



# **SOCIAL CARE SYSTEM IN CROATIA IN REGARDS TO THE NEEDS OF PERSONS LIVING WITH RARE DISEASES**

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# INTRODUCTION TO SOCIAL CARE IN CROATIA



- Social work is a practice-based profession and an academic discipline that **promotes social change and development, social cohesion, and the empowerment and liberation** of people.
- **Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work.**

*(International Federation of Social Workers, 2014.)*

- Basic human rights – the right to health, adequate health care including equal access to health care and the right to quality of life after provision of medical care.



# SOCIAL CARE SYSTEM

- **centralized** system – financial and administrative - **one governing body** (Ministry of social policy and youth)– **local Centres for social care** – 80 in Croatia with 24 subsidiaries and **Zagreb Center for social care** with 11 offices
- two major **categories of users**:
  - people without means of living – in the poverty line
  - other vulnerable groups not necessary with low income but high life expenses (due to unexpected life circumstances, such as diseases and disabilities)



# SOCIAL CARE SYSTEM

- **methods of assistance**
  - financial
    - advisory
    - social and psychological support

**Social care** – should provide **prevention and social services**



# ACCESS TO FINANCIAL SUPPORT

- **Unique body of expertise** – January 2015
  - single body of expertise with territorial jurisdiction offices for evaluation of determining disability, and physical and psychological disability degree, rehabilitation needs and possibility of employment of persons with disability



## SERVICES IN THE COMMUNITY

- a great number of services for persons with RD are provided by civil society organisations - help lines, accomodation for families during childs hospitalization, financial support ,seeking of second medical oppinions (foreign experts), social and psychological support for the families

the system needs to provide secure government funding for these organisations – secure their **sustainability**



## ISSUES WITHIN THE SYSTEM

- different systems (health, labour and pension, social, education and city and county social services) provide different support possibilities – many of which exclude one another
- patients and their family are provided with little information of their rights in the system, especially if they don't seek information themselves
- shame associated with social services – labeling users as government dependent or disabled



# CHALLENGES

- how to adapt the existing social services system to the diversity of the needs of persons living with RD?
- how to ensure cooperation between different systems providing care for persons with RD?
- how to provide equal access to medical and social care to families living in remote local communities?





# PROPOSED SOLUTIONS

- **specialized social services** – persons living with rare diseases have to be singled out in the system and provided with specialized tools –we need to provide visibility
- **rare disease coordinator in general hospitals** – person educated in specific needs of rare disease patients – coordinating medical care in in different areas (exp. Urgent care, medical appointments etc.) - working closely with reference centers for specific rare diseases in the hospitals
- organizing **social prevention programs** - aiming to empower persons with RD and enable them to participate in the society as equal citizens



# IMPROVING THE PROFESSION

- more **specialized social workers** in the health systems – training and social guidelines
- we need professionals with the ability to see the **users perspective** – most of the individual experience of the disease is suppressed under the medical information – how does the person feel living with their disease, what are their needs?
- Croatian National Alliance for Rare Disease-representatives participating in the VI. Conference of social workers – **future projects with the Croatian association of social workers and local Centres for social care**



## CONCLUSION

- We need to open a dialogue that focuses on empowering persons living with rare diseases in a ability based perspective with holistic, multidisciplinary services and transcending separate government systems that acknowledge the complexity of living with rare diseases.





**THANK YOU FOR YOUR  
ATTENTION!**

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