

A Need for Visibility in Support Systems

Second High Level Event at United Nations
for NGO Committee on Rare Diseases

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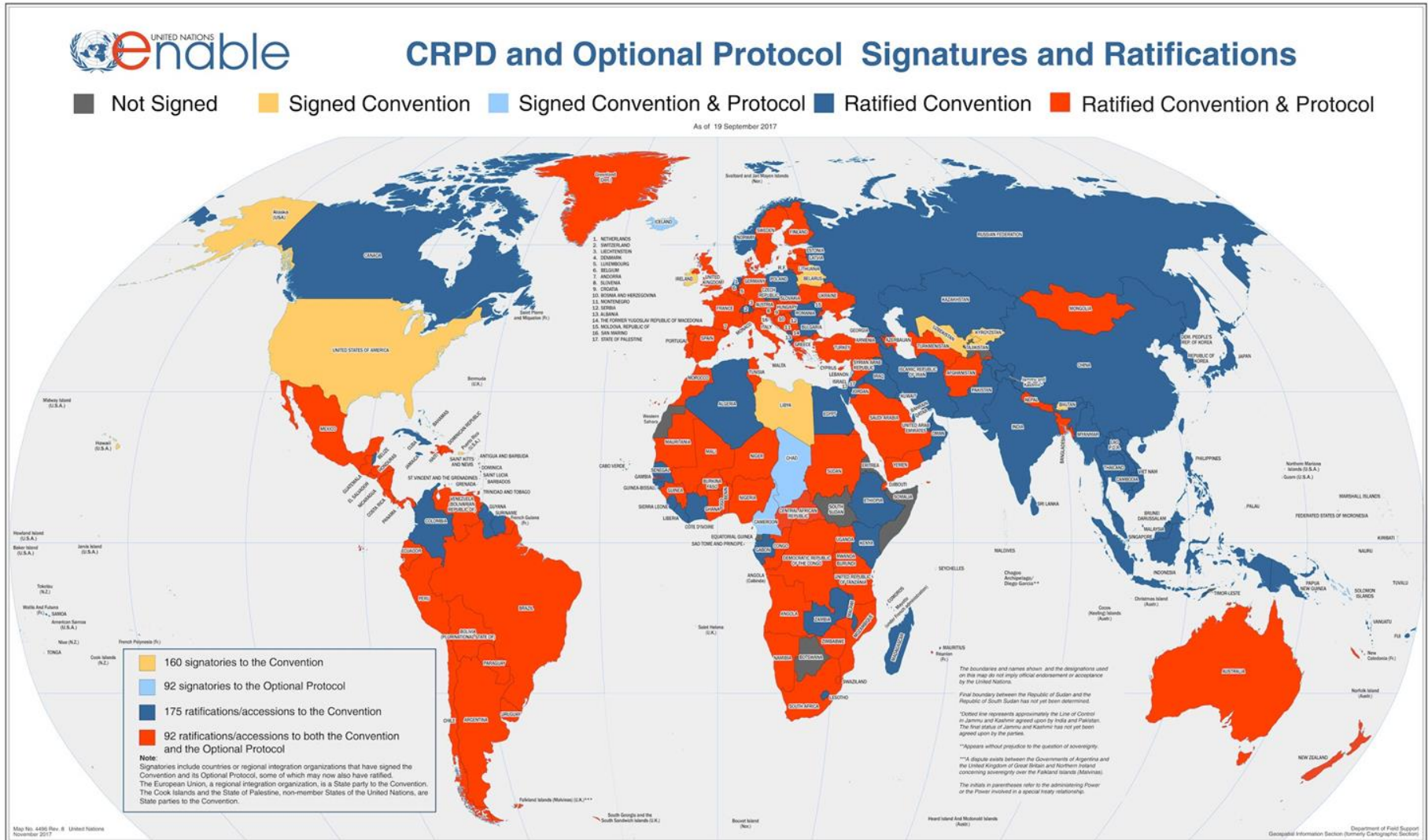


Leave No One Behind!



RARE
DISEASES
INTERNATIONAL

Nothing About Us, Without us!





Invisible?



RARE
DISEASES
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Article 18 - Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including ...
2. **Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.**



Example from Ethiopia



RESEARCH ARTICLE

High burden of neural tube defects in Tigray, Northern Ethiopia: Hospital-based study

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Abstract



Original article

Nutritional status among women whose pregnancy outcome was afflicted with neural tube defects in Tigray region of Ethiopia

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Perception



It i

Rare diseases are complex and often invisible

Symptoms vary & can be invisible in many ways...



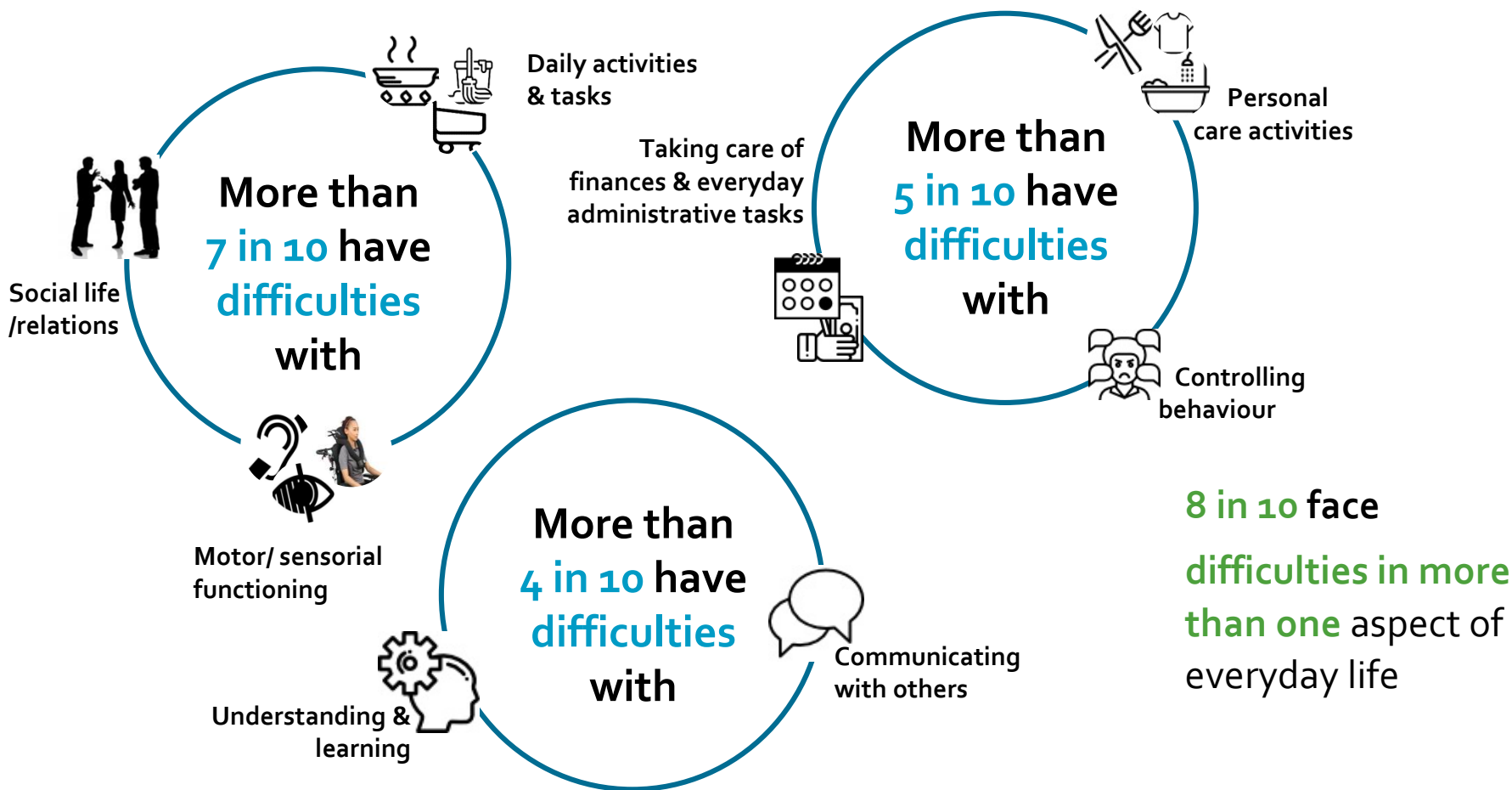
“One day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again” Female, Spain

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

...underreporting, unknown diagnosis or stigma.

Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo. Source: [EURORDIS Photo Contest](#)

People living with a rare disease have serious difficulties with several Activities of Daily Living



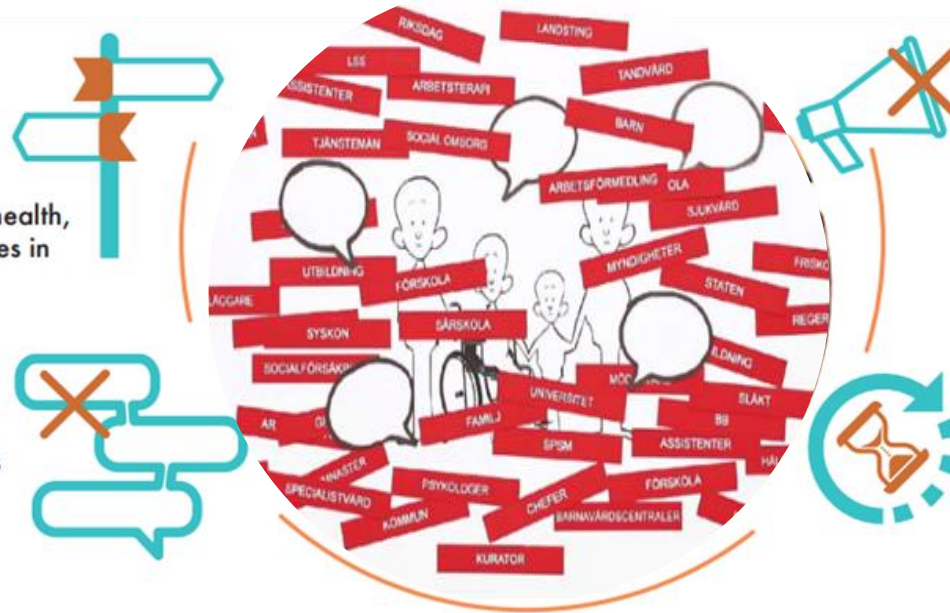
Care pathway is complex and hard to manage

65%

have to visit different health, social and local services in a short period of time

67%

feel that these services communicate badly between each other



7 in 10

do not feel well informed about their rights

7 in 10

find that organising care is time-consuming; 6 in 10 find it hard to manage

Image on care pathway used for illustration purposes.
Source: [Nationella Funktionen Sällsynta Diagnoser](#), Sweden

“ The **appointments should be multidisciplinary** allowing for the various specialists to see the person on the **same day and the same place**

Besides **facilitating communication** and the definition of **adequate treatment** it would also **avoid that the person has to travel** to different appointments and places, **being absent from work (losing income** and facing **discrimination** at the workplace) and **spending** a lot in travel”

Female, Portugal

Significant impact on professional life

7 in 10

73% of women; 63% of men

People living with a rare disease & family carers had to **reduce or stop professional activity** due to the disease



The rare disease led to an **income decrease for 69%**



58% absent from work over 15 days/year
41% asked for special leave from work but could not obtain it

Deteriorated mental health

3 times
more people

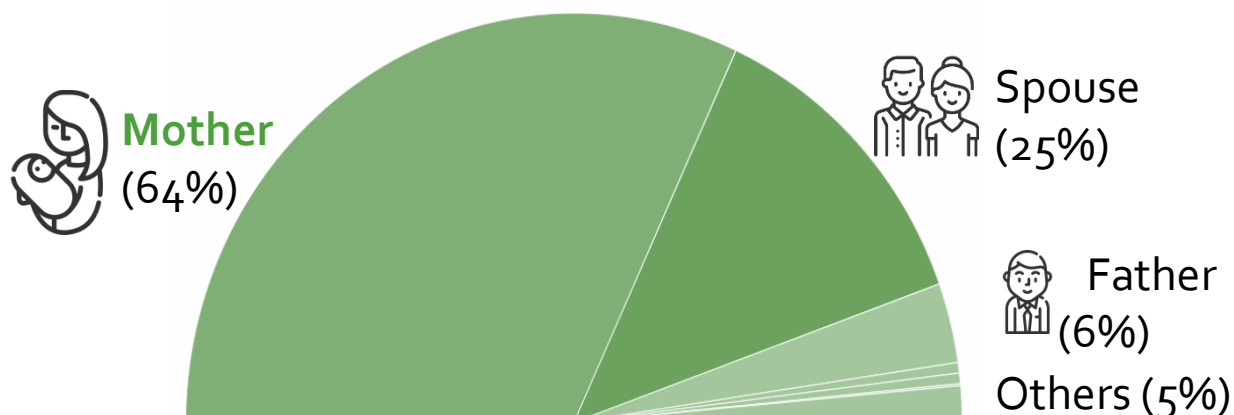
living with a rare disease
and carers report being
unhappy and depressed than
the general population*



* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

A burden that heavily falls on women

The role of the primary carer for people living with a rare disease is primarily assumed by women



Who organises and coordinates care in your household?

Concluding: leaving no one behind



Thank you!

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