

LEGAL AND SOCIO-CULTURAL SUPPORT TO RARE DISEASE PATIENTS IN SERBIA – QUALITATIVE RESEARCH OF THE PROJECT „Equitable services for patients with rare diseases“

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OBJECTIVES

The objective of the poster is to present qualitative data obtained through qualitative research within the project „Equitable services for patients with rare diseases patients“. Obtained data relate to challenges and obstacles in health, social and educational system.

EVALUATION

1. Healthcare system:

- Discrepancies between formal structures of the health care system and situation on the field (in some regional centers there are no specialists for some rare diseases)
- Malfunctioning of the health institutions network
- Inter-institutional and intra-institutional rivalries
- Lack of basic diagnostic means (equipment does not exist or is dysfunctional, etc.)
- Difficulties in the access to treatment and rehabilitation
- Limited access to treatment abroad for conditions not classified as “curable”

2. Social care system:

- Lack of information on some social rights (inadequate provision of information by social care centers)
- Systemic discouraging of ill persons and their family members in realization of their social rights
- Unstable availability of certain services: (a) personal assistants, (b) adapted transportation, (c) day care centers, and (d) different rehabilitation opportunities
- Insufficient institutional aid to single mothers whose partners leave upon finding child's health condition

3. Educational system:

- In smaller towns in Serbia there are almost no special kindergartens/schools.
- Insufficient information for parents of children with rare diseases as the basis for selection of adequate educational institution – specialized or regular with inclusive schooling programs
- Insufficient institutional support for home schooling (covering only salaries, but not other related expenses)
- Architectural unconformity of the existing school buildings
- Insensibility of employees in relation to special needs of their pupils/students
- Insensibility of other parents in relation to special needs of the children with

METHOD

Research was conducted through series of focus group interviews with patients suffering from rare diseases, as well as through expert interviews with the stakeholders' representatives. Further, the data were analysed against the existing legal regulation, showing gaps and overlappings in the regulation.

CONCLUSIONS

1. Elimination of discrimination among patients with rare diseases:

It is necessary to enable all rare diseases patients and not only those with “curable” diseases to access the public funds and seek diagnoses and treatments abroad. It is also necessary to regulate the equal access to diagnostics and treatment both for adults and children.

2. Diagnostics:

Public Health System attention to the problems of the rare diseases should be increased. Education of health personnel on the obligation of setting the timely diagnosis in accordance with the Law, is needed.

3. Provision of the adequately territorially allocated specialists:

It is necessary for selected physicians (GPs) to refer patients, without obstacles to Centers for rare diseases on the tertiary level of health care.

4. Education of health personal at all levels of health care system on rare diseases and patients' rights

Education of physicians (in primary health care institutions) for the purpose of initial identification of rare diseases is needed. Education of all health professionals related to the patients' rights (in particular patients with rare diseases) is necessary.

5. Provision of information and aid in social care centers on the rights for persons affected:

Social care centers should systematically provide information and aid to patients with rare diseases and their families as to enable them to enjoy all the prescribed social rights.

6. Improving educational opportunities for children with rare diseases

Systematic implementation of existing legislation on specialized/inclusive education and aid to parents of children with rare diseases is needed.

RESULTS

Analyses resulted in recommendations which should contribute to the development of a coherent policy framework – Strategy:

- Informing and education of health professionals on the obligation of setting the diagnosis in the due time, in line with the health legislation.
- Adequate and equitable territorial distribution of the specialist, when approving specializations.
- Primary health care physicians should refer patients, without obstacles, to centers for rare diseases on the tertiary health care level, in the case of doubt of rare diseases existence.
- Education of physicians for the purpose of recognizing of rare diseases and related to patients rights, is necessary.
- Facilitating of procedures for acquiring right to frequent and continuous physical rehabilitation for persons with rare diseases.
- After setting the diagnosis, it is necessary to inform the patient and/or his family on further steps in therapy, rehabilitation, as well as on possibilities in using other rights in the areas out of health care.
- Introducing positions of psychologist or psychotherapist into systematization of working places within health system.
- Acknowledgement of right to early pension due to the rare disease.
- Necessity to expand the legal basis for sending patients or biological material for diagnostics abroad, if there are no possibilities in RS.
- Necessity to introduce the continuous education for social workers related to working with rare diseases patients.
- Introducing the easier administrative procedures for realisation of different rights on the basis of disability.
- Criteria for realisation of right to care and support of other person should be more sensitive and should take into consideration position of the persons with rare diseases.
- Centres for Social Work on the level of local municipalities should have transparent and available guidelines on the rights of persons with rare diseases and their families, as vulnerable group.
- Introducing the role of „parent-caregiver“, as a paid position, into the system, for parents which take care of the child and cannot be employed.
- Enabling full salary for the parents working part time due to the necessity to care about the child.
- Providing the medicines, planning the needs for medicines and shortening of procedures for import of unregistered medicines for rare diseases.
- Undertaking measures for employment of persons with disabilities.
- Passing the Law on social entrepreneurship

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