



The Italian network of social and health-social services to address the needs of people living with RD

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- The institutional and regulatory framework of the social and social -health system in Italy, the basic concepts of reference
- The needs of people living with RD
- The answers offered by the system, potentialities and limits
- The work done by UNIAMO in this field, towards the ideal model of care

# Why do we speak of social and social and health systems in general and NOT dedicated systems for RD ?

In Italy :

- **the National Health System that addresses all the health needs related to the diseases** .PLWRD are recognized with a specificity in the processes of care, in the Centres of reference and in the exemptions (Ministerial Decree of 18 May 2001, n. 279 "Regulation for the establishment of the national network of rare diseases and exemption from the participation in the cost of related health care services ")
- **The Social and Socio-health system that addresses social issues from the care needs** .PLWRD fall into this path as bearers of needs related to the loss of autonomy without the definition of dedicated paths



Italy = 20 Regions

= 20 different  
social- health  
systems

Why?

# The National regulatory framework

2 key elements:

Law n. 328 /2000 "Framework Law for the implementation of the integrated system of social interventions and services"

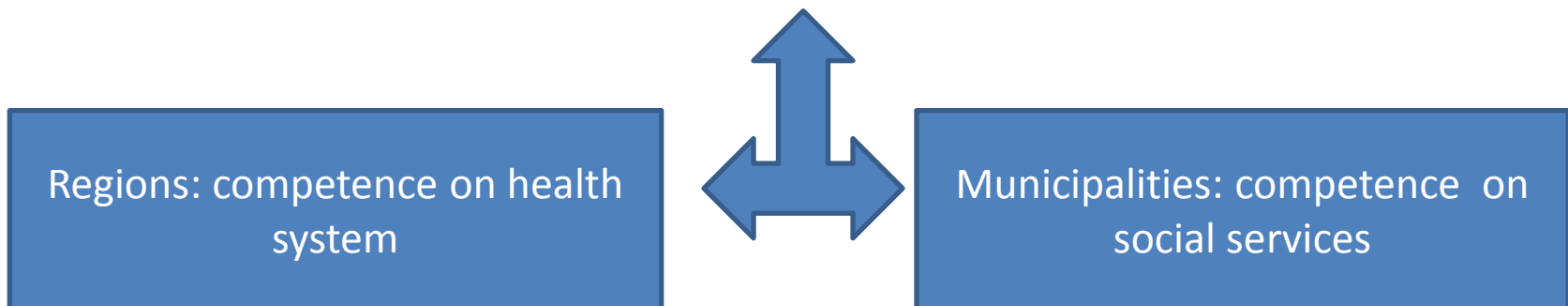
- sets out the principles on which the system relies indicates the tasks and functions of each articulation of the state and society
- identifies the main tools for the adjustment of the system services to individuals
- defines a number of areas in relation to which the regions would have to define their own rules

The V ° article of the Constitution was amended in 2001

Allocates responsibilities to the different institutional articulations of the State

# The V<sup>o</sup> article of the Constitution

1. The government action takes place at a lower level and as close to the citizens, except the power to replacement of the next higher level of government in the event of failure or default of the lower level of government, **the principle of subsidiarity**
2. **To the Regions it has been recognized the legislative autonomy**, *the power to issue rules of primary level, divided on 3 levels of competence*
3. **The municipalities**. Local authorities , with statutory, organizational, administrative, taxation and financial autonomy. **They represent, take care and promote the development of the local community and are the main recipients of administrative functions**, because **they are closer to the citizen** and considered most suitable to carry out the administrative tasks.




# The underlying principles contained in L.328/2000

## *Articolo 1 – Comma 1:*

*The Republic guarantees to the people and families an integrated system of interventions and social services, promotes measures to ensure the quality of life, equal opportunities, non-discrimination and citizenship rights, prevents, removes or decreases the conditions of disability, need and individual and family distress resulting from inadequacy of income, social difficulties and conditions of non-autonomy, in accordance with articles 2, 3 and 38 of the Constitution.*

- The integrated system of interventions and social services is **universalistic, right to the benefits for all citizens**
- Inspired by the concept of **subsidiarity**
- It promotes the **integration of institutional levels and public and private entities**
- Encourages the **participation of citizens**
- Promotes **equity of access to care and services, provides for the approval of the LEPS** (essential levels of social benefits)

# Guaranteed benefits at national level

- In the healthcare the Essential Levels of Assistance (LEA) that guarantee equal health services throughout the country , have been approved many years ago
- After 14 years L. 328/2000 the LEPS, the analogue of the LEA for social services, have not yet been issued  different treatment and services between regions and even within the same region (eg. Different municipalities)



# What does this framework entail?

- Regional rules with different criteria for the authorization and accreditation of residential and semi-residential services
- Different methods of planning and monitoring of social and health -social services
- Different opportunities for patients and their families in the social and social health field

# Needs

## THE RESULTS OF THE PUBLIC CONSULTATION ON RARE DISEASES – 2010

*"Consider not only the clinical , medical, research, diagnostic side, but also the human one such as: removal of architectural barriers, psychological support not only to the patient but also to those around him, job placement for those for whom this is possible, civic campaigns to let know that disability, RD can affect everyone without exception ... "*

# What we mean by social services

**Everything dealing with the integration of the person with RD and his/her family and that reduces social isolation**

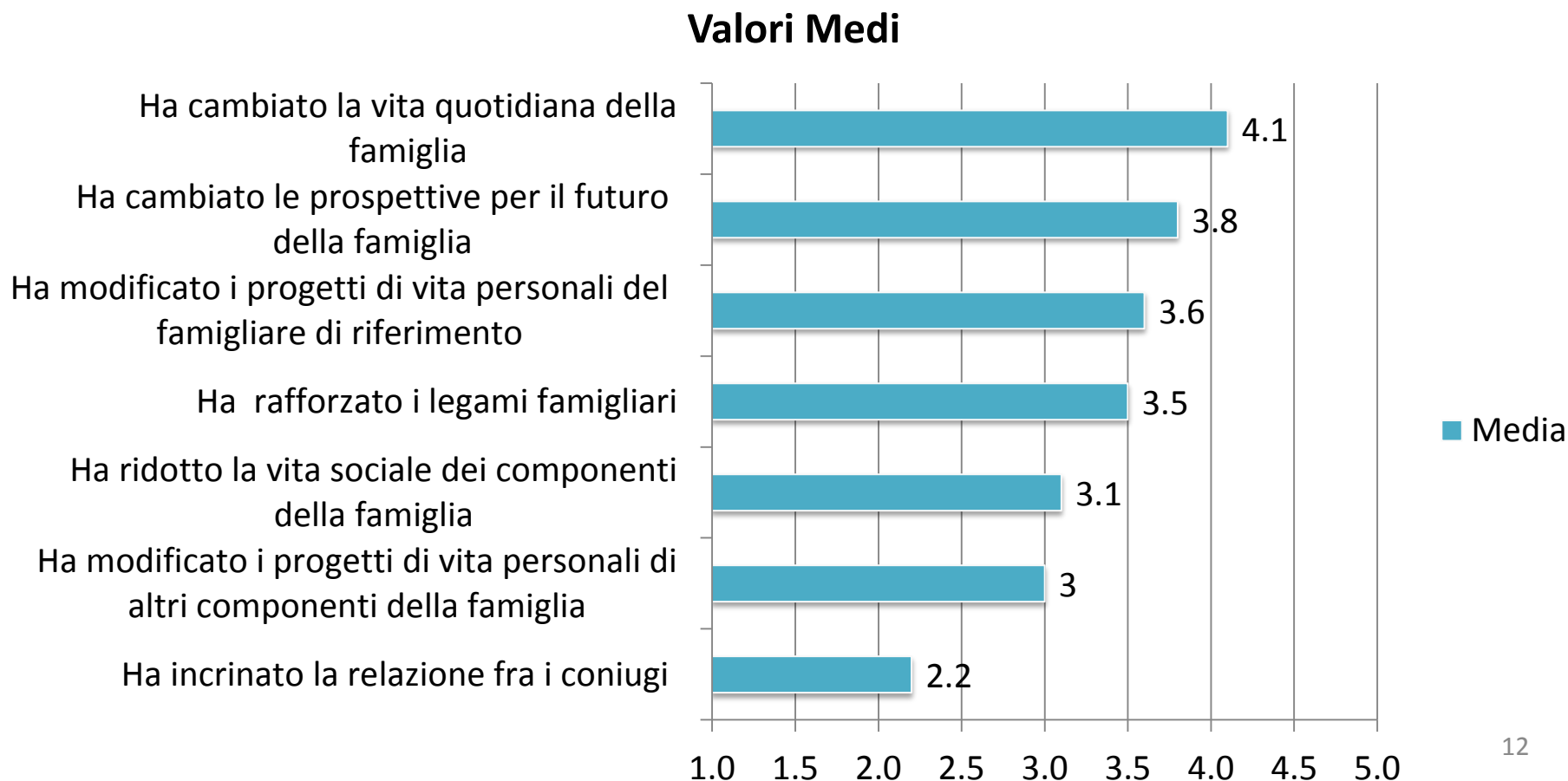
- school integration
- Job placement (working integration projects)
- Integration in free time activities: sports, leisure, tourism
- Day care centres if the work placement is impossible(individual projects of social integration)
- Housing communities in the absence of a family of reference or in case of difficulty of the care-giver
- Home care (not specifically healthcare)
- Opportunities of movement in the territory
- Independent living schemes
- ...

**We do not mean all the activities/structures more strictly related to the healthcare:**

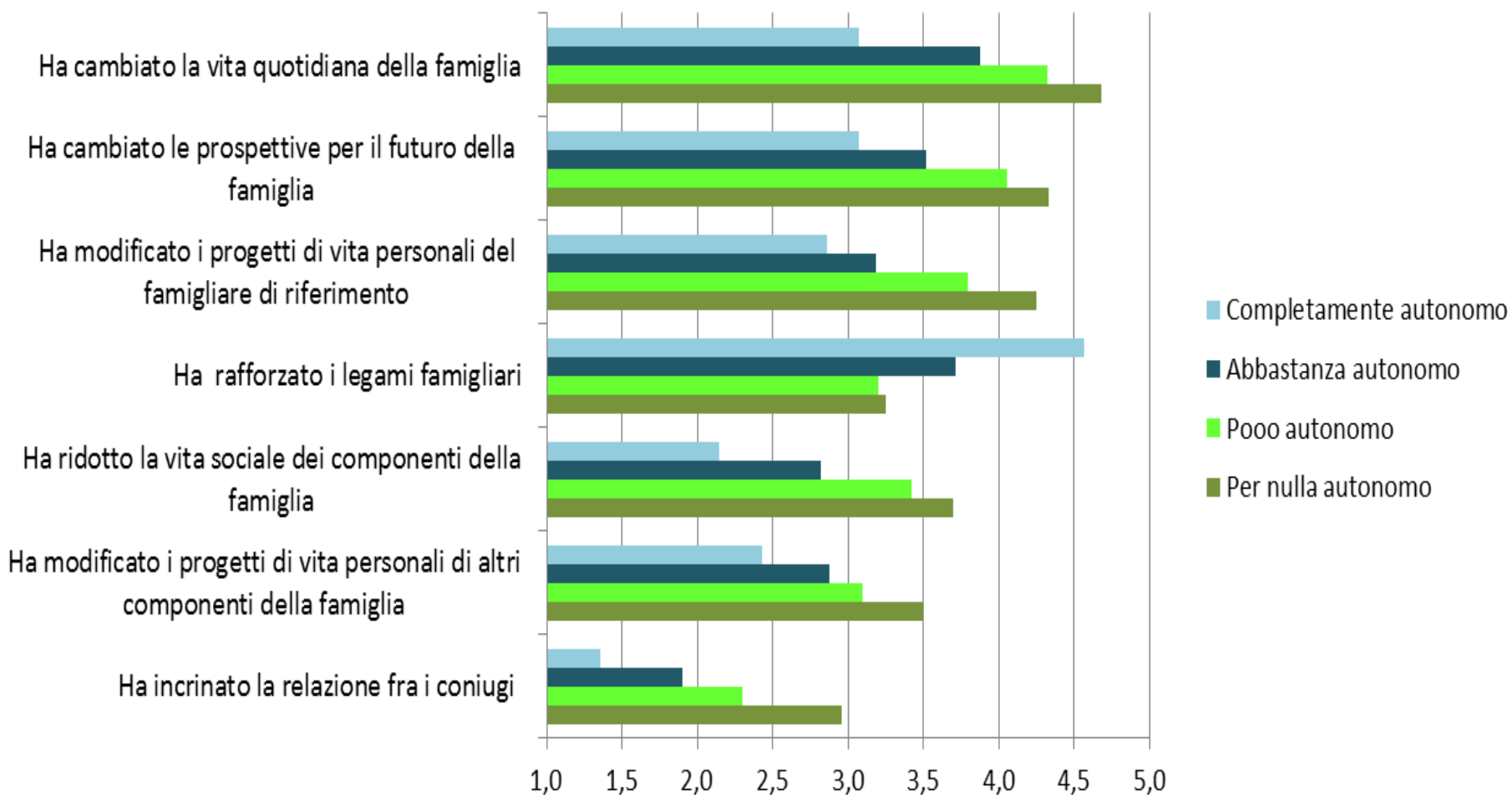
- presidi / reference centres for rare diseases
- Rehabilitation
- Diagnosis and treatment
- drugs
- ...

# Extract from “Diaspro Rosso” Project on the costs borne by families with a person with Rare Disease and social impact

The presence of a component with a rare disease in the family (the rating scale 1 = not at all, 5 = very much):



The presence of a component with a rare disease in the family (the rating scale 1 = not at all, 5 = very much) for **DEGREE OF SELF - AUTONOMY**



# Family, home, school / work

(Survey Diaspro Rosso on the costs borne by families with a component with Rare Disease and social impact)

## 1. The person with RD

1. 14% is in preschool age and 53% student
2. A few rare patients (> 16 years) find a proper place in the world of work (just 6% are employed)
  1. 3,7% is employed
  2. 2,2% is in job placement
  
1. 4,2% is unemployed
2. 2,6% is looking for the first job

3. The onset of the rare disease has led to the abandonment of the work for 8.6% and the reduction of the employment activities for 5.7%

# Family, home, school / work

(Survey Diaspro Rosso on the costs borne by families with a component with Rare Disease and social impact)

Relative of reference for the organization of the care

1. Usually women (in 60% of cases)
2. Married (82% of cases)
3. Parent or spouse of the MR
4. With good schooling level (22% with university degree and 52% with high school diploma or higher diploma professional school)
5. 67.4% work: 47.4% full-time and 20.4 part-time

# The paradigms underlying the work of Uniamo

- Starting from the WHO concept of health as "a state of complete physical, mental, social wellness" to support the territorial care that includes all aspects of the daily life of the person with RD (education, work, leisure, transport, sports, etc..) not only those related to the disease



# UNIAMO CARE MODEL

**QUALITY OF LIFE**

I° Level:  
Knowledge/awareness

II° Level:  
Healthcare Taking charge/presa  
in carico (Network Presidi )

III° level:  
Local health-social care

# How to address the specific characteristics of RD patients 'needs

- Assign a key role to Presidi / Centres of Competence that have to link with the social and social health services 'suppliers on the territory

The "Community" project on the quality of the Centres of competence has defined the following elements :

## PROCESS

- Continuity of care
- Connections (interactions and collaborations)
- **Social-healthcare integration**
- Research and innovation
- Training

# Outcomes of the experimentation of the evaluation model in 5 centres for Thalassaemia

	Centro A	Centro B	Centro C	Centro D	Centro E
Indicator 1: Continuity of care (healthcare )	0,92	0,79	0,92	0,47	0,92
Indicator2: Connections(interactions and collaborations)	0,72	0,75	1,00	1,00	0,48
Indicator 3: Social and health care integration (continuity of care)	0,31	0,35	0,75	0,33	0,20
Indicator 4: Research and innovation	0,44	0,86	0,92	0,56	0,58
Indicatore5: Training	0,80	0,54	1,00	0,85	0,14
<b>Indicatore complessivo di Processo</b>	<b>0,64</b>	<b>0,66</b>	<b>0,92</b>	<b>0,64</b>	<b>0,46</b>

**The social and health care integration is among the elements less performed by the Centers of Competence**

# Open Issues

## Common and general issues in social and social-healthcare services provision

- Progressive contraction of resources dedicated to the integrated system of services
- Lack of a shared national framework on services provided to citizens
- Increase and change of the fragile sections of the population, increased demand for services
- Increased social isolation of the weaker sections of the population

## Specific issues for RD patients

- Difficulties in setting up the functional classification system based on 'ICF: Who should evaluate the level of dependence(percentage) **does not** receive information based on **care needs (social approach)** but on **diseases (health approach)**
- Difficulties to have a real social taking charge by the territory - local service providers (who is the case manager?)
- Poor communication and integration between the Centre of Competence and the territory and among the different professionals who take care of the people with rare disease

# Social Tourism

Per informazioni scrivere a:

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# L'empowerment



La FEDERAZIONE ITALIANA delle associazioni di pazienti affetti da patologie rare  
da sempre impegnata nella tutela dei diritti e nel miglioramento della qualità della vita del paziente e della sua famiglia

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