



## THE NORO CENTRE

### SECTOR

Integrated social and health care services

### COUNTRY

Romania

### LEAD ORGANISATION

The [NoRo Centre](#), partner of [Eurordis](#), a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases

### CONTACT

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**EURORDIS**  
Rare Diseases Europe

### DESCRIPTION

The NoRo Centre is a resource centre providing therapeutic and medical services. Its main objective is to provide integrated social and care services to people affected by rare diseases and their families through improving access to care, information, research, and education.

The NoRo Centre regularly organises training for patients; groups of 12-14 patients with the same rare disease participate in one-week sessions where they are provided with therapy, education, and rehabilitation. It also provides training for people with intellectual disabilities with the aim to teach them independent life skills.

Moreover, the Centre is in charge of a day care centre that organises individual and group therapy for around 50 children with

rare diseases and autistic spectrum disorders.

A help line is available for clients or professionals looking for information and support.

The Centre has set up a network of videoconference facilities with seven medical universities across Romania, contributing to continuity of care and direct access to information and meetings between patients and professionals while avoiding travel costs. Sharing knowledge and exchanging good practices on remote management consultations, medical and social advice and training are essential in the sector of rare diseases, since expertise is scarce.

To make this project a success, the Centre cooperates with non-governmental organisations, health care providers, social workers, teachers, employers, and

several institutes with expertise in rare diseases. At local level, the Centre organises meetings with kindergarten and schools where children from the day care centre are integrated. The Centre also works in partnership with public authorities and stakeholders at national level, which is important to promote positive measures in the areas of health, fighting poverty and social exclusion, and education. It collaborates with the Ministry of Health, the National Authority for Disabled People, and the Romanian National Alliance for Rare Diseases (RONARD).

The day care centre is partly funded by the local council and the county council, and the medical outpatient clinic of the Centre has a contract with a health insurance company.

### **A SOCIAL INVESTMENT APPROACH**

Through collaboration with experts, medical universities and social services at different levels, the Centre is able to bring together new ideas. It also contributes to the European Union's INNOVCare project, representing an innovative care pathway that brings together national resource centres for rare diseases in partnership with public bodies.

Participation is a guiding principle of the project. The Centre holds regular meetings with service beneficiaries and their families to discuss potential improvements. They are involved at all stages of the process, from planning to implementation. Every patient has the chance to fill in a questionnaire about

the quality of services provided. Moreover, the managing board consists of seven people living with rare diseases and family members, which guarantees that every decision takes into account service users' concerns.

The activities undertaken by the project are meant to empower people and strengthen their skills and capacity. The objective is to enable them to fully participate in community life and advocate for their fundamental rights; for example, through access to therapists who conduct home visits to families in order to help parents to continue care interventions for their children.

The Centre embraces a preventive approach through the therapeutic education of beneficiaries and by connecting with other services to ensure continuity of care. For people living with rare diseases early and continuous intervention is very important.

Once combined, these factors produce a return on investment in the long-term, since family members are more likely to remain in employment as their child or relative is well cared for and provided with the necessary skills for an independent life.

### **MAIN ACHIEVEMENTS**

Thanks to the high quality social and integrated services the Centre provides, it is now recognised by the Ministry of Health as a health care provider and a specialised social service with research capacity. In the last three years, 479 people have registered to its therapy and therapeutic education

services. Many other beneficiaries take part in information and training services.

### **LOOKING FORWARD**

Securing funding from local and national authorities for the medium- and long-term will be important for the Centre. Public authorities should provide support equivalent to at least the minimum costs standards for service provision established by the Ministry of Health and the Ministry of Work in Romania. Moreover, having one point of contact for accreditation and recognition of integrated services and another for funding integrated care would make the work of the Centre much easier.

Through the INNOVCare project, opportunities to upscale the model of integration are analysed with the intention of extending it to other Member States and beyond rare diseases. Partnerships between public, private, and civil society organisations will also have to be strengthened.