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OFFICE OF THE HIGH COMMISSIONER

STUDY

**The Human Rights of
Children with Spina Bifida
in the Republic of Moldova**

February 2015

NOTE

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This report has not been formally edited.

PREFACE

The Office of the United Nations High Commissioner for Human Rights (OHCHR) – the United Nations Human Rights Office – commissioned the study that follows concerning the human rights of children with spina bifida in the Republic of Moldova for, essentially, two reasons:

First of all, it is evidently in the public interest to examine the impact of corruption on human rights in the Republic of Moldova. Corruption is viewed broadly by the public in the Republic of Moldova as among the largest challenges for the advance of the country.¹ However, corruption is a phenomenon seen or alleged in nearly all spheres of life in the Republic of Moldova – in the Justice sector, throughout various areas of the administration, as well as in the major social services areas. It is therefore not clear how, methodologically, to begin the undertaking of documenting the impact of corruption, with a view to supporting processes to end it.

Within our modest resources, OHCHR has endeavored to articulate one possible human rights answer: we have endeavored to document in an area where the human rights harms are most urgent. Left untreated or inadequately treated, spina bifida leads to the extremely painful death of children. Ján Jařab, regional representative for Europe of the United Nations Office of the High Commissioner for Human Rights, himself a doctor, has commented with respect to failure to treat spina bifida correctly: “This is not a fast death, but a slow and painful one – with an enormous head, blindness developing over months or years, and horrendous pain. It is probably the most torturous preventable death that exists.”

In the Republic of Moldova, there have been persistent, plausible allegations that corruption is a key factor in preventing children with spina bifida from having access to the operation to insert a “shunt” – a drain of the spinal fluid – during the key days and weeks when the operation would be needed to prevent hydrocephalus, the swollen head and painful death described by Ján Jařab. This report aims to contribute to the Republic of Moldova’s anti-corruption efforts by investigating these allegations and bringing forward the Office’s findings in this regard.

The second limb driving our inquiry concerns the increasing attention paid within human rights to questions of stigma. The international human rights system has increasingly devoted attention to the role of stigma in driving human rights abuse.² The problem of stigma as a social phenomenon plays out powerfully in law in a number of areas, and in

¹ In 2014, the Republic of Moldova ranked 103rd out of 175 countries globally and scored 35 out of 100 on the global Corruption Perceptions Index published annually by Transparency International (please see: <http://www.transparency.org/country/#MDA>). In 2012, Moldova ranked 94 according to the same index. UN Special Rapporteur on Human Rights and Extreme Poverty Magdalena Sepulveda has recently stated, with respect to the Republic of Moldova: “Corruption is a major obstacle to reducing poverty as it impedes economic growth and discourages foreign investment. More importantly, corruption has a devastating impact on the poorest people in society because it distorts public policies and diverts resources that could be invested in public infrastructure and services that are essential elements of poverty eradication strategies.” (A/HRC/26/28/Add.2)

² Report of the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, 1 February 2013, A/HRC/22/53.

particular in the ban on discrimination. There are increasingly recognized international law obligations to take positive measures to end all forms of stigma, in particular those given rise to human rights abuse.

In the Republic of Moldova, there are allegations that non-treatment or inadequate treatment of children with spina bifida arises from embedded views among medical providers, social workers and the public-at-large, that some lives are worth more than others, and indeed that some lives may not be worth living at all. Such views, if indeed influencing treatment, are at fundamental odds with international law and indeed with the very essence of the human rights idea. Such attitudes are affiliated with the eugenics movement, which among other things was a key influence on the rise of Nazism, and the euthanasia programs to which persons with disabilities were subjected by the Nazis and their allies. We set out to examine if and to what extent it is the case that such views influence medicine in the Republic of Moldova.

This study is of necessity primarily empirical, given the subject matter. In order to carry out this study, the Office reviewed available information concerning law, policy and practice in the Republic of Moldova concerning prevention, treatment and amelioration of spina bifida and hydrocephalus. Families of children with spina bifida were interviewed in detail, with a view to documenting their experiences. The World Health Organization (WHO) helpfully reviewed a draft of the report and provided comments. A number of people were not available for interview for this study, in particular children who died painful deaths in institutions as a result of being placed there by their families, as a result of combinations of stigma, and pressure. Their voices will never be heard.

This study is, of necessity, not the final word on these matters – neither about prevention and treatment of children with spina bifida, nor about corruption in the health sector, nor about the rights of persons with disabilities. The sole intention of this modest study is to further the Republic of Moldova’s efforts at health care reform, done on a human rights basis, as well as to further its aspirations to advance reforms, as part of the democratic family of Europe.

EXECUTIVE SUMMARY

Statistical data on the number of children with spina bifida in the Republic of Moldova is unclear and does not appear to accurately reflect the number of children who, by sheer statistical probability, are likely to be born annually with this disorder.

As concerns prevention, new policies to fortify flour with folic acid, while welcome, do not yet ensure that fortification enhances all flour. As of now, fortified flour and bread is not readily accessible. It is anticipated that universal introduction in 2015 is a key moment in prevention of spina bifida. Monitoring in this regard is particularly encouraged. Similarly, coverage of folic acid vitamin supplements does not reach all or even most women at the crucial pre-pregnancy stage. As such, considerable further work is needed to ensure that all of the population-at-large receives folic acid, via fortified food products, in accordance with international best practices.

With regard to treatment, although this appears improved over practices two decades ago, testimony of parents of children with spina bifida indicate consistently that indifference or ignorance on the part of medical providers, corruption in the form of demands for informal payments, as well as continuing imbedded negative views that “some lives are not worth living” – based on stigma against the children and families concerned -- continue to drive an outcome whereby children who need shunt implant operations are not receiving them in a timely fashion. As a result, children continue to be threatened with extremely painful death, although this is avoidable. Although an estimated 130 children are born annually in the Republic of Moldova with spina bifida, research was only able to identify 24 first-time shunt operations carried out in the Republic of Moldova in the year 2013. It is unclear what is happening with the remaining circa 100 children born annually with spina bifida in the Republic of Moldova. The research found strong indications that tens of children annually are not gaining access within the urgent time required to a shunt operation.

In as far as palliative care is concerned, in 2010 there has been issued a National Standard on Palliative Care which describes clearly the key principles, criteria and types of services available at the state level. Still, for persons who have developed hydrocephalus, this does not appear to be reaching all persons in need of such care, again at least in part as a result of the high degree of stigma on persons with disabilities.

The research documented stereotypes and negative attitudes, including among medical providers, including views to the effect that spina bifida occurs among “uncultured” families, and that treating spina bifida is a waste of the state’s resources. Despite evident barriers to effective care, some medical professionals interviewed blamed parents for issues facing children with spina bifida.

Stigma and shame also gives rise to cases of domestic violence, as spouses blame women for having “unhealthy children”. This research effort also encountered and documented the problem that Moldova’s shelters for victims of domestic violence are not yet accessible in practice, due to rigid and arbitrary administrative formal admission

requirements and practices. Parents also continue to be pressured to institutionalize children with spina bifida, against the legal requirements set out under Article 19 of the Convention on the Rights of Persons with Disabilities, requiring that all persons have a right to independent living in the community. Heads of institutions and other policy-makers stated continuing beliefs that institutions constitute an appropriate mode of managing spina bifida cases, despite Moldova's 2010 ratification of the Convention on the Rights of Persons with Disabilities.

This report concludes with recommendations aimed at improving law, policy and practice, and ending the extreme states of exclusion, stigma and pain experienced by children and adults with spina bifida, and by their parents.

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INTRODUCTION AND OVERVIEW

"I'm sure that if we had been given good guidance by specialists and then operated on, I would have a normal girl now. I knew nothing about hydrocephalus and no one in our local hospital explained clearly what steps should be taken and who can help us." – Ms. O.C., the mother of a child with spina bifida and hydrocephalus

"The state wastes a lot of money on this problem." – Dr. A.P., a surgeon

"This is a young, irresponsible woman with no normal education and no job. She has a disabled child, so she should not make too much noise about her personal problems." – Ms. L.R., a social worker

The current report is the result of data and fact-based research on the situation of children with spina bifida in the Republic of Moldova. The Office of the United Nations High Commissioner for Human Rights (OHCHR) undertook desk research into law, policy and practice, interviewed key Moldovan and international experts in this area, including administrators and medical providers in contact with spina bifida cases, as well as more than 20 families who raise children with spina bifida in the Republic of Moldova. Research was conducted during the period April-September 2014. This report has also been submitted to key medical and legal experts, including the World Health Organization (WHO), for review and supplementary comment as to the issues arising.

It is not known exactly why spina bifida appears with an approximate prevalence of 1-2 cases in 1,000 births worldwide. This prevalence may vary from region to region, the average indicator in EUROCAT³ being 0.28-1.72 to 1,000 births.⁴ Spina bifida is a birth defect that occurs in the infant's spine. It occurs about 24-26 days after pregnancy. The bones of the infant's spine are not closed over the spinal cord (central tube of nerves). A part of the spinal cord which is located under these bones may be abnormally formatted or even damaged. A soft and unprotected area will be present on the infant's back. This area may be covered by skin or, more commonly, may be an open wound that may bulge through the skin as a dark bag. This bag is covered by a very thin layer of skin which may leak liquid from the spinal cord and brain.

No separate studies on human rights issues facing children with spina bifida have ever been carried out in the Republic of Moldova. Therefore, it was not clear, what happens with a child born with spina bifida, where and how such children are diagnosed and

treated (or indeed if they are diagnosed and treated), and whether their human rights are fully respected.⁵

On average, around 40,000 children are born annually in the Republic of Moldova. According to the National Bureau of Statistics, around 1,300 of these have a certified disability.⁶

The National Scientific Pediatric Surgery Centre Natalia Gheorghiu provides some information about the incidence of spina bifida in the Republic of Moldova for the period 2008-2013, as follows: in the year 2008 spina bifida has been detected in just 4 births according to official evidence, in 2009 – 5 children were born with spina bifida, in 2010 – 9, in 2011 – 13 children, in 2012 – 12 and 12 spina bifida cases as well have been officially registered in the year 2013. According to this data, the number of cases of spina bifida appears to have increased dramatically during the period 2008-2013.⁷ It is unclear whether this is due to an actual increase in the number of cases, or of previous underreporting having been rectified.

Leading experts in the Republic of Moldova stated in the course of this research that there are evidently more cases of spina bifida which, for unknown reasons, are not reflected in official data. They estimated that there are circa 130 cases of spina bifida per year in the Republic of Moldova.⁸

While conducting the research, some doctors and parents stated that, in their view, the mortality rate among children with spina bifida was very high. Some alleged that cases were hidden from official reporting.

Attention by many national experts is apparently paid to identifying potential risk groups among young woman, developing pre-conception and pre-natal screening services, consolidating efforts in raising awareness of possible risks in case of unplanned pregnancies, among other priorities. Less attention, however, is paid even today to ensuring the universal availability of food products enriched with folic acid. Enrichment – generally of flour – is generally deemed the most effective mode of preventing spina bifida.

³ EUROCAT – European surveillance of Congenital anomalies – a World Health Organization Collaborating Center, conceived in 1974.

⁴ Manual "A VI-lea Conferinta Nationala Zilele Neonatologiei Moldave. Patologia malformativa neonatala" under edition of Prof. Dr. Maria Stamatin and Prof. Dr. Petru Stratulat, 27-90.06.2013, Section title: "Monitorizarea malformatiilor congenitale a populatiei Republicii Moldova".

⁵ A major interest for the investigated issue was prompted by experience shared by the Romanian Association of Spina Bifida and Hydrocephalus (RASBH), an organization which assisted such children more than 10 years, providing complicated operations in collaboration with the leading specialists in neurologic surgery from Romania. The experience showed that until 2004 children with spina bifida were not operated and in 90% developed hydrocephalus as a complication and as a result, a great majority of these children died in blindness, fever and pain. Since 2004 more than 1200 shunts were donated to children with spina bifida and hydrocephalus and that fact made possible to save all these lives.

⁶ <http://statbank.statistica.md/pxweb/Dialog/Saveshow.asp>

⁷ The official statistical data is provided by National Scientific Pediatric Surgery Center "Natalia Gheorghiu" as average number of spina bifida cases per 1 000 of births for 2008-2013 – the total number of officially identified spina bifida cases was calculated based on the number per thousand as provided in the official data. Ms. Natalia Cojusneanu, Deputy Director of the Centre, confirmed the figures included her as correct.

⁸ Three competent experts in the field independently arrived at the figure of 130 as to be expected from a country the size of the Republic of Moldova, with no regular practice of folic acid fortification. A fourth interviewed expert stated that spina bifida incidence was likely to be higher than 130 per year in Moldova.

In the Republic of Moldova, a number of bread factories, with the support of UNICEF⁹, have started supplementing flour with folic acid and iron since the beginning of 2013 – as the adopted policy stipulates three stages of the mentioned process to be implemented at the national level. Law nr.171 from 19.03.2012 on Undertaking Measures to Reduce Diseases Caused by Iron and Folic Acid Deficiency¹⁰ states: “All locally produced and imported wheat flour, meant for being used in alimentation industry and public feeding enterprises, is hereinafter fortified with folic acid and iron in three stages: 1) Since December 1, 2013, the flour produced by economic agents which benefit of the UNICEF support ... is further fortified; 2) Beginning on March 1, 2014 flour produced by national economic agents with the volume of production exceeding 150 tonnes of flour monthly is to be fortified; 3) Beginning on January 1, 2015 all locally produced and imported flour is to be enriched with folic acid and iron”. In 2016 the Ministry of Health is to assess the impact of flour fortification on population health.

At the time of publication of this report, fortified flour and bread is not widely and readily accessible in the Republic of Moldova. It is anticipated that universal introduction in 2015 is a key moment in prevention of spina bifida. Monitoring in this regard is particularly encouraged.

Since 2008, the treatment of children with neural tube defects – including spina bifida – has been undertaken in the Republic of Moldova. This is according to a standard Clinical Protocol elaborated by a committee of experts and doctors at the national level, approved by the Ministry of Health, and updated every three years. The Protocol is accessible only by health care professionals who deal with the treatment and rehabilitation of children with congenital malformations. It is unclear why the Protocol is not a public document.

Under the existing policy, children with disabilities can enjoy medical support within a health care institution which is fully insured from the medical insurance funds, as stated in the Law on Insurance nr.1585 from 27.02.1998.¹¹ The right of enjoyment of a highest standard of health care and rehabilitation for children with disabilities is clearly specified in the recently adopted Law on Social Inclusion of Persons with Disabilities.¹² Article 43 of Law specifies the obligation of central and local public health care institutions to provide consultation, treatment and rehabilitation of a highest quality, including special assistive devices which shall be insured as well. Point 4 and 5 of article 43 guarantees the right for palliative care within the medical-sanitary institution or, in case of need, this care shall be provided at home.

The National Institute of Mother and Child is the main state health care facility, in the Republic of Moldova, for children born with spina bifida and other congenital anomalies of development. This institution provides pre- and post-natal coaching to women from all corners of the country. According to data derived by this institution, in 2013, 24

9 UNICEF – United Nations Children’s Fund – provides a long-term humanitarian and developmental assistance to children and mothers in developing countries.

10 Hotarirea Guvernului nr. 171 from 19.03.2012 “Cu privire la aprobarea unor masuri de reducere a afectiunilor determinate de deficient de fier si acid folic pina in anul 2017”, point 4.

11 Legea cu privire la asigurare obligatorie de asistenta medicala nr.1585 from 27.02.1998, art.4, p.4, letter (i)

12 Legea privind incluziunea sociala a persoanelor cu dizabilitati nr.60 from 30.03.2012, chapter 6, art.43

operations were performed to implant shunts, and 22 operations undertaken to replace or repair shunts implanted earlier. There is evidently a gap between this figure and the estimated 130 children born with spina bifida annually in the Republic of Moldova. It is unclear what happens with the circa 100 children with spina bifida born annually who are not operated on at the National Institute of Mother and Child.

In the course of research, the researcher interviewed more than 20 families from various parts of the country, who shared experiences and challenges in the process of treatment and rehabilitation of their children. The researcher identified cases of discriminatory attitudes regarding life of children with disabilities, physical abuse and high stigma facing women who gave birth to children with spina bifida and lack of competence among local health care providers that has been led to very serious impacts on children’s health. An extremely high level of corruption in health care institutions was confirmed repeatedly by a great part of the interviewed parents. More than that, many of these mothers were strongly threatened by their doctors with a short but understandable phrase: “You’ll come back to our institution anyway...”. Names of the interviewed parents are changed or otherwise masked for reasons of confidentiality.

Some families of children with spina bifida – particularly those living in poverty or other forms of exclusion – have difficulty accessing vitally needed health care services and being less supported by local social institutions. This situation was observed particularly in rural areas, where children with spina bifida and hydrocephalus are isolated from the rest of the world, staying at home, not attending kindergartens or schools, not having even specific learning assistance and relevant support. Such a situation happens in families, who raise children with severe forms of spina bifida – one of the parents is usually not employed and the other one is abroad. Single mothers with 4 or 5 children face severe economic and social exclusion, living on the monthly allowance offered by the state for the disabled child.

The Republic of Moldova is party to 7 of the 9 core international human rights treaties, guaranteeing inter alia the right to life, the right to the highest attainable standard of physical and mental health, as well as equality and non-discrimination rights for persons with disabilities.¹³ In her June 2012 report to the United Nations Human Rights Council, UN Special Rapporteur on Extreme Poverty stated: “Those who require special and regular medical attention, including children with cystic fibrosis, spina bifida or other curable or manageable diseases, lack effective access to adequate services or medication, and their parents are required to make (often large) out-of-pocket payments to meet their children’s health-care needs.”¹⁴

This report aims to shed further light on issues facing children with spina bifida and their parents, and it brings recommendations for urgent action for improving law, policy and practice in this area. Names of nearly all of the persons interviewed for this report have been anonymized at their request.

13 International Covenant on Economic, Social and Cultural Rights; International Covenant on Civil and Political Rights; International Convention on the Elimination of All Forms of Racial Discrimination; Convention on the Rights of Child; Convention against Torture; Convention on Elimination of All Forms of Discrimination against Women; Convention on the Rights of Persons with Disabilities.

14 A/HRC/26/28/Add.2

I.

WHAT IS SPINA BIFIDA?

Definition and types

It is not known exactly why spina bifida appears with an approximate prevalence of 1-2 cases in 1,000 of births worldwide. This prevalence may vary from region to region, the average indicator in EUROCAT¹⁵ being 0.28 – 1.72 to 1,000 of births.¹⁶

Spina bifida comes from two words: “Spina” – meaning spine and “Bifida” – meaning split. This is a defect that occurs in the infant’s spine. It occurs about 24-26 days after a woman became pregnant. The bones of the infant’s spine are not closed over the spinal cord (central tube of nerves). A part of the spinal cord which is located under these bones may be abnormally formatted or even damaged. A soft and unprotected area will be present on the infant’s back. This area may be covered by skin or, more commonly, may be an open wound that may bulge through the skin as a dark bag. This bag is covered by a very thin layer of skin which may leak liquid from the spinal cord and brain.

There are four types of spina bifida: occulta, closed neural tube defects, meningocele, and myelomeningocele.

Occulta is the mildest and most common form in which one or more vertebrae are malformed. The name “occulta,” which means “hidden,” indicates that a layer of skin covers the malformation, or opening in the vertebrae. This form of spina bifida, present in 10-20 percent of the general population, rarely causes disability or symptoms.

Closed neural tube defects make up the second type of spina bifida. This form consists of a diverse group of defects in which the spinal cord is marked by malformations of fat, bone, or meninges. In most instances there are few or no symptoms; in others the malformation causes incomplete paralysis with urinary and bowel dysfunction.

In the third type, *meningocele*, spinal fluid and meninges protrude through an abnormal vertebral opening; the malformation contains no neural elements and may or may not be covered by a layer of skin. Some individuals with meningocele may have few or no symptoms while others may experience such symptoms as complete paralysis with bladder and bowel dysfunction.

¹⁵ EUROCAT – European surveillance of congenital anomalies, a World Health Organization collaborating center, conceived in 1974

¹⁶ Manual “A VI-lea Conferinta Nationala Zilele Neonatologiei Moldave. Patologia malformativa neonatala” under edition of Prof. Dr. Maria Stamatina and Prof. Dr. Petru Stratulat, 27-90.06.2013, Section title: “Monitorizarea malformatiilor congenitale la populatie in Republica Moldova”

Myelomeningocele, the fourth form, is the most severe and occurs when the spinal cord/neural elements are exposed through the opening in the spine, resulting in partial or complete paralysis of the parts of the body below the spinal opening. The impairment may be so severe that the affected individual is unable to walk and may have bladder and bowel dysfunction.¹⁷

Complications associated with spina bifida

Complications arising as a result of spina bifida can range from minor physical problems with little functional impairment to severe physical and mental disabilities. Spina bifida’s impact is determined by the size and location of the malformation, whether it is covered, and which spinal nerves are involved. All nerves located below the malformation are affected to some degree. Therefore, the higher the malformation occurs on the back, the greater the amount of nerve damage and loss of muscle function and sensation.

A relatively high number of infants born with spina bifida get extra fluid in and around the brain, a condition called hydrocephalus, or water on the brain. The extra fluid can cause swelling of the head, which may lead to brain injury. If not treated in a timely fashion, hydrocephalus may cause blindness, paralysis and even death. Many studies show that hydrocephalus is developed in over 80% of untreated spina bifida cases and can be detected often by measuring of the baby’s head size.

Some children with an open spina bifida may also have Chiari II malformation, in which the brain is positioned abnormally. The lower part of the brain rests farther down than normal, partially in the upper spinal canal. The cerebrospinal fluid can become blocked and cause hydrocephalus. While most affected children have no other symptoms, a few may have upper body weakness and trouble breathing and swallowing.

A so-called progressive tethering (tethered spinal cord) is another serious defect that may occur in an infant born with spina bifida. Typically, the bottom of the spinal cord floats freely in the spinal canal, but for many people with spina bifida, the spinal cord is attached to the spinal canal. Thus, the spinal cord stretches as a person grows, and this stretching can cause spinal nerve damage. The person might have back pain, scoliosis, weakness in the legs and feet, bladder or bowel control problems, and/or other problems.

Open types of spina bifida, as the baby grows, might become a reason of paralysis and mobility limitations. Children with spina bifida high on the back (near the head, for instance) might not be able to move their legs. Children with spina bifida low on

¹⁷ National Institute of Neurologic Disorders and Stroke from United States, Publication nr.13-309 “Spina bifida” from June 2013.

the back (near the hips) might have some leg mobility and be able to walk unassisted or with crutches, braces, or walkers. Some children with spina bifida often cannot control their bladder and bowel movements. They also can develop urinary tract infections.

In many cases children with spina bifida have additional physical and psychological conditions, including digestive, vision, sexual, social, and emotional problems; obesity; and depression.¹⁸

Spina bifida risk factors

The reasons why some children are born with spina bifida even today are not clear. Still, there are some factors that may lead to spina bifida and other birth defects associated with this, including the following:

- Folate deficiency (lack of vitamin B12 – folic acid): many studies have shown that getting enough folic acid can reduce essentially a woman’s chance of giving birth to a baby with spina bifida, if she consumes 0.4 milligrams of folic acid each day before becoming pregnant and in the first trimester of pregnancy. If it is to be effective, folic acid supplementation must begin before pregnancy, because the spinal column forms so early after fertilization. In addition to its ability to prevent spina bifida, folic acid appears to reduce its severity as well. An efficient solution that has been implemented worldwide is a mandatory enrichment of food products with folic acid and iron for primary prevention of all birth anomalies of development.
- Family history is another cause of spina bifida. If a woman has previously had a child with spina bifida, her risk of having other children with the condition is significantly higher.

Some types of medicine have been linked to an increased risk of spina bifida or other birth defects. These are the medicines are used to treat epilepsy and some mood disorders, such as bipolar disorder. Therefore, if a woman plans pregnancy – there’s of vital importance to consult a doctor on which type of drugs it is better to use.

Women with diabetes have an increased risk of giving birth to a child with spina bifida. This may be due to the excess glucose in the blood interfering with the child’s development.

Women with obesity are at increased risk of giving birth to a child with spina bifida. The more obese the woman is, the higher the risk. Obese means having a body mass index (BMI) over 30, a severe obesity is when the BMI exceeds 40.¹⁹

¹⁸ Eunice Kennedy Shriver National Institute of Child, Health and Human Development. Section “Health and Research”, edited in November 30, 2011.

¹⁹ BMI – body mass index or Quetelet index – is a measure of relative weight based on an individual’s mass and height: Devised between 1830 and 1850 by the Belgian polymath Adolphe Quetelet.

Treatment and rehabilitation

There is no commonly accepted cure for spina bifida. Each case should have an individual approach and careful evaluation. The nerve tissue that is damaged cannot be repaired, nor can function be restored to the damaged nerves. Treatment depends on the type and severity of the disorder. Generally, children with the mildest form need no treatment, although some may require surgery as they grow.

While spina bifida occulta usually requires no treatment, the more severe types of spina bifida usually require surgery to close the opening in the back, to preserve spinal cord function, and to reduce the risk of infection. Additional surgeries often are required. **Shunting**, a procedure that drains excess fluid from the brain into the abdomen, controls hydrocephalus and can prevent or reduce many of the consequences of this condition.

A shunt is a simple device which diverts the accumulated cerebral spinal fluid around the obstructed pathways and returns it to the bloodstream. It consists of a system of tubes with a valve to control the rate of drainage and prevent back-flow. It is inserted surgically so that the upper end is in a ventricle of the brain and the lower end leads either into the heart or into the abdomen. The shunt may be a programmable (adjustable) type.

In most cases, shunts are intended to stay in place for life, although alterations or revisions might become necessary from time to time. The tube or catheter may become too short as the individual grows and an operation to lengthen it might be necessary. Occasionally, as with any implant, there can be mechanical failure. Also, it is important to be aware that problems can occur with blockage or infection of the shunt.

Some health care institutions continue to perform fetal surgery for treatment of spina bifida myelomeningocele. Some doctors believe the earlier the defect is corrected, the better the baby’s outcome. Although the procedure cannot restore lost neurological function, it may prevent additional loss from occurring. The surgery is considered experimental and there are risks to the fetus as well as to the mother. Still, the benefits of fetal surgery are promising, and include less exposure of the vulnerable spinal nerve tissue and bone to the intrauterine environment, in particular the amniotic fluid, which is considered toxic.

Any surgical intervention done to close the defect of the neural tube is rather a beginning of treatment. Even if the child with spina bifida has been operated timely and successfully, damaged nerves generally cannot be restored. Physical therapy for managing partial paralysis and mobility problems is needed. In addition, rehabilitation for spina bifida frequently includes occupational and recreational therapy; speech therapy may be indicated for patients with speech and/or swallowing difficulties.

Physical therapy programs are designed to parallel the normal achievement of gross motor milestones. Occupational therapy should be initiated early to compensate for

motor skill deficits and should progress along the normal developmental sequence. Recreational therapy is helpful for promoting independence by enhancing play and recreational opportunities.

In the process of rehabilitation some children with spina bifida may require assistive devices such as braces, crutches, or wheelchairs. The location of the malformation on the spine often indicates the type of assistive devices needed. Children with a defect high on the spine will have more extensive paralysis and will often require a wheelchair, while those with a defect lower on the spine may be able to use crutches, leg braces, or walkers. Beginning special exercises for the legs and feet at an early age may help prepare the child for walking with those braces or crutches when he or she is older.

The earlier an infant with spina bifida sees a competent doctor, the more chances for an independent life he will have. Even the disability which is inevitably caused in complicated forms of spina bifida or if this is associated with other defects, may be managed successfully – such children can and should be fully integrated in society.

International legal framework

The fundamental rights of children with spina bifida are guaranteed and protected by international laws which the Republic of Moldova has ratified, being party to 7 of the core 9 international human rights treaties (footnote of which ones). The right to life is one of the inalienable rights recognized for all human beings since birth. It must be upheld for all persons, without exception. Article 6 of the International Covenant on Civil and Political Rights (ICCPR)²⁰ and article 2 of the European Convention on Human Rights (ECHR)²¹ set out that every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life intentionally. States have strong positive obligations to act effectively to protect all lives under threat. Where information has come to the attention of the public authorities, including doctors and other medical personnel indicating that a particular person's life is under threat, and where the authorities have failed to act adequately to protect this life, states have been deemed by bodies such as the United Nations Human Rights Committee and the European Court of Human Rights to have violated their international human rights obligations. The non-treatment of children with spina bifida implicates this right, in particular when influenced by the views that some lives are not worth living.

20 International Covenant on Civil and Political Rights, adopted and open for signature and ratification by General Assembly Resolution 2200A (XXI) of 16 December 1966, entry into force on 23 March 1976

21 Convention for Protection of Human Rights and Fundamental Freedoms (better known as "European Convention on Human Rights") was adopted and open for signature and ratification in Rome on 4 November 1950, entry into force on 3 September 1953

An extensive discussion is held last period of time on inhuman treatment and torture in health care settings.²² In case of children with spina bifida, even a short delay in their treatment leads to the development of severe complications which inevitably lead to a lifelong disability or painful death. Particularly as a result of the high degree of pain, as well as physical and mental anguish, these issues implicate the international law ban on torture and other forms of inhuman and degrading treatment or punishment, as set out inter alia under the ICCPR Article 7, ECHR Article 3, as well as the UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.²³

Questions of the right to health are most clearly set out under international treaty law as a result of Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR),²⁴ which sets out a right to the highest attainable standards of physical and mental health. In 2000, the Committee on Economic, Social and Cultural Rights, the expert arbiter of the treaty, issued General Comment Nr.14, which addresses substantive issues arising in the implementation of the ICESCR with respect to Article 12 and the right to the highest attainable standards of physical and mental health. The General Comment makes the direct clarification that "the right to health is not to be understood as a right to be healthy." Instead, the right to health is articulated as a set of both freedoms and entitlements which accommodate the individual's biological and social conditions as well as the State's available resources. Article 12 tasks the State with recognizing that each individual holds an inherent right to the best feasible standard of health, and list non-exhaustively 'freedoms from' and 'entitlements to' that accompany this right. Core items in the Committee's elaboration of normative requirements in the right to health include ensuring availability, accessibility – including non-discrimination, physical accessibility, economic accessibility, as well as informational accessibility – adequacy, and quality.

Health is set out at several points in the Convention on the Rights of the Child (CRC).²⁵ CRC Article 3 requires states parties to ensure that institutions and facilities for the care of children adhere to health standards. CRC Article 17 recognizes the child's right to access information that is pertinent to his/her physical and mental health and well-being. Article 23 makes specific reference to the rights of children with disabilities, in which it includes health services.

Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD)²⁶ specifies that "persons with disabilities have the right to the enjoyment of the highest

22 See in particular Report of the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, 1 February 2013, A/HRC/22/53.

23 United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, adopted by the General Assembly Resolution 39/46 on 10 December 1984, entry into force on 26 June 1987

24 International Covenant on Economic, Social and Cultural Rights, adopted and open for signature and ratification by General Assembly Resolution 2200A (XXI) of 16 December 1966, entry into force on 3 January 1976

25 Convention on the Rights of the Child, adopted and open for signature and ratification by General Assembly Resolution 44/25 of 20 November 1989, entry into force on 2 September 1990

26 Art.7, 25 of the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol (A/RES/61/106) is adopted on 13 December 2006 at the United Nations Headquarters in New York.

attainable standard of health without discrimination on the basis of disability.” The sub-clauses of Article 25 state that the State shall give the disabled the same range, quality, and standard of health care as it provides to other persons. Further provisions specify that health care for persons with disabilities should be made available in community. A core principle of the CRPD Convention is ending all forms of stigma against persons with disabilities.

II

DATA, POLICY AND HEALTH CARE FACILITIES FOR CHILDREN WITH SPINA BIFIDA IN THE REPUBLIC OF MOLDOVA

Data

There are no separate studies on spina bifida in the Republic of Moldova. Information on spina bifida is quite limited and not accessible for all interested persons, as the researcher has seen. In all or nearly all official documents spina bifida is included in the category “Congenital Malformations”²⁷ and is just briefly characterized without any specification or relevant statistical data. Nevertheless, the National Institute of Mother and Child²⁸ where children with spina bifida are basically treated declares that a systematical evidence of the incidence of birth defects in the Republic of Moldova is effectuated since the year 1991 and that since 2009 the national register book on congenital anomalies is included in EUROCAT²⁹. This public health care institution is empowered to lead various scientific research meant to monitor the dynamics of birth defects, including spina bifida, and to report on collected data.

Annually, in the Republic of Moldova, on average around 40,000 children are born. According to the National Bureau of Statistics, around 1,300 of these have a certified disability.³⁰ According to the data, presented by National Institute of Mother and Child, in the period 2008-2012 the number of all births in Republic of Moldova was 190,448. Of these, around 3,500 were born with congenital malformations.³¹

The National Scientific Pediatric Surgery Center provides some information about the prevalence of spina bifida in the Republic of Moldova for the period 2008-2013, as follows: in the year 2008 spina bifida has been detected in just 4 births according to official evidence, in 2009 – 5 children were born with spina bifida, in 2010 - 9, in 2011 – 13 children, in 2012 – 12 and 12 spina bifida cases as well have been officially registered in the year 2013. The number of cases of spina bifida appears from the data to have

27 The term “congenital” is further used in the report – means something that a person acquires since birth (a condition that develops in the womb to the fetus) – congenital – malformation, defect, anomaly of development, disease – this is related to spin bifida – a birth defect of the neural tube.

28 The Institute of Mother and Child is a state health care institution which works at national level, was founded in September 01.1989, provides medical assistance, treatment and rehabilitation for newborn children and their mothers, holds various scientific researches and is considered a key health care facility for children born with spina bifida and other congenital defects.

29 EUROCAT – European surveillance of congenital anomalies – a WHO Collaborating Center

30 <http://statbank.statistica.md/pxweb/Dialog/Saveshow.asp>

31 Manual “A VI-lea Conferinta Regionala Zilele Neonatologiei Moldave. Patologia malformativa neonatala” under edition of Prof.Dr. Maria Stamatina and Prof.Dr. Petru Stratulat, 27-30.06.2013. Chapter: “Monitorizarea malformatiilor congenitale la populatia Republicii Moldova

grown dramatically during the period 2008-2013³². It is unclear whether this is as a result of an actual growth in the number of cases, or of previous underreporting being rectified.

Leading experts in the Republic of Moldova stated in the course of this research that there are evidently more cases of spina bifida which, for unknown reasons, are not reflected in official data. They estimated that there are at least 130 cases of spina bifida per year in the Republic of Moldova.³³

“In many cases spina bifida is associated with other serious defects,” stated Ms. Natalia Cojusneanu, Deputy Director of the National Scientific Pediatric Surgery Center “Natalia Gheorghiu”.³⁴ “Therefore, it may not be mentioned at all or put as secondary condition in the final diagnosis. The official data shows cases where spina bifida has been detected only.”

On 1 January 2013, there were 712,096 children in the Republic of Moldova, age 0-18. Official data on infant mortality in the Republic of Moldova is as follows:

- Children under the age of 1: In 2013, 359 children under the age of 1 have passed away, which makes a rate of 9.8 deaths out of 1000 children born alive. The causes of death are: perinatal conditions – 42.6%, congenital anomalies – 27.3%, respiratory diseases – 9.8%; accidents, intoxication and traumas – 5.9%.
- Children of ages 0-5 years: Total number of deaths in 2013 - 449. Causes: infectious diseases -3.1% ; diseases of the nervous system – 2.0%; diseases of the respiratory system – 11.1%; perinatal conditions – 34.1%; congenital anomalies – 24.7%; accidents, intoxication and traumas -25%
- Children of the ages 0-18 years: In 2012 has been registered a number of 664 deaths, out of which 26.2 % were caused by congenital anomalies and in 2013 – 590 such deaths.³⁵

Doctors and parents stated during the research that they deem the mortality rate among children with spina bifida to be high, while the official data seemed implausibly low. Some alleged that these cases were hidden from official reporting. This is the opinion of two experts and three interviewed mothers who stayed for 10 days in the health care institution, seeing children born with complicated forms of spina bifida dying.

“It is not in the interest of any public health care facility to show the real rate of mortality” – stated Mr. N.M., a geneticist who declined to be identified by name.³⁶ “This may attract an unwilling extra control and an exhausting paper work for each case separately. The data should ideally be presented in such a way as not to raise undesirable questions.”

32 The official statistical data is provided by National Scientific Pediatric Surgery Center “Natalia Gheorghiu” as average number of spina bifida cases per 1 000 of births for 2008-2013 – the total number of officially identified spina bifida cases was calculated based on the number per thousand as provided in the official data. Ms. Natalia Cojusneanu, Deputy Director of the Centre, confirmed the figures included her as correct.

33 Three competent experts in the field independently arrived at the figure of 130 as to be expected from a country the size of the Republic of Moldova, with no regular practice of folic acid fortification. A fourth expert stated that spina bifida incidence was likely to be higher than 130 per year in Moldova.

34 Interview with Ms. Natalia Cojusneanu, Vice-Director of the Scientific Pediatric Surgery Center, Chisinau, September 27, 2014

35 Yearly Statistics Book for 2013, Demographics

36 Private discussion with Mr. N.M. – a leading genetic expert, Chisinau, July 21 2014

Law and Policy

Prevention

In the Republic of Moldova, some bread factories with the support of UNICEF³⁷ have started supplementing some sorts of flour with folic acid and iron since the beginning of 2013 – as the adopted policy stipulates three stages of the mentioned process to be implemented at the national level. Law nr.171 from 19.03.2012 on Undertaking Measures to Reduce Diseases Caused by Iron and Folic Acid Deficiency³⁸ states: “All locally produced and imported wheat flour, meant for being used in alimentation industry and public feeding enterprises, is hereinafter fortified with folic acid and iron in three stages: 1) Since December 1, 2013, the flour produced by economic agents which benefit of the UNICEF support ... is further fortified; 2) Beginning on March 1, 2014 flour produced by national economic agents with the volume of production exceeding 150 tonnes of flour monthly is to be fortified; 3) Beginning on January 1, 2015 all locally produced and imported flour is to be enriched with folic acid and iron”. In 2016 the Ministry of Health is to assess the impact of flour fortification on population health.

As of now, fortified flour and bread is not readily accessible. As of now, this kind of bread is not accessible in all shops and its price is relatively higher than the price of an ordinary bread. It is anticipated that universal introduction in 2015 is a key moment in prevention of spina bifida. Monitoring in this regard is particularly encouraged.

In addition to mandatory enrichment of flour with folic acid and iron, the state health insurance fund reimburses at a rate of 100% pills which contain the mentioned substances for all women who plan a pregnancy or are already pregnant. A recently updated Order of Ministry of Health on Drugs Compensated from Medical Insurance Funds³⁹ gives a list of 100% compensated and partially insured drugs for pregnant women and children of the age 0-5. The insured or “compensated” essential drugs can be prescribed by a health care specialist to all persons, including those who have no statute of an insured person as states the Unified Program on Obligatory Insurance of Medical Support⁴⁰. All insured persons shall be informed on the existing list of relevant compensated drugs, which are recommended and prescribed by presenting an identity act, all these services shall be provided without pay.⁴¹ This policy however manifestly does not have as extensive a positive impact as enrichment of cereals and grains, for the reason that, as noted above, folic acid needs to be taken *prior* to pregnancy to be fully effective in preventing spina bifida.

37 UNICEF – United Nations Children’s Fund – provides a long-term humanitarian and developmental assistance to children and mothers in developing countries.

38 Hotarirea Guvernului nr. 171 from 19.03.2012 “Cu privire la aprobarea unor masuri de reducere a afectiunilor determinate de deficient de fier si acid folic pina in anul 2017”, point 4.

39 Ordin al Ministrului Sanatatii nr.492/139-A from 22.04.2013 “Cu privire la medicamente compensate din fondurile asigurarii obligatorii de asistenta medicala”.

40 Programul National Unic al Asigurarii Obligatorie de Asistenta Medicala, art.4. p.(2) adopted by Government Disposal nr.1387 from 10.12.2007

41 Hotarirea Guvernului nr.1372 din 23.12.2005 “Cu privire la modul de compensare a medicamentelor in conditiile asigurarii obligatorii de asistenta medicala.

In addition to the above, in 2013 the Government of the Republic of Moldova adopted a National Programme on Preventing and Diminishing Mortality and Morbidity among Children by Congenital Malformations and Hereditary Diseases (2013-2017).⁴² Chapter 4 of this policy specifies a number of steps which are planned in purpose of strengthening preventive measures - pre-conception, pre-natal screening and diagnostics of possible anomalies in development. Among other measures, the policy sets out measures for raising awareness among young women and young families in factors which may lead to birth anomalies.

The foregoing prevention measures are crucial for replacing the current approach, the primary element of which appears to be counselling abortion. The following examples illustrate this tendency:

"I can't understand why doctors told me that I have too many children and I had to think carefully before giving birth to another one." – stated Ms. S.V.⁴³ "I love this baby and I just need a human treatment to our situation – I don't need advices how to interrupt pregnancy or do different kinds of screening tests!"

"I was at the last stage of pregnancy, expecting to give birth to a beautiful baby with all help and psychological support from the medical personnel, as this was my first pregnancy," stated Ms. O.F.⁴⁴. "When I came to a planned ultra-sonic screening, I found out that I will have a baby with a very complicated defect of the neural tube. The doctor began to shout at me, like: 'From which forest have you come?! This baby will die in the first hours after birth!' He proposed an abortion."

Ms. C.L.⁴⁵ stated as well that since the moment it became clear that she will give birth to a disabled child, psychological pressure to abort came from the doctors' side. "I was delicately explained that this is inhuman to make the child live the life in doors, lying in bed and being fully dependent on drugs. One day I was sure of this view and my mother stopped me from the biggest mistake I could commit in my life." According to one study, annually around 270 of women abort their pregnancies as a result of finding out that the child will be born with a congenital condition.⁴⁶

Treatment

The Unified Program on Obligatory Insurance of Medical Support mentioned below specifies in chapter II, point 5 a list of diseases which require an urgent medical assistance, financed from the funds of medical insurance – congenital malformations and chromosome anomalies being mentioned in the actual policy under the letter Q, according to World Health Organization 10th revision of diseases classification

42 Chapter 4, letter D, section II and IV of Programul National de prevenirea si reducerea mortalitatii si morbiditatii copiilor prin malformatii congenitale si patologii ereditare pe anii 2013-2017, nr.998 from 5.12. 2013, implemented by Order of Ministry of Health nr.1606 from 31.12.2013

43 Interview with Ms. S.V. – mother of five years old girl who has hydrocephalus, Salcuta, April 11, 2014

44 Interview with Ms. O.F. – mother of 2 year old girl, diagnosed with spina bifida myelomeningocelle, Chisinau, July 08, 2014

45 Interview with Ms. C.L. – mother of 3 years old boy with spina bifida, Ialoveni, June 28, 2014

46 Manual "A VI-lea Conferinta Regionala Zilele Neonatologiei Moldave. Patologia malformativa neonatala" under edition of Prof.Dr. Maria Stamatina and Prof.Dr. Petru Stratulat, 27-30.06.2013. Chapter: "Monitorizarea malformatiilor congenitale la populatia Republicii Moldova.

(q.00 – q.99). Children with spina bifida fall into the mentioned category, which means that they should fully benefit from medical assistance within a public health care institution. Point 23 of the mentioned below policy gives a clear description of services that are accessible in equal mode to all insured categories of people, including children of age 0-18. The point 23 states: "Medical assistance provided within a health care institution represents a 'resolved case' which includes the following: Consultation and investigations for diagnostics, medical and surgical treatment, specific care, consumables, sanitary materials, accommodation facilities and food. Children of the age 0-3 can stay in the hospital with one of parents".

In the Republic of Moldova, the treatment of children with congenital defects of the neural tube (including spina bifida) has since 2008 been regulated by a standard Clinical Protocol, elaborated by a profile committee of experts and doctors at national level, approved by the Ministry of Health, and updated once every three years. The protocol is accessible only for profile experts and health care professionals who deal with treatment and rehabilitation of children with congenital malformations.

However, under the existing policy, children with disabilities can enjoy of all medical support within a health care institution which is fully insured from the medical insurance funds, as stated in the Law on Insurance nr.1585 from 27.02.1998.⁴⁷ The right of enjoyment of a highest standard of health care and rehabilitation for children with disabilities is clearly specified in the recently adopted Law on Social Inclusion of Persons with Disabilities.⁴⁸ The article 43 of this law specifies the obligation of central and local public health care institutions to provide consultation, treatment and rehabilitation of a highest quality, including special assistive devices which shall be insured as well. Point 4 and 5 of the article 43 guarantees the right for palliative care within the medical-sanitary institution or, in case of necessity this care shall be provided at home p.6).

The Order of the Ministry of Health nr.432 from 25.05.2011⁴⁹ specifies the policy on rehabilitation which is inevitably needed for children with severe congenital diseases. The mentioned law explains clearly the structure of the rehabilitation services, the way these facilities are organized and the principles of their functioning. In the annex 4, section II, point 7.8 it is clearly stated that the rehabilitation services are provided to children with disabilities in purpose of improvement of their health conditions. The point 7.15 specifies the short and long term rehabilitation courses until the optimal results are achieved. The exact duration of a rehabilitation course for each case is established in an individual mode by a leading doctor after a careful evaluation of the patient health conditions.

Palliative Care

Palliative care services have been developed in the Republic of Moldova since 2000, particularly at the non-governmental level. Still, over the last years this issue has been put on public agenda, causing a lot of debates and discussions. In 2009, the Ministry

47 Legea cu privire la asigurare obligatorie de asistenta medicala nr.1585 from 27.02.1998, art.4, p.4, letter (i)

48 Legea privind incluziunea sociala a persoanelor cu dizabilitati nr.60 from 30.03.2012, chapter 6, art.43

49 Ordin al Ministerului Sanatatii nr.432 from 25.05.2011 "Cu privire la organizarea si functionarea serviciului de reabilitare medicala si medicala fizica", annex 4, Setion II.

of Health adopted an Order on Functioning of Palliative Care Services⁵⁰ which provides definitions of palliative care; sets out who can benefit of these types of services, as well as conditions of agreement between the patient and personnel; articulates rights and responsibilities of beneficiaries and obligations of personnel; and provides details as to financing and functioning of palliative care services.

In 2010, a National Standard on Palliative Care⁵¹ was issued, including further description of basic criteria, principles, activities and types of palliative services, nursing and social support for beneficiaries, as well as for their families. The document states that “Not only adults but children, having congenital diseases or other conditions diagnosed in childhood (cancer, congenital malformations, neurologic and muscular dystrophies, cystic fibrosis, HIV AIDS and other conditions with a limited prognosis) can and should benefit of all existing palliative services. Palliative care becomes an essential and indispensable service when all other methods of treatment are not opportune any more for persons who shall die in peace and dignity, painlessly, without any overwhelming symptoms ...”.

According to the current regulatory framework in force in the Republic of Moldova, palliative care services include the following actions: decision to take over palliative care services; initial assessment; setting a treatment plan; reassessment and monitoring; medical supervision; transferring; deregistration; communication and education of patients and their families/care givers; promotion of palliative care services; training for personnel, researches.

Health Care Facilities

The National Institute of Mother and Child is the main state health care facility providing services for children born with spina bifida and other congenital anomalies. The institution provides pre- and post-natal coaching to women from all parts of the country.

This institution administrates a National Center of Family Planning, where pre-conception screening is executed, including genetic testing, including via the Center’s Scientific Genetic Center. The Institute of Mother and Child administrates as well a Scientific Pediatric Surgery Center “Natalia Gheorghiu” and a separate maternity, pathology, psycho-neurology and surgery departments for new-born children. Within the above-mentioned facilities, children with different types of spina bifida are treated, assisted and monitored.

According to the data of National Institute of Mother and Child, in the year 2013, there were executed 24 operations with the use of shunts and 22 revisions of shunts, introduced earlier. “All these operations are done without any fee. In many cases there’s a necessity to change the shunt, because the pump is not functioning properly. When taking into account this aspect, we use around 35 shunts annually,” stated Stefan

50 Ordin nr.154 “Cu privire la Organizarea Serviciilor de Ingrijiri Paliative”, Ministry of Health, June 01, 2009.

51 Standard National de Ingrijiri Paliative, elaborated by the Ministry of Health, Chisinau, 2010.

Gatscan,⁵² the General Director of the mentioned institution. “However, we observe that the number of children, who need a surgery intervention with the implantation of a drainage system, is increasing, approximately to 5-7% every year.”

Apart from the above-mentioned institution, the operations for shunts implanting are also performed in the National Neurologic Institute, but basically for children and adults with hydrocephalus. This health care institution is specialized strictly in the treatment of neurologic diseases and assists people of different ages – spina bifida being a congenital condition, detected and diagnosed in a relevant health care facility.

At present, the National Institute of Mother and Child appears to be the only medical facility in the Republic of Moldova which performs the operation to insert shunts for newborns with spina bifida. In light of estimates that there are circa 130 children born annually with this defect of the neural tube, it is entirely unclear what happens to the remaining circa 100 children born with spina bifida, and whether they in fact are gaining access in practice to shunt operations.

During this research, the management of the National Institute of Mother and Child additionally raised concerns as to the quality of the shunts currently procured. They stated that the shunts available and used are generally of relatively low quality and problems with their functioning might appear as a result. The price of the shunts varies from 300 to 600 euro per unit. The devices are brought from Taiwan. The market price of a European shunt may be higher, depending on the price negotiated. Some experts in the Republic of Moldova do believe that European shunts are much superior to the Asian ones. Besides mechanical problems, shunts may fail as a result of infections and some individual conditions.

However, a number of doctors that in the Republic of Moldova, a key reason for shunt failure is the low quality of the devices procured. Some interviewed mothers also stated that they believe that the reason why the shunts are blocked after a short period of time is the quality of such devices. For example, Ms. L.B. told the researcher that the insured shunt that was implanted in her child was blocked soon: “They suggested to change it and so we did. In a short period of time the shunt stopped working again. So now my daughter has two shunts – the last one was implanted in Austria. Now everything seems to be all right and we are in the process of rehabilitation”.⁵³

“Of course, we need shunts of better quality. The tender wins the company that offers devices for a lower price,” stated Natalia Cojusneanu.⁵⁴ “This year we would need at least 10 ventricular drainage systems from Netherlands. We received such shunts a couple of years ago and I should say, their quality is very good. We get from time to time some devices of a good quality, but of a very limited number. Still, without donations or other funds it’s hard to resist nowadays to afford good quality devices. We do inform parents on the origin and quality of the shunts and if they have possibility to find the shunt

52 Interview with Stefan Gatscan, Director of Institute of Mother and Child, Chisinau, May 29, 2014

53 Interview with Ms. L.B. – a young mother of two-year-old girl diagnosed with spina bifida and hydrocephalus, Ialoveni, May 17, 2014

54 Interview with Natalia Cojusneanu, Vice-Director of the National Scientific Pediatric Surgery Center, Chisinau, May 29, 2014

from another place, they are welcome to do so. Then we are doing the operation with the shunt they bought themselves from Germany, usually, or from Russia. If parents have no resources, we operate on the child, implanting an insured shunt.”

Each child with spina bifida after operation and post-operation treatment may be directed to one of the existing public rehabilitation centers – there are three such institutions that work at national level. The rehabilitation course is designed individually in accordance to the recommendations made by doctors who treated the child. The doctor recommends on the needed therapies, desired duration and amount of rehabilitation courses per year.

Besides the state health care facilities, there are some non-governmental entities providing medical assistance and rehabilitation for children with spina bifida and effects associated with this condition, including:

- “Voinicel”: an early treatment services and rehabilitation centers for children of age 0 – 4. Ms. Alla Cojocar, the director of the centre, stated that they periodically have requests from parents who raise children with spina bifida and hydrocephalus. Such children can receive consultancy and assistance from a well-trained team of doctors and then a specific rehabilitation is made taking into account individual needs;
- Deutsches Haus “Hoffnung”: an organization, located in Chisinau, which identifies children with complicated diseases, consults them on all existing treatment and rehabilitation opportunities in the Republic of Moldova and abroad. The organization does not provide any surgical treatment locally, but matches if necessary a child with a needed specialist in the Republic of Moldova or, if the condition cannot be managed for locally, a team of medical specialists from Austria come in the Republic of Moldova and consult parents on further actions. The NGO itself has a long-term collaboration with Austrian doctors in providing complicated complex treatment which is not always available in the Republic of Moldova (a complicated diagnosis, needed competence, devices and other resources). In such cases, the national health care institution is usually asked to present an illness history sheet, individual treatment scheme and write up a referral for further specific treatment in Austria. During the period of work the organization consulted circa 130 of children with congenital defects and anomalies of development and 12 of them were operated on in Austria. The NGO provides assistive devices as well, assisting children in rehabilitation. Some experts from the Republic of Moldova stated that they believe there is a need for a well-qualified health care team from abroad for children with complicated forms of spina bifida for consultation on the needed surgical interventions, and training for local practitioners;
- Hospice Angelus is an organization with doctors and specialists in palliative home care, who identify, examine and assist seriously ill children, including those with spina bifida and hydrocephalus in Chisinau and in a 30 km radius outside the capital.

III

FACT AND EXPERIENCE BASED FINDINGS ON SITUATION OF CHILDREN WITH SPINA BIFIDA IN THE REPUBLIC OF MOLDOVA

Some issues related to current practice have been described above. Other issues arising in the course of this research are described in the current section.

Discriminatory attitudes regarding life of children with disabilities

At initial stages in the research, the researcher had discussions with various people who may hear or know something about this issue. Among the first comments on the asked questions there were: “You can find such children, probably, in some residential institutions – all of them are placed there...” or “The disability is so severe that they do not survive” and “In Moldova a person with an ordinary influenza virus may not survive – life costs nothing, especially of a disabled child’s...”. Such comments were made by ordinary people, working in different spheres. Initially, the impression that such children are hidden somewhere and all information about them is secret, was quite strong. However, the researcher identified 20 families who shared their experiences. As a result, the researcher was able to establish empirically an understanding of what is happening with children born with spina bifida in the Republic of Moldova.

Many interviewed parents stated that from the moment they found out about the diagnosis of their child, they were strongly discouraged by health care personnel. According to the researcher’s findings, the attitudes towards the lives of children born with spina bifida are either totally negative or cold and indifferent. The doctors consider that such children have no sense to survive, because they will anyway remain “vegetables” for their whole life and their treatment will not bring essential results.

“Doctors told us that our baby is dying and there’s no sense to transport him to capital,” stated Ms. G.P.⁵⁵ “We implored them to explain what actually is going on. They continued to repeat

⁵⁵ Interview with Ms. G.P. – the grandmother of M.P. the boy of 4 years old with a complicated form of spina bifida, Soroca, April 27, 2014.

that he will die on the way to Chisinau. Finally we obtained a written referral to the Institute of Mother and Child, but precious time was lost.”

“If a child is born with spina bifida in Soroca, which is about two and a half hours from the capital, beginning with the first hours of his life, the doctors just discourage his mother, saying ‘Oh, some children die, it happens...’ They delay the decision to transport the child to Chisinau. It is a matter of lack of competence or it’s just a matter of an ignorant attitude towards the life of that baby as less worthy of living,” stated A.P.⁵⁶ “Even when the decision to transport M. to Chisinau was finally taken, it wasn’t done in an ambulance with at least a doctor present in case of emergency. Doctors knew well, how complicated was the case of our boy.”

When the researcher came to a local health care institution where M. was initially treated for the purposes of talking to the doctor who analyzed his situation, she had great difficulty in identifying and finding the practitioner concerned. Then, finding the needed person, the researcher asked the surgeon for some details of the case. In response, she received just a short explanation from the doctor’s side: “We cannot save all children! Some of them die and it happens elsewhere in the world, not only in Soroca”⁵⁷. The door was closed immediately after those words in front of the researcher.

Some doctors also made general statements filled with prejudice and stereotypes about women, their sexual habits and other matters. “The state wastes a lot of money on this problem,” stated Dr. A.P, a surgeon.⁵⁸ “In rural areas especially, women are uneducated and careless, living in poverty, having more than one sexual partner and knowing nothing about the risks of unplanned pregnancy. Then she comes to the hospital being at 10th week of pregnancy with a number of intra-uterine infections, being psychologically unprepared for motherhood – no husband, no job. I do believe that we should develop pre-conception screening services and oblige all young women of the reproductive age to pass these tests at least once a year. Even now it is possible to start identifying potential risk groups and work with them more intensively – it will obviously cost us less than financing treatment and rehabilitation for these children.”

Stigma and abuse of women who gave birth to children with spina bifida

In the Republic of Moldova, a woman giving birth to a child with spina bifida, frequently finds herself in a position of extreme isolation, without support from others. She may be easily humiliated and physically abused in her family and strongly condemned by care providers in the hospital. Stigmatizing views such as “Children with spina bifida are born mostly in socially vulnerable families, in families which have no culture and do

56 Interview with A.P. – the aunt of M. – the boy, mentioned above; Soroca, April 27, 2014.

57 Interview with N.L. – a surgeon from a health care institution, Soroca, April 28 2014.

58 Interview with a surgeon from the Institute of Mother and Child, Chisinau, June 04 2014.

not know nothing about the responsibility of planning a child...”⁵⁹ exist among leading doctors, as documented by the researcher during interviews in the hospitals, and as further examples show.

Similar views may have been in the minds of those doctors who had driven away a young woman, who suffered of physical abuse and psychological violence at home. She turned to a local hospital in the 7th month of pregnancy: “I wanted this baby even when I remained alone without any support.” – stated Ms. S.V.⁶⁰ “I turned to the hospital after a strong blow in the stomach that I’ve got from a friend of my former husband. I spent two weeks without any specific assistance from the medical personnel. I felt, something happened with the baby, because I had terrible pains in my abdomen. I was given some pills, a couple of injections and driven home without any explanation.”

Ms. S.V. stated as well that even when the baby was born with spina bifida, all medical examinations with the same phrase: “Go home, she is ok, many children are crying and have problems with sleeping”. Hydrocephalus was subsequently detected when the child had 4 months. “Since that moment I was blamed by my family doctor and all staff in the hospital that such women as I am do not deserve to be mothers at all.”

In case of Ms. N.G. from Cirpesti, the stigmatizing views expressed by her family, health care workers and local social support specialists made her become a victim of domestic violence, searching for a refuge in neighbouring houses with two minor children, without any support. Such a situation lasted for more than two weeks. When N.G. came to have an interview with the researcher, her face was strongly injured and she was depressed, saying that her relatives, social and health care workers blamed her for “acting irresponsibly” by challenging domestic violence and for giving birth to a child with a disability: “I and my children suffered of physical and psychological violence from my husband.” – stated N.G.⁶¹ “We need a good medical and social rehabilitation. Everybody in the village I live considers that I am mentally disabled and I deserved that attitude from my husband’s part. Our social worker tells me to be silent and not to ‘create problems’. Doctors say that I should not have given birth to one more child in such, being irresponsible and having no resources for this. With the help of a private association, D. will go to Austria for a treatment, but I need help. I feel worse since the day I was beaten in my head and face by him. Since that time I started to have terrible headaches, especially in the nights and even vomiting. My husband goes on with threats and I’m afraid of him...”.

With the help of the UN Human Rights Office (OHCHR)⁶² team in the Republic of Moldova, Ms. N.G. was temporarily placed at a shelter in Chisinau. Still, the social worker with whom the researcher tried to discuss the case remained with her initial opinion: “This is a young irresponsible woman with no normal education and job. She has a disabled child, so she should not make too much noise about her personal problems.” – stated L.R, the social worker. “She dared to call the police because her husband was

59 Interview with Mr. A.L. – a leading surgeon from Institute of Mother and Child, Chisinau, June 05 2014.

60 Interview with Ms. S.V. the mother of a five years girl with hydrocephalus, Salcuta, April 11, 2014.

61 Interview with N.G. – the young mother of two children from Cirpesti. The younger daughter has an open form of spina bifida), Chisinau, June 03 2014.

62 United Nations Office of High Commissioner on Human Rights in the Republic of Moldova.

aggressive. So what? We have many cases of such type and believe me, these cases are really horrible. A wise woman would keep silent for the sake of her children and her personal well-being.”⁶³

Evident lack of competence among health care providers

Many expert practitioners appeared unaware of what spina bifida is. The researcher was an eyewitness of such a situation: trying to request some data about the children with spina bifida in Causeni, Sorooca, Donduseni, Vulcanesti, Cantemir, the researcher either received some irrelevant and confusing information or simply was asked: “What is that?” or “I heard something about this...” and so on. Such views were expressed by leading medical personnel and family doctors. There were received at least 6 answer-questions of the mentioned above sort.

“Our doctor didn’t know anything about our illness, probably, because we were told that everything is ok and we should go home,” stated Ms. D.R.⁶⁴ “My baby had spina bifida and hydrocephalus and he died in a month since his birth. He died, I think just because of the ignorant behavior of our family doctor. I told her that baby’s head gets bigger and this is not normal to my mind, but she ignored my concerns and did not even try to undertake some diagnostic measures. When the baby was transported to Chisinau it was too late.”

Interviewed mothers from Gratiesti, Salcuta, Taraclia, Cainari, Cirpesti and Donduseni stated as well that in their case the precious time has been with various consultations, and trying to get a clear diagnosis of their child, or at least a written referral to an institution in Chisinau. In many cases, a seriously ill child was transported to capital when doctors observed developing complications.

“I’m sure that if we were timely consulted by good specialists and then operated, she would have received proper treatment.” stated Ms. O.C.⁶⁵ “I knew nothing about hydrocephalus and no one in our local hospital never explained clearly what steps should be taken and who can help us. This delay in accessing an urgent treatment strongly influenced I.’s mental and intellectual development.”

All interviewed parents complained that they had to search the information about the illness their children have themselves, using different sources, including internet. Many of them took the decision to go to a capital institution without any written referral from the local health care providers.

63 Telephone discussion with L.R. – a social assistant from Cirpesti, June 12, 2014.

64 Interview with D.R. – a young woman who gave birth to a child with an open form of spina bifida and internal hydrocephalus – the case of death, Cahul, August 02, 2014.

65 Interview with O.C. – mother of I. – the girl of 10 years old diagnosed with hydrocephalus. Gratiesti, March 21 2014.

“When I see that my doctor is looking at me for 10 minutes and doesn’t say anything about how should we act and where should we go, the only possibility is to consult people who had similar problems and go to another hospital.” says N.C.⁶⁶. “I told our doctor: ‘His head is growing, he has a fever and it’s not going down’. After extensive discussions she finally sent us for further medical tests without offering us any explanations.”

Institutionalization of children with disabilities

The current research revealed that pressure to institutionalize children with disabilities remains a problem in Moldova. Children with disabilities, institutionalized from an early age, are frequently thereby effectively condemned to life-long institutionalization. Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Moldova in 2010, states that: “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community (...)”. UNICEF and OHCHR have called for an immediate moratorium on any 0-3 child institutionalization, with a view to beginning to roll back the effects of long-term reliance on institutions, in violation of international law.

The researcher identified examples or reported achievements in working with children who have various neurologic impairments, but all of these successes are locked inside the institution. The institution has a status of a temporary placement center for children with neurologic impairments and is situated in Chisinau. This residential institution is mentoring more than 170 of children of the age 0-7 years old, from different regions of Moldova. They have children with spina bifida and hydrocephalus, who have been operated in collaboration with the Institute of Mother and Child.

Research indicated that most of the children with disabilities placed within the institution actually have living biological parents, who were initially discouraged and in some cases psychologically pressured by doctors and/or social workers, to “give this child away – that’s a hopeless case”. Many interviewed parents stated that once they understood that their baby has spina bifida, they were blamed by doctors, who tried to discourage the parents and in some cases even pressured them to place the child in state care.

“I was told by a doctor from Neurologic Institute, ‘This is a vegetable, you understand? He is disabled for the whole life. You will spend a lot of money and no progress will be observed’,” said Ms. I.C.⁶⁷ “He recommended a residential institution where my baby could stay. He told me that only there would my child receive the needed assistance and only there would he live in safety.”

66 Interview with N.C. – the mother of 17 years old boy with hydrocephalus, Gratiesti, March 21, 2014.

67 Interview with I.C. – a single mother with three children, the younger girl has spina bifida meningocelle. Balti, July 04, 2014.

Corrupt practices giving rise to blocked access to treatment

Many families identified during this research initially were wary of discussion of issues facing families of children with spina bifida. Once they spoke however, a number of parents described what they deemed as mistreatment, ignorance and corruption among medical personnel, including doctors, nurses and even cleaning personnel in the ward. These parents shared experiences only anonymously, evidently fearing negative repercussions.

16 of 20 interviewed mothers confirmed the fact of an unwritten rule of so-called “financial thanks” before and after the operations, as well as while the post-surgery rehabilitation of the child. The parents namely mentioned the fact that the doctors hinted on the necessity to pay some extra money to all personnel, who assisted the child in the hospital.

“The anesthesiologist did not want to leave the room before I put some money in his pocket”, recalled Ms. T.I. from Chisinau. “I gave him 500 MDL (circa 30 EUR, at the time of the research)⁶⁸ and about 2000 MDL (110 EUR) to the surgeon, and about 300 MDL (15 EUR) to some other assistants. They surround you and look in your eyes continuously, as if you’ve committed a crime by not giving them at least 50 MDL (3 EUR). It’s something that you do, because you have to, if you care about the safety of your child during the operation and after it.”

Ms. G.P. from Soroca stated that she had paid the medical assistants in the reanimation section, because her child was left alone without any supervision for certain periods during the day, despite the fact that the baby’s health condition was critical and he needed a permanent presence of someone at least first days after operation: “I’ve seen other children in reanimation in a critical condition left without any supervision just because some parents refused to pay and told that they would complain about efforts to get them to pay informal payments. I know they did not actually pay. After a short conversation with a surgeon all of them paid.”

“The average informal price for an operation varies from 2000 to 3000 MDL (110 – 150 EUR), around 500 MDL (30 EUR) usually takes an anesthesiologist, 300 MDL (15 EUR) – medical assistants and 50 MDL (3 EUR) per day takes a cleaning person, who says that she can wash the floor in your ward with a dirty water, if you refuse to pay.” said A.S⁶⁹. “I had no money, but I borrowed some and paid every day until we left”.

Some mothers dared to ask medical assistants why they require extra payments for the work they are obliged to do. The answer was low salary and big volume of work:

68 Approximate EUR values are provided throughout the report, according to exchange rates prevailing during 2014.

69 Interview with A.S. – mother of 6 years old boy, diagnosed with spina bifida and hydrocephalus. Cainari, April 06, 2014

“We have families at home that also need support,” a cleaning person from the National Institute of Mother and Child reportedly told a mother.

Parents who bring children with spina bifida to a health care facility may meet corruption from the very beginning of their stay at the hospital. Some interviewed parents complained on a long waiting list for the operation with the implantation of an ensured shunt. Some mothers complained that they had to wait for a long period of time for an insured shunt for their child. The doctors reportedly hinted at a faster solution of this problem – money. This is the bitter experience of G.P. from Soroca, T.I. from Chisinau, and A.O. from Donduseni: “We waited for 4 months for the operation with a shunt covered by the health insurance system. I just had no money to buy a shunt from abroad. That’s a real torture through which M. had to pass just because I had no money to facilitate this process” – stated Ms. G.P. In the case of children waiting for first shunt operations, such a delay would be deadly.

Ms. T.I. from Chisinau stated that they were told by a doctor from the surgery section that there were no more free shunts and if they wanted an operation as soon as possible, they would have to purchase a shunt themselves – so they did. They bought a shunt for 1800 EUR from Germany, being told that this one is of the best quality. However, the operating doctor evidently stole their shunt and inserted a different one: “When A.P. – our surgeon -- saw the shunt we brought from Germany, he was surprised. He started to say that in our case there’s no need to implant this expansive device, that we could buy a cheaper one from him for 300 EUR right now. We asked him to remember that he is a doctor and to show a human attitude towards the child and do the operation as soon as possible. The implanted shunt was blocked in a short period of time and D. felt very bad. We decided to operate her in Austria and there we discovered that our baby had another shunt, not that one from Germany. Where was our shunt then? We were shocked. We could not understand how a doctor could do something like that. The doctors in Austria told us that the quality of the shunt we had before was very low, therefore, we had complications.”

Multiple parents spoke with a common voice, stating that they were told by doctors after being asked for under-the-table payments: “You will come back here anyway. So please do not make trouble, and think about the safety of your child.”

Discrimination

In some cases, agreeing to pay informal payments in any case seems to have limited or no effect on standards of care. The doctors appear to fear the risk of a possible death of a severely disabled child. As the researcher was told by some experts, it’s a very bureaucratic procedure when a child or another person dies during your working day. It’s a great responsibility and a lot of paper work.

An example to all mentioned above is the case of a 12-year-old girl from Chisinau, who is receiving palliative care at home from an NGO specialized in this area. The size of her head is 1 meter and 20 centimeters. Each day is a challenge for her parents, who are

trying to do their best to relief terrible headaches and pains that their daughter suffers. M.'s mother complained that in case of emergency the doctors from the local hospital refuse to assist their child: "A doctor told us 'Take these pills and go home!' when we brought M. in the hospital. M. had a very high fever, and we had been waiting for at least someone, holding her in our arms, because she could not walk. We were ready to pay money, but the doctors would not take it. They were scared, I think, seeing the size of M.'s head" – says Ms. L.C.⁷⁰

In another case, Ms. L.C. recounted the time she had a heart attack and called emergency services. These, however, reportedly never came. Apparently the doctors, looking at the address that was registered by assistants, refused to come. They knew that a child with hydrocephalus lived at the address, and L.C. believes that this fact scared the medical personnel, so they simply did not respond to the call.

Lack of physical accessibility to health care services

Moldova is a small country and many basic health care facilities are concentrated in its capital. The researcher identified that the physical accessibility to some vitally needed health care services is limited, especially for poor families of children with disabilities from rural areas. Many parents who raise children with spina bifida underline the incapacity of local health care and social support systems, lack of needed financial resources for transportation of children in cases of emergency. In many cases parents transport their ill children to Chisinau themselves, paying money to private taxi drivers, because public buses are old, uncomfortable, crowded and it takes more time to get to a hospital.

"My daughter is in such a complicated health condition that she simply can't stand long trips," stated A.O.⁷¹ "It's absolutely impossible for us to travel in public buses, she can't hold her back and should stay in a lying position. I have to spend more than 1000 MDL for a taxi on the way to Chisinau and in the town itself, because we go to the doctor in one hospital and then we have to go to a rehabilitation center located in the other part of the town. I'm not working as I have to stay with A. all day long and my husband is abroad – someone has to feed this family. We cannot visit the doctor in capital regularly, for us that's expensive".

"We spent almost all our money on travelling here and there with M. without any support," stated G.P. from Soroca. "In many situations he felt so bad, that we had to call for a taxi that transported us to Chisinau as fast as possible. This cost us more than 1500 MDL. M. has a very complicated form of spina bifida and we need a regular

⁷⁰ Interview with L.C. – the mother of M. – a 12 years old girl diagnosed with hydrocephalus. Chisinau, May 21, 2014

⁷¹ Interview with a mother A. O. of a girl of 6 years old who has spina bifida meningocelle and hydrocephalus, Donduseni, May 28, 2014

monitoring and specific assistance and rehabilitation services that do not exist in Soroca. We practically have no money for elementary expenses. The monthly allowance we get from the state is miserable and in such case such families as ours need additional support."

Poverty and exclusion

In a great number of families children with spina bifida are socially isolated, staying at home with one of the parents, not able to go to kindergarten or school, because of limited mobility and barriers or opposition in local schools. Parents report that they are generally not supported by local authorities in creating learning and communication opportunities for their children. All their life is limited to playing indoors or visiting a rehabilitation institution three or four times a year. In all cases documented in the course of this research, mothers had limited or no possibilities to find a job, because of the complicated health condition of the child. In three of 20 interviewed families, the researcher witnessed evident extreme poverty facing single mothers with three and more children. These were living in extremely substandard housing conditions. These mothers had not succeeded in enrolling their children in any educational institution, fearing plausibly that they would not be accepted and tolerated there.

Such is the case of M.D. from Taraclia. He is 13 years old and has hydrocephalus, as a complication of spina bifida: "He doesn't attend school, no... This is impossible in our case. We are not accepted in the ordinary school, because M. is mentally disabled," stated Ms. N.D.,⁷² M.'s mother. "I believe he needs assistance and a special program of learning, maybe. I think he will not be able to go to an ordinary school without an assistant. Sometimes he can be aggressive and there should be someone next to him in such situations... We need good support from social workers but we do not receive such assistance. They always complain on a big volume of work and low salary".

Some mothers complain that they do not have any support from local authorities in the process of their child's rehabilitation. Many of the interviewed parents told that they had to pay a lot of money for some extra devices and drugs needed for their children. Taking into account complications that children with spina bifida have even after operation, many of them need diapers or incontinence bags, or special orthopedic corsets and shoes, which are expensive. In some cases, some support was provided by charities: "Thanks to some good people we have some incontinence bags for D." – stated Ms. N.G. from Cirpesti.

Some of the interviewed mothers stated that the extreme poverty they faced made them accept proposals of a hard work while pregnancy. Such proposals came often from their own relatives and were low paid. Two of 20 interviewed mothers painted walls, doors and windows in the houses of their native village during the period of

⁷² Interview with N.D. – mother of 13 years old boy M. with spina bifida occulta and hydrocephalus. Taraclia, April 11, 2014

pregnancy; three of them carried heavy objects and 6 mothers reportedly had a 10-hour work day until, practically, the last day of pregnancy.

“I have five children and one of them is severely disabled,” stated S.V. “I work as a cleaning person in two private companies, I’m paying the nurse for A. for the working hours and I have to pay the monthly invoice for our house services, and my older children shall eat something, going to school. My husband left me when he learned that A. has spina bifida and hydrocephalus, and will never be able to take care of herself. I am not complaining. I just need more understanding from the state and equal opportunities for all my children.”

Difficulty in establishing cooperation between NGO services and state institutions

Many persons interviewed in the course of this research emphasized the importance of cooperation between NGOs or a private health care facilities on the one hand, and public institutions on the other – the latter in principle having a wider range of resources and possibilities. In many cases, NGOs dealing with children with spina bifida trying to develop collaboration with public health care institutions. Together they could consolidate all efforts in identifying and assisting children with spina bifida. However, some NGOs report difficulties in establishing such cooperation.

Ms. T.I. from Chisinau, the grandmother of a 2 year old girl, diagnosed with spina bifida declares that she found the contacts of a Romanian Association of Children with Spina Bifida and Hydrocephalus, (ARSBH). Staying in a surgery section together with 5 other mothers, who had children with the same problems, T.I. suggested them to complete a number of questionnaires in order to get shunts of a better quality for free for operations.

“When the some doctors learned that I’m trying to help the desperate mothers to get the necessary devices for free, they became angry, screaming at me, that I have no right to misinform the parents,” stated Ms. T.I.⁷³ “But these mothers stood in a long waiting list for months. Because of the unwillingness of the doctors to cooperate and do all best to save those dying children, nothing was done. And then I was the witness of how some of those children died in agony.”

The experience of Ms. Adriana Tontsch, the Director of Romanian Association of Children with Spina Bifida and Hydrocephalus (RASBH), shows that a step-by-step, focused cooperation with public health care institutions is possible and evidently can lead to measurable results: “At the very beginning of our activity it was terribly hard to

⁷³ Interview with T.I. – the director of a private association from Chisinau and a grandmother of the 2 years old girl with spina bifida. Chisinau, June 07, 2014

identify children with spina bifida and hydrocephalus in Romania,” stated Ms. Tontsch.⁷⁴ “Even now it is not easy, because much depends upon the correct diagnosis put on time. Therefore, in 2005 we addressed an official request to all Children Protection Departments in Romania, asking for all relevant data and information about such children. Only 25 from 55 regions responded. The number of children who needed a surgery intervention at that time of the age 0-18 was 800. Unfortunately, we succeeded to operate only on 100 children from that list, and the rest died. Then I appealed to another source, which was media. A newspaper in Romania wrote an article in which I expressed an intention to help children with spina bifida and hydrocephalus. After some time I found a neurologist who was willing to assist such children and we started doing operations at a clinic in Cluj. By the year 2006, we had 7 hospitals from all parts of the country in our team. To date, we have been involved in the provision of shunts to circa 1200 of children with spina bifida and hydrocephalus.”

The researcher was interested on the origin and price of the CSF drainage systems which RACSBH provides to children with spina bifida, pointing out that Moldovan health care institutions use the cheaper shunts from Taiwan for the price of 300-600 EUR. Ms. Tontsch noted that they get shunts from Germany for a factory price of 300 EUR – as the producer itself is strongly interested in helping such children. The RASBH also organized and financed trainings for 20 specialists in neurologic surgery in Germany.

Ms. Tontsch stated: “It is vitally important that the doctors you’ve chosen to work with would have a strong desire and personal motivation to help children with such serious neural tube defects. I say this because having more than 10 years of experience I have to say that such good will is not always present in doctors. We also often still do not have a reasonable cooperation between specialist in neurologic surgery and the other doctors, who should continue the process of post-operation treatment and further rehabilitation of the child with spina bifida and hydrocephalus.”

⁷⁴ A private electronic communication with Adriana Tontsch, Director of Romanian Association of Children with Spina Bifida and Hydrocephalus, June 18, 2014

CONCLUSIONS AND RECOMMENDATIONS

Statistical data concerning the number of children with spina bifida in the Republic of Moldova is unclear and does not appear accurately to reflect the number of children which, by sheer statistical probability, are likely born annually in Moldova with spina bifida.

As concerns prevention, new policies to fortify flour with folic acid, while welcome, do not yet ensure that fortification enhances all flour. As of now, fortified flour and bread is not readily accessible. It is anticipated that universal introduction in 2015 is a key moment in prevention of spina bifida. Monitoring in this regard is particularly encouraged. Similarly, coverage of folic acid vitamin supplements does not reach all or even most women at the crucial pre-pregnancy stage. As such, considerable further work is needed to ensure that all of the population-at-large receives folic acid, via fortified food products, in accordance with international best practices.

As concerns treatment, although this appears improved over practices two decades ago, testimony of parents of children with spina bifida indicate consistently that indifference or ignorance on the part of medical providers, corruption in the form of demands for informal payments, as well as continuing imbedded negative views that “some lives are not worth living” – based on stigma against the children and families concerned -- continue to drive an outcome whereby children who need shunt implant operations are not receiving them in a timely fashion. As a result, children continue to be threatened with extremely painful death, although this is avoidable. Although an estimated 130 children are born annually in the Republic of Moldova with spina bifida, research was only able to identify 24 first-time shunt operations carried out in the Republic of Moldova in the year 2013. It is unclear what is happening with the remaining circa 100 children born annually with spina bifida in the Republic of Moldova. The research found strong indications that tens of children annually are not gaining access within the urgent time required to a shunt operation.

Shunts also appear to cost far more in Moldova than elsewhere (including in Romania), and reportedly tend to be of poorer quality.

As concerns palliative care in 2010 there has been issued a National Standard on Palliative Care which describes clearly the key principles, criteria and types of services available at the state level. Still, for persons who have developed hydrocephalus, this does not appear to be reaching all persons in need of such care, again at least in part as a result of the high degree of stigma on persons with disabilities.

The research documented stereotypes and negative attitudes, including among medical providers, including views to the effect that spina bifida occurs among “uncultured” families, and that treating spina bifida is a waste of the state’s resources. Despite evident barriers to effective care, some medical professionals interviewed blamed parents for issues facing children with spina bifida.

Stigma and shame also gives rise to cases of domestic violence, as spouses blame women for having “unhealthy children”. This research effort also encountered and documented the problem that Moldova’s shelters for victims of domestic violence are not yet accessible in practice, due to rigid and arbitrary administrative formal admission requirements and practices. Parents also continue to be pressured to institutionalize children with spina bifida, against the legal requirements set out under Article 19 of the

Convention on the Rights of Persons with Disabilities, requiring that all persons have a right to independent living in the community. Heads of institutions and other policy-makers stated continuing beliefs that institutions constitute an appropriate mode of managing spina bifida cases, despite Moldova’s 2010 ratification of the Convention on the Rights of Persons with Disabilities.

This report concludes with recommendations aimed at improving law, policy and practice, and ending the extreme states of exclusion, stigma and pain experienced by children and adults with spina bifida, and by their parents.

Recommendations

On the basis of the research presented in this report, the following recommendations for action are proposed:

1. Review data on the incidence of spina bifida in the Republic of Moldova to ensure accuracy. Identify all cases of spina bifida, with a view to ensuring effective and timely treatment;
2. Ensure timely entry-into-effect of folic acid fortification programming for all flour in the Republic of Moldova. Monitor efficacy of fortification policy and programming, with a view to ensuring that all flour is fortified at the earliest possible date;
3. Make public the Protocol on treatment of spina bifida;
4. Redouble efforts to ensure that all relevant health care professionals and providers are aware of modes of identifying and treating spina bifida, and that they act urgently to ensure access of all children born with spina bifida to effective treatment;
5. Renegotiate contracts with providers of shunts to ensure that affordable, quality shunts reach all children who need them;
6. Strengthen effective access to palliative care for children with hydrocephalus and other conditions arising as a result of spina bifida;
7. Provide accessible information of spina bifida, its side effects, and modes of treatment;
8. Investigate and prosecute effectively allegations of corruption or other human rights-destructive acts or omissions with regard to the treatment of spina bifida;
9. Review histories of spina bifida-related deaths – including deaths of children in institutions – with a view to establishing the public record and ensuring justice where relevant as concerns such cases;
10. Support the strengthening of civil society supporting children with spina bifida and their families;
11. Provide further training for national health care providers in relevant human rights and anti-discrimination law;
12. Undertake public campaigns to combat stigma of children with spina bifida and their families;
13. Improve cooperation between relevant public health care institutions and national and international non-governmental associations working with children with spina bifida.

