional communication works only through the efforts of particular professional individuals. This is one of the main difficulties in the lives of families. Today, departments communicate with each other primarily through patients themselves or their parents. ”

Male, Czech Republic



Commission Expert Group on Rare Diseases

Recommends:

Member States should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with a rare disease

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Laura, arthrogryposis multiplex congenital, Spain

Making holistic care a reality for people living with a rare disease



- 1. Disability, autonomy, accessibility**
- 2. Adapted and sustainable employment**
- 3. Non-discrimination: access to equal opportunities**

More than 7 in 10
people living with a rare disease
have difficulties with motor and
sensorial functioning

**“ One day you appear completely healthy,
the next day you are sick ”**

Female, Spain

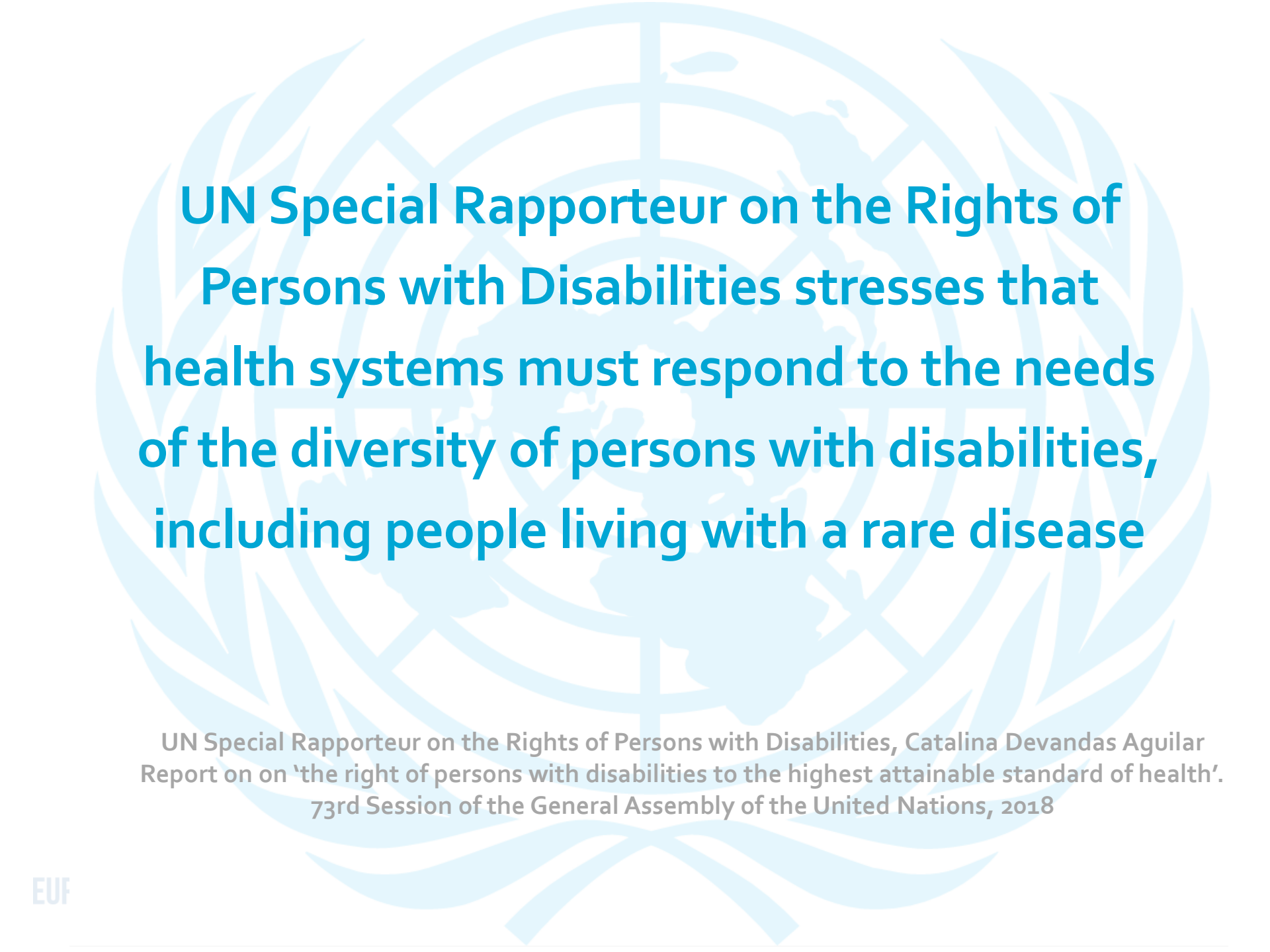
**“ I don't look ill but am very ill with a condition
which no one understands or has heard of ”**

Female, United Kingdom



**Commission Expert Group on Rare Diseases
Recommends:**

Rare diseases specificities should be integrated into national systems where assessing a person's level of functioning, in line with the UN Convention on the Rights of Person with Disabilities



UN Special Rapporteur on the Rights of Persons with Disabilities stresses that health systems must respond to the needs of the diversity of persons with disabilities, including people living with a rare disease

UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar
Report on on 'the right of persons with disabilities to the highest attainable standard of health'.
73rd Session of the General Assembly of the United Nations, 2018

7 in 10 people living with a rare disease
and their family carers **had to reduce
or stop professional activity**
due to the disease

“ We were **looking for a diagnosis, which took roughly 6 years.**

By asking a year **"non paid break"**, I received a **refusal from the employer.** So I decided to **give up my job** and stayed **unemployed for 4 years.**

After the diagnosis, I decided to pick up work. One year: **part-time** and thus **earning half** as much as before. ”

Female, Luxembourg

“ I felt that **employers are "afraid" to employ me**, but this was officially never the reason.

It took me 8 years to get a new part-time job. ”

Male, Poland

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- ✓ Disseminate
- ✓ Take action

The time to act is now!

Full paper at www.eurordis.org/carepaper

Thank you!

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