

Krivnia, and elsewhere. A health education and screening program was carried out covering most young Roma from the risk groups. In Rouse the research team visited the large Kardarash community where there is a high occurrence of hereditary diseases and a high percentage of people with disabilities. A genetic screening for the most common diseases in the community was conducted; patients were tested clinically and consulted in their homes. In the Gotze Delchev Region the team cooperated with Annie Karagiozova and Feya Mehmedova from the local Integro Association and visited all villages with Roma population – Ognianovo, Marchevo, Dehren, Dubnitsa, Musomishte and others. Clinical tests and consultations were conducted in all villages. The team also met local general practitioners and local authority officials. In Omurtag the research was actively supported by Dr. Mustafa Chakur, therapist in the Roma neighborhood.

Upon receiving the results of the genetic tests the team visited and consulted personally all the people tested and carefully and thoroughly explained to those who have been tested positive for genetic defects what is the risk of having unhealthy offspring and how can this risk be prevented.

### **Chronically Ill and Disabled Roma**

In its report "The Access of Roma to Health" I. Tomova (2000) notes that according to data from representative research studies conducted in the last 6 years almost half of the Roma families in Bulgaria have a chronically ill member, while in one fifth of them there are two or more patients with chronic diseases. A 1999 research, solicited by the World Bank and covering 831 families in 8 extremely poor Roma communities, identified chronically ill patients in two third of the Roma families living in poverty; in one third of them there are two or more cases of chronic diseases. According to a representative research on "Roma in the Transition Period" the average disability rate among Roma in 1994 was 81 per 1000, not including disabilities among children, while in 1999 in the poorest Roma communities it reaches 186-207 per 1000 (I. Tomova, 2000).

A research on disabilities in the Roma communities in Kyustendil, Senovo and Tulovo conducted by the Minority Health Problems Foundation indicated that 1 to 3.6% of Roma in these three towns and villages have been officially registered as disabled. The actual number of disabled people however is at least three times higher. Many chronically ill or disabled Roma are unable to prepare the necessary documents for official registration due to financial reasons. In many places there are also discriminatory attitudes on behalf of the medical staff who deliberately tries to prevent registration. Many disabled people have no access to wheelchairs, orthotic elements, antidecubital mattresses. It is a common practice three or more disabled patients to share one wheelchair. Sometimes patients have been asked money to have their documents issued and processed. We discovered that many Roma with neurodegenerative diseases have not been advised to get corrective orthopedic surgery, which has led to early and severe disability. Meanwhile, Bulgarian patients with similar diseases from the same communities have received adequate treatment.

Health reform has further worsened the situation of chronically ill and disabled Roma. The majority of them are immobilized, they live in remote places and are financially unstable, their access to healthcare establishments and social services is very limited and they are in a dire situation. In fact they get no treatment at all, they are not involved in rehabilitation programs, they have no health insurance and have not filed the proper documents for medical retirement. They are often unable to see their family physician, let alone go to a specialized hospital. Our numerous visits and meetings revealed a number of neglected and untreated cases, which lead to premature disability and early death. Most disabled Roma have virtually no access to cor-