



JUGGLING CARE AND DAILY LIFE

The balancing act of the rare
disease community

EURORDIS Membership Meeting 2017
Budapest

Social Revolution Workshop, 20^o May

EURORDIS.ORG

The challenge of coordination of care

Raquel Castro, EURORDIS

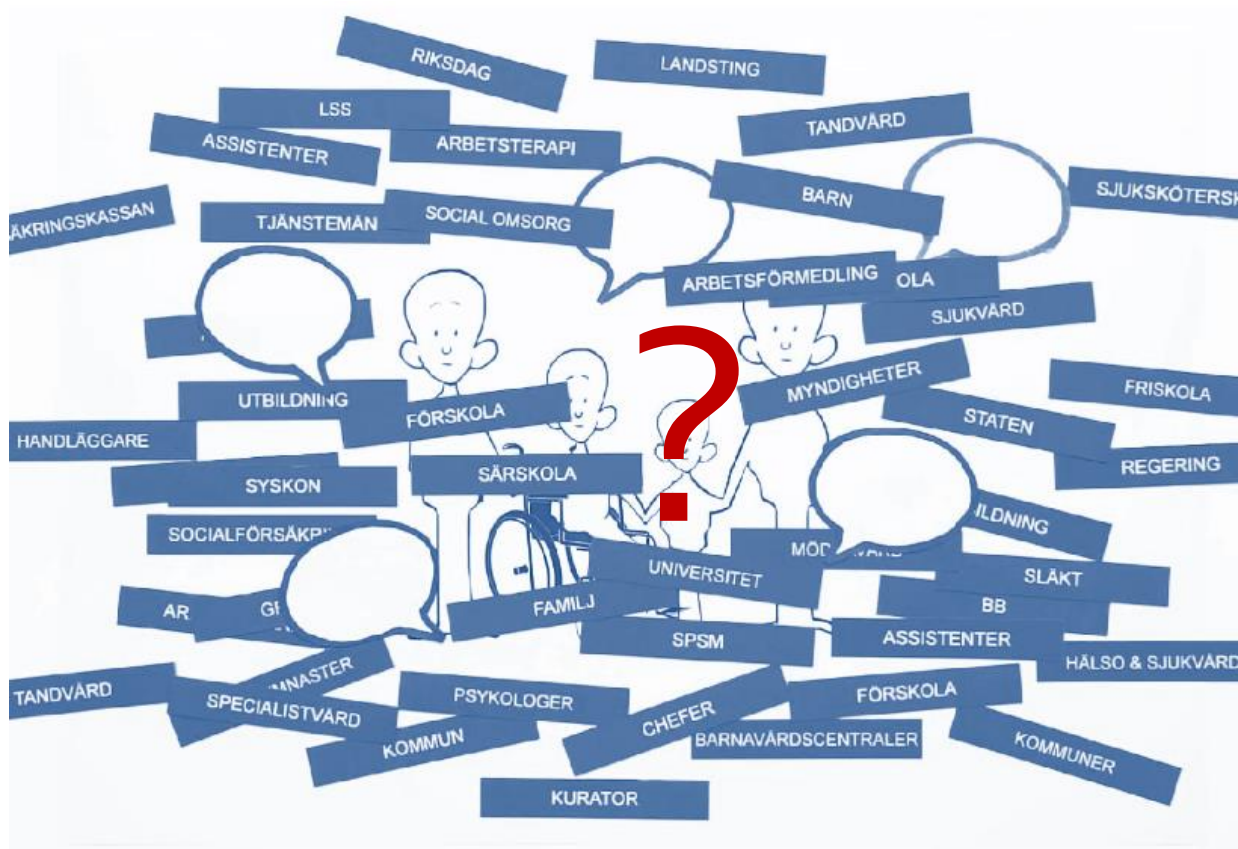
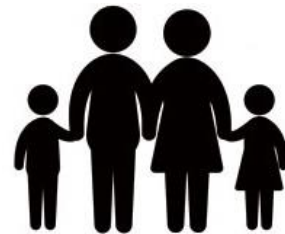
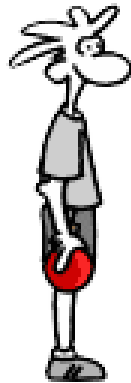
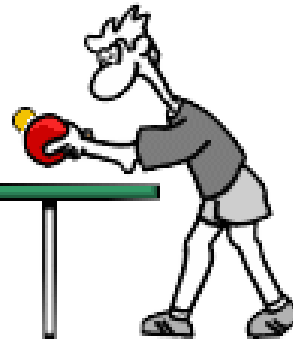
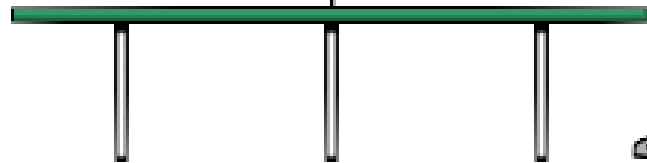


Image used for illustration purposes. Source: [Nationella Funktionen Sällsynta Diagnoser](#), Sweden

Healthcare



People Living with a Rare Disease and their Family



Social & local care and support





“Everyone becomes self-involved in their own tasks and forgets about the bigger picture.

The disabled person has to deal with several different services to receive help and benefits.

There are often waiting times (...), whilst dealing with each service or waiting for service A to send your paperwork to service B.

During this time, you have not had time to employ someone and you are still not working.» **Female, France**

Illustrative photos. This presentation does not necessarily reflect the position of the patients and carers in these photos

Source: [Specialised social services for rare diseases](#)

Professionals from social services are poorly prepared to support people living with a rare disease and their carers

75% of respondents consider that their **level of knowledge** on their disease and its consequences **is deficient**

71% consider they are **not sufficiently prepared** to support them

Over 7 in 10 people!

A clear lack of communication between the different service providers

67% of the respondents say that they communicate the disease-related information badly

“ We face an absence of communication and coordination between the health teams and, on a broader scale, between therapists» **Female, Portugal**

“ Interprofessional communication works only through the good intentions and efforts of particular professional individuals, but not as a course of action» **Male, Czech Republic**

Almost 7 in 10!

The lack of coordination and communication has a serious impact on patients' situation

“ It took **two years to obtain social care support...departments don't talk to one another** so records weren't passed on (...) so I was discharged without help...

This isn't the first time...

It's a constant battle. »

Female, United Kingdom

Patients are badly informed about their rights

74% have poor knowledge **about their disease-related rights**

73% on the **financial help** they may be entitled to

71% on the relevant **social services that can support them**

Over 7 in 10 people!

The difficulty of visiting various social and healthcare care providers in a short space of time

65% of the respondents **have to visit different health, social and local support services in a short space of time**

51% find it **hard to manage**

Over 6 in 10!
5 in 10 find it hard to manage!

The difficulty of visiting various social and healthcare care providers in a short space of time



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

Besides facilitating communication and the definition of adequate treatment it would also avoid that the patient 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

Illustrative photo. This presentation does not necessarily reflect the position of the patients and carers in these photos

Source: [EURORDIS Photo Contest](#)

The challenge of coordination of care

Summary of key results

- ✓ Professionals from social services are poorly prepared: reported by **over 7 in 10 people**
- ✓ A clear lack of communication between the different service providers: **over 6 in 10 people**
- ✓ Lack of coordination and communication has a serious impact on patients' situation: **a constant battle**
- ✓ Patients are badly informed about their rights: **Over 7 in 10**
- ✓ Visiting various social and healthcare care providers in a short space of time: **6 in 10. 5 in 10 find it hard to manage**

raquel.castro@eurordis.org

Thank you!

