







# Guide for parents of children with disabilities: help and support

«Our goal is to create adequate and comfortable living conditions for disabled people, to create a fully-fledged rehabilitation system that will help citizens with disabilities enjoy a full life. Ultimately, we simply must change the way society views people with disabilities.»

Dmitry Medvedev, President of the Russian Federation May 13, 2008 Information Office of the Nordic Council of Ministers in Kaliningrad

Nordic Centre of Welfare and Social Issues together with the Information Office of the Nordic Council of Ministers in Kaliningrad

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http://www.norden39.ru

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was founded in 1971. It is an intergovernmental forum for cooperation between Denmark, Finland, Iceland, Norway and Sweden. It submits proposals on cooperation between the governments of the five Nordic countries to the Nordic Council, implements the Council's recommendations and reports on results, while directing the work carried out in targeted areas. The Prime Ministers of the five Nordic countries assume overall responsibility for the co-operation measures which are coordinated by the ministers for cooperation and the Nordic Co-operation Committee.

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operates on the basis of the «Nordic welfare model» dealing with equality, social solidarity and social security for all. The work is aimed at promoting inclusion of vulnerable groups, equal treatment of citizens as well as accessibility and quality with regard to social services. The Nordic Centre for Welfare and Social Issues is led by a board with representatives from the Nordic countries and appointed by the departments.

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was opened in 2006. The overall objective of the office is to give a significant contribution to sustainable integration of the Kaliningrad Region in the Baltic Sea Region as a global growth region. The office facilitates development of cooperation between the Nordic countries and Kaliningrad of Russia.

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## **Preamble**

### Dear Reader.

Protecting children's rights to life and development is an objective requiring the collective efforts and aspirations of society regardless of religious, cultural and other beliefs.

In Russia and the Kaliningrad Region every child has the right to receive social assistance according to his/her needs and requirements. The process of human socialisation of children with special needs encourages open discussion of the problems and makes it possible for parents to claim their rights.

Creating favourable social conditions and supporting society will help improve the lives of children with special needs and of their families. The rights of children with disabilities and their families to healthcare, education, social services and medical rehabilitation are enshrined in laws and decrees of the President of the Russian Federation and resolutions of the Russian Federation Government. Today, there is a range of social benefits and guarantees to compensate for the limitations of the health of disabled children and to help them to achieve the real level of their possibilities.

Over many years, the Kaliningrad Regional Government has created a system of assistance to children with disabilities and their families, and worked on ensuring their social integration.

This Guide gives examples of decisions and measures aimed at supporting children and their families in the Kaliningrad Region. It is striking that the work done in preparing the Guide has given rise to better interdepartmental cooperation and coordination of healthcare, social, educational and other types

of assistance to families raising children with disabilities.

The Guide you are holding is very unusual. It is a legal Guide and a source of advice on many issues, e.g. how to spot abnormalities in a newborn, what educational path to choose for him/her, where and how to register the child's disability, what benefits are available for a family raising a disabled child.

In order precisely and knowledgeably to answer these questions, the Guide was developed in cooperation with the Kaliningrad Region's Ministry for Social Policy and Labour, Ministry of Education and Ministry of Health, together with the non-governmental organisations 'Maria' and 'Apparel'. This cooperation was aimed at giving you, the parents confronted with a great deal of psychological, social and personal problems, important information about where and how much support you can get.

This Guide will also be helpful to the staff of rehabilitation centres, physicians, psychologists, social workers and social welfare agencies.

The text was written by staff of the Modern Educational Technology Institute of the Immanuel Kant State University of Russia and approved by the working group of participating ministries. The work was coordinated by the Nordic Council of Ministers Information Office in Council of Ministers Information Office in Kaliningrad and the Nordic Centre for Welfare and Social Issues.

Marina Orgheyeva, Acting Deputy Chairperson of the Kaliningrad Regional Government 9th November 2010, Kaliningrad City



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### Introduction

This Guide is in the first place addressed to you - parents who are expecting or already have a child with disabilities, in order to provide them with some general information about the basic resources of state and public help and support, in other words – assistance which can be offered by social, medical, cultural and educational institutions. The Guide will help you to find information according to the age of your child or information about services, measures to be taken during pregnancy and issues requiring your special attention after childbirth. The Guide looks at the upbringing and education of a child with disabilities at different stages of development. It describes the system of social protection for a disabled child and its family, and their basic rights and benefits. You will also get information about the legal procedure for acquiring the status of a «disabled child».

The psychological issues for families raising children with disabilities and the recommendations of specialists are described in the section «Psychological support for the family».

At the end of the Guide you will find tables with the development indicators of the newly-born, as well as a scheme for evaluating the neuro-psychological condition of a child.

In this Guide the term «disability» is used as a general one in reference to all degrees and forms of impairments. However it is primarily targeted at those parents whose children have severe and permanent impairments.

The Guide is directed not only at you – parents of disabled children – but at a broader audience as well. Families of children need the support of our society and the kindly attitude of the people around them. Thus, there needs to be a better awareness in society about the problems existing in such families and a better social integration of people with disabilities.

This Guide is the result of cooperation between the Ministry of Social Policy, the Ministry of Education and the Ministry of Health Care of Kaliningrad Region, the Russian State University of Immanuel Kant, the Kaliningrad regional children-youth public organization for disabled people «Maria», the Kaliningrad association of disabled young persons «Apparel», and the Nordic Council of Ministers within the framework of the program «Assistance to children with disabilities and their families in the Kaliningrad Region».

The «Guide for parents of children with disabilities: help and support. Attachments» has been published separately (henceforth, «the other publication»).

That publication contains the following attachments with contact information about the social, medical and educational state

institutions and public organizations:

**Attachment 1.** Centres for psychological, pedagogical and medical social support.

**Attachment 2.** Basic municipal educational institutions for organizing preschool education and upbringing of children with disabilities.

**Attachment 3.** Special (correctional) educational institutions.

**Attachment 4.** Basic municipal, comprehensive educational institutions for organizing integrated education and upbringing of children with disabilities.

**Attachment 5.** Institutions of further learning for education of children with disabilities.

**Attachment 6.** State educational primary professional institutions for education of children with disabilities.

**Attachment 7.** Social service and support institutions.

**Attachment 8.** Public organizations for disabled persons in Kaliningrad Region.

The complete text of the Guide and the attachments in PDF format can be found at this website:

http://www.norden39.ru, the Information Office of the Nordic Council of Ministers in Kaliningrad.





# Section I. If you have a child with disabilities



The problem of disability affecting children and teenagers every year is acquiring greater medical, socio-economic, moral and spiritual significance. The number of children with disabilities in present day Russia is about 80 thousand which accounts for 2% of all children and teenagers. According to scientific studies Russia will experience an increase in the numbers of children and teenagers with disabilities in the coming decade.

Psychologists identify four phases of the psychological conditions of parents in the development of their attitude towards their disabled child. The first phase – «shock», which is characterized by confusion, helplessness, fear, and a growing sense of personal failure. The second phase – «inadequate attitude to a

defect» that is characterized by negativism and denial of the objective diagnosis, which is a form of defensive reaction. The third phase – «partial understanding of a child's defect», which is accompanied by the feeling of «chronic sorrow». This is a depressive condition «the result of permanent dependence of the parents on the child's needs, and the absence of positive changes». The fourth phase – the beginning of sociopsychological adaptation by all the family members accepting the defect, developing satisfactory relations with the specialists and following their recommendations properly.

In 60-80% of cases child disability is caused by pathologies of pregnancy, birth, or the first days of the child's life. Nowadays there is an increasing tendency for children to suffer from infantile

cerebral paralysis, hearing impairment, congenital and inherited visual pathologies.

Among other factors inducing disability in children are an unfavorable ecological situation, increase in trauma rates, insufficient resources and parents' lack of awareness of healthy life-styles, parents' poor health, inappropriate nourishment.

The upbringing of a disabled child involves a number of questions, and the need for additional information and resources, including medical ones. They are: the possibility of obtaining timely and full information about the child's illness, the special characteristics of its development, a prognosis, and future social difficulties; acquisition of practical skills for implementing medical recommendations. speech correction; finding possibilities for additional consultations, hospital admission. and sanatorium pass.

Prenatal diagnosis of child's health

The current state of medical science makes it possible in many cases to detect an incurable disability of a child before its birth and to estimate the risk of genetic defects.

Prenatal diagnosis is provided to all mothersto-be who want it. Several diagnostic methods are applied: genetic consultations for future parents before conception, ultrasonic examination of the fetus for detecting congenital defects, biochemical blood tests, testing the waters, umbilical blood tests and fetal tissue biopsy.

Because the majority of hereditary diseases do not respond to therapy, prenatal diagnostics are generally carried out as a preventive measure. This allows the detection of an incurable disease long before the child's birth and thus enables parents to make a timely decision.

If there is a history of hereditary ailment in a family it is advisable to consult a geneticist to assess the possibility of a genetically inherited disease of a future child.

Biochemical blood tests of the pregnant woman can detect Down's Syndrome and other deviations in the development of the nervous system of a fetus. Only if the mother's blood shows the presence of a high level of the so-called feto-protein, other more traumatic but more accurate tests are employed: testing of the water, umbilical blood tests or fetal tissue biopsy itself. The tissue cells extracted during biopsy are studied under the microscope (cytoscopy) or, if it is necessary, their DNA is examined. These methods

have close to 100% accuracy, as they

identify the actual cause of a disease - the qualitative and quantitative characteristics of chromosomes or genes.

The possibility of giving birth to a child with developmental defects, including genetic ones, increases many fold if a woman is over 35, if a mother has suffered from gynecological diseases, if she has had a long

period of infertility, or if she has experienced miscarriages. This category of expectant women should undergo prenatal diagnostics to have the option of making a timely decision on whether to continue with the pregnancy and give birth to an disabled child.

Currently, according to the recommendations of the World Health Organization (WHO), all newborns undergo tests for five severe forms of metabolic disorders: congenital hypothyroidism, phenylketonuria, mucoviscidosis, galactosemia, adrenogenital syndrome. Why is this done? First of all these conditions are relatively frequent. Secondly, nowadays there is the possibility of medicated substitution for insufficient elements in a child's organism. Thirdly (which is the most important!), it allows medical treatment from the first days after birth. Untimely treatment of these diseases leads to rapid development of severe and irreversible disorders.

An expectant mother should register for check-ups, timely medical and prophylactic treatment and preparation for the birth.

### Parental care: Nota Bene

Parents should not worry that they will be left alone, face-to-face with their concerns and doubts about their child's health. Medical workers will give you professional answers to all your questions and give you timely recommendations.

If you, parents or foster-parents, notice some delay in development: «does not start walking», «does not speak», «has motor

Prenatal diagnostics are available in Kaliningrad Regional Centre for Family Planning and Reproduction, Kaliningrad, Komsomolskaya Street, 25, 236000, Tel.: +7 (4012) 214-711. anxiety», «indifferent to the surrounding» – you must see a pediatrician and/or other specialists.

Doctors recommend that you pay special attention to the psychophysical indicators of a child's development which are listed in *Table 1* on page 44.

You should be aware that there is a mass standardized examination (screening of psychological and physical development) of all under-three-year-olds, which is carried out to detect those children at risk of delay in psychophysical development and to send them for psychological, medical and pedagogical consultations (PMPC), and to provide them with correctional developmental assistance. The screening is conducted by medical staff of maternity homes, infant polyclinics, and primary medical aid institutions and sanatoria.

As well as an evaluation of the level of physical development, one of the most important characteristics of health is an assessment of the neuro-mental development of a child. Early diagnosis of deviations in mental development and referral to specialists is the duty of a pediatrician, as a neuropathologist examines a child only after thorough medical inspections, while a psychiatrist gives consultations to children based on their indications. The scheme of screening for neuro-mental development of a child is described in *Table 2* on page 46.

# Therapeutic-medical benefits for your child and for you

There are a number of laws in our country regulating the issues which are aimed at supporting families raising children with disabilities.

According to Article 1 of the Law of the Russian Federation «On social protection of disabled persons in the Russian Federation» a disabled person is one with a health disorder of sustained disturbance of the organism's functions caused by diseases, after-effect of traumas or defects, which lead to the limitation of a vital activity, and calls for the necessity to provide social protection for such a person. The term «limitation of vital activity» means a full or partial loss by a person of a capability or capacity to be self-supported, move independently, orient oneself, communicate.

control one's behaviour, learn

and carry out work activities.

Depending on the extent of the disorder of the functions of the organism and the limitations of a vital activity, a category of a disability shall be established, and for persons under 18 years of age, a category of «disabled child» shall be established.

A child with mental or physical disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. (Article 23, Convention on the Rights of the Child).

Therapeutic-medical care is provided for people with disabilities in accordance with Article 13 of the Federal Law «On social protection of people with disabilities in RF». Thus, skilled medical care of disabled persons, including the provision of medicine, shall be carried out free of charge or under preferential conditions, in accordance with the legislation of the

Russian Federation and the legislation of the subjects of the Russian Federation. Free medical assistance to citizens is provided in accordance with programs of compulsory medical insurance.

> According to Article 27 of «Principles of legislation of the RF on health protection of the citizens»

disabled persons, including children with disabilities, have the right to medical-social care under preferential conditions.

Information
about a citizen's health
is given to him, or to
the legal representative
of a person under 15, or to
the legal representative (doctors.

heads of medical and prophylactic institutions, other specialists taking part in the patient's examination and treatment) in cases where a person is officially recognized as being incapacitated.

All information in the medical documents of a citizen is confidential to the patient.

In order to guarantee the rights of children to health protection, according to the legislation of the Russian Federation, state and municipal institutions of healthcare provide free medical care for disease prevention, medical diagnostics, therapeutic treatment including clinical observation, medical rehabilitation of disabled children and children suffering from chronic diseases, and sanatorium and health resort treatment of children. Regional programs of state guarantees for free medical care to the citizens of the Russian Federation can also define additional conditions, types and amount

of medical care (Article 6 and Article 41 of the Constitution of the Russian Federation; Article 20 of «Principles of legislation of the Russian Federation on health protection of citizens»).

### Provision of medicine

Disabled children are provided with all medicine and facilities for medical rehabilitation for free until the age of 18 (Decree of Russian Federation Government of July 30, 1994, № 890).

Citizens entitled to benefits including the right to free medicine during outpatient treatment can get prescriptions for:

• Medicine included in the package of medicine covered by state benefits.

In this case a prescription can be written by the doctor in charge in the state or municipal outpatientpolyclinic institution at the place of the citizens' permanent residence, or at a place which they are attached to for medical care (hereafter referred to as a polyclinic institution):

Medicine not included in the benefit package, as well as narcotics, psychoactive and potent drugs, special medication (anti-tumor, anti-tuberculosis, anti-diabetic, immunosuppressant). In this case a prescription can be written by the doctor in charge on the basis of a decision by a committee of polyclinic institution clinical experts, or by corresponding specialists of a polyclinic institution, or by doctors of corresponding specialized therapeutic-prophylactic institutions (dispensaries).

Apart from the doctor in charge in

the polyclinic, benefit prescriptions can be written by: doctors of departmental polyclinics of federal (and subject of federation) level; doctors in private practice working within an agreement with a regional healthcare administration body and/or a fund of obligatory medical insurance and providing medical aid to citizens entitled to benefits within the framework of state guarantee programs.

Benefit prescriptions are written only during outpatient treatment by a doctor of policlinic, subject to all the documents ensuring free medicine and articles of medical designation. Thus a parent of a disabled child must present a document of medical and social expertise (MSEX)

 see section «Social protection») on identification of disability as well as a pension certificate.

It is not allowed to write a prescription for medicine for a quantity exceeding the amount that is required for the patient for the period between the visits to the doctor in charge, and who is in control of the medical therapy, or exceeding one month's

course of treatment for chronic diseases.

Medicine covered by beneficial and free prescriptions can be obtained in pharmacy institutions (organizations), which have an agreement with the regional body for healthcare administration on expense reimbursement for providing medicine on preferential terms, or an agreement on the financing of providing benefit medication to the population if the compulsory medical insurance facilities are used for these purposes.

Qualified staff in a pharmacy institution (organization) have the right to provide an equivalent substitute for a medicine prescribed on preferential conditions when that medicine is not available, but only if the price difference does not exceed 30%.

### Sanatorium and health resort treatment

Children with disabilities have the right to free sanatorium and health resort treatment once a year with free transportation to the health resort treatment location and back. (Decree of the Government of the Russian Federation of *December* 29, № 864).

Vouchers for sanatorium and health resort treatment are issued by executive bodies of the Social Insurance Fund in the place of residence of recipients entitled to social services and, due to the medical condition, in accordance with the Order of the Ministry of Health Care and Social Development of the Russian Federation of December 29, 2004 No 328 on «Providing the number of social services to certain categories of citizens».

One of the parents or other member of the family designated by the parents has a right to stay with a child in a medical

### The required documents for sanatorium health resort treatment vouchers:

- an application form; •
- an inquiry for the voucher
- vou are entitled to the benefit.

institution in the interests of the treatment during the course of stay, regardless of the age of the child. The person who stays with a child in a medical institution of state or municipal system of healthcare is granted sick leave. (Article 22 of the Law of the Russian Federation on «Principles of legislation of the Russian Federation on health protection of citizens»).

Qualified medical care is rendered to disabled people in accordance with the legislation of the Russian Federation and legislation of Russian Federal Subjects within the framework of state guarantee programs on providing free medical aid to the citizens of Russia (Article 13 of the Law of the Russian Federation «On social protection of disabled persons in the Russian Federation»).

The state guarantees to disabled persons the provision of rehabilitation measures, acquiring the technical means of rehabilitation and services stipulated by the federal list of rehabilitation measures. technical means and services granted to disabled persons at the expense of funds from the federal budget (Article 10 of the Law of the Russian Federation «On social protection of disabled persons in the Russian Federation»).

### Tax deductions for parents

Working parents have the right to social tax deductions for education and treatment of children under 18 years in educational and medical institutions of the Russian Federation. The total amount of the social tax deduction stipulated by this article is of actual expenses, but not more than 50,000 rubles per every child in total for both parents (Article 219 of the Tax Code of the Russian Federation).

# Technical means of rehabilitation

Disabled persons have the right to technical means of rehabilitation, manufacturing and repair of orthopedic and other types of prosthetic articles (except dental prostheses made of precious metals) but:

- institutions of medico-social expertise determine thecs or other equipment (see Section 3 «Social protection of your disabled child»);
- disabled persons are provided with technical means of rehabilitation, prosthetic and orthopedic appliances at their place of residence except in cases where there is no availability of prosthetics in the region. In this case all costs associated with travel to and back from the place of prosthetics will be refunded;
- if the individual program of your child specifies a rehabilitation facility or orthopedic appliance, you are free to buy it at your own expense with the subsequent reimbursement through the Social Insurance Fund.)

The majority of parents focus all their efforts on diagnosing a disease, the child's examination and medical treatment, and they do not always know that the success of the treatment depends so much on the people surrounding their child, on adults' participation in the child's games and, most importantly, on timely, systematic, specialized training. The next section of the book, "Education", will be devoted to the upbringing and training of a child with disabilities at different stages of its development.

# **Technical means of rehabilitation:** (in the amended version of Federal Law № 122-FL of 22.03.2004)

- special means for self-sufficiency;
- special means for care;
- special means for orientation (including Guide-dogs with the set of equipment), communication and information exchange;
- special means for teaching, education (including reading for blind people) and sessions of work activities;
- prosthetic appliances (including prostheses and orthopaedic appliances, orthopaedic footwear and special clothing, ocular prostheses and hearing aids);
- special training and sports equipment.



# Section II. Education for children with disabilities

The right to education is one of the fundamental and inalienable constitutional rights of every citizen of the Russian Federation.

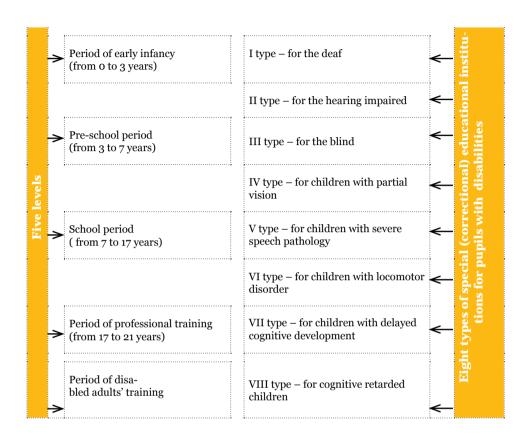
The state creates the conditions for education, correction of development deviations and social adaptation on the basis of the special pedagogical approaches for citizens with disabilities, i.e. having deficiencies in physical and (or) mental development (henceforth, with disabilities) (Law of the Russian Federation «On education»).

In order to extend the availability of education for children with disabilities regardless of their residence, severity of deviation and ability to acquire the required level of education, regional and municipal education authorities are working at developing a differential network of educational institutions, and creating educational conditions for children with disabilities at ordinary educational institutions.

# Special education in Russia

- The vertical structure of special education based on the age characteristics of the children and levels of educational programs
- The horizontal structure of special education that takes into account the psychophysical development of a child, features of its learning activity and the nature of the disorder

### Structure of special education in Russia



### **Period of early infancy**

Children at an early age of infancy are provided with special aid through the Service of Early Assistance, from the very moment of detection of development deviations or peculiarities of physical and mental development, or factors of biological or social risks.



The Service of Early Assistance for education in Kaliningrad Region is being established at the present time. Almost all educational institutions for children in need of psychological and pedagogical, medical and social assistance (PPMS centres) (Attachment 1 of the other publication) already have the Service of Early Assistance (hereafter, Service).

The main objectives of the Service are: prevention of children's disabilities and development deviations, diagnosis of early development and timely correctional works. This new structural element of the special aid system is aimed at the creation of favourable conditions for a child's development.

The main activities carried out by the Service are: consultations, information and psychological support of families over issues connected with individual features and conditions of the child's development; creation and implementation of educational programs of individual support for a child and family; ensuring cooperation and succession between the Service, educational institutions, and institutions of health care and social protection of the population.

### Preschool education

There is a widely differentiated system of specialized (correctional) education in Kaliningrad Region, which includes: pre-school educational institutions (PEI) – specialist nurseries, combined nurseries.

The Ministry of Education of the Kaliningrad Region, together with municipal education authorities, is implementing a range of measures for ensuring the availability of education for children at preschool age: groups with different priorities in educational activities, short-stay groups, consulting offices for parents of children with disabilities at pre-school age, and pre-school learning groups for children who do not attend pre-school institutions. Furthermore, every municipal educational institution has a specialised nursery for the integrated education of children with disabilities (Attachment 2 of the other **publication**). In these basic nurseries children with special educational needs are taught together with ordinary children.

### **Schooling period**

According to Section 1 of Article 52 of the Law of the Russian Federation «On Education» parents (or legal representatives) of under-age children have a legal right to choose educational formats and educational institutions; they protect the legal rights and interests of children, and take part in the management of educational institutions. Thus parents (legal representatives) who bring up a child with disabilities have a legal right to choose either a specialized or an ordinary educational institution.

The network of specialized (correctional) educational institutions includes eight types of specialized (correctional) comprehensive schools (boarding schools) – see scheme on page 20.

In Kaliningrad Region there are five types of specialized (correctional) comprehensive educational institutions (Attachment 3 of the other **publication**) for pupils with disabilities.

Taking into consideration that 80% of children in Kaliningrad Region with disabilities go to general educational and comprehensive schools at the place of their residence, every municipality has designated basic schools to provide integrated education (Attachment 4 of the other **publication**) in order to concentrate together specialized pedagogical staff, material and financial resources, and to ensure that the number of pupils requiring specialized (correctional) classes and groups, and classes with integrated forms of education, obtain what they need.

Basic educational institutions are a transition stage before entering mass integrated education of children in general educational institutions. Integrated education in an ordinary educational institution requires obligatory complex psychological and pedagogical support of a child, special training of all pedagogical staff, learning fully the specialized (correctional) programs, correction of physical and mental deviations and providing professional training for pupils, especially for those who study within the framework of specialized (correctional) programs of VIII type.

There is a network of child and teenager cultural and educational centres. centres for children creativity which provide education to children with disabilities in extra-curricular programs (Attachment 5 of the other publication).

In addition, there is an innovative educational institution, «School of distance learning for children with disabilities», in Kaliningrad Region which has been functioning since 2007 (Attachment 3 of the other **publication**). This educational institution was established for disabled children, who cannot attend schools due to health problems, and are thus provided with education over the internet. Every pupil has an individual computerized work-place at home. Each work-place is equipped with a modern computer, such as a laptop, video- and audio-conferencing devices including web-camera, laser printer, scanner, wireless network, software and, depending on the form of disability, additional equipment. Education is delivered in accordance with programs of comprehensive and extra-curricular education, which is provided by 30 highly qualified teachers, including 14 pedagoguestutors.

Throughout the entire educational process, starting from early age through to professional training, a child receives psychological and pedagogical, medical and social support from the specialists of the PPMS-centres (Attachment 1 of the other publication). The main objectives of such centres are: to provide psychological and pedagogical support for children with problematic school adaptation, who experience difficulties in learning educational programs, and who find themselves in difficult life situations; to carry out diagnostic examinations of children in order to provide adequate correctional work and to provide consultations to parents and children; to organise individual classes; to prevent socially dangerous diseases.

### **Professional training**

Professional training is the key issue in social adaptation and future life prospects for young people with disabilities. Kaliningrad Regional institutions of primary and secondary vocational training can offer specialized (correctional) groups for young people with disabilities (Attachment 6 of the other publication).



Apart from this, young people have the right to get higher professional education according to their chosen specialization. Citizens with disabilities, having a defective physical and(or) mental development, are accepted into the educational institutions on the grounds of both the results of the Unified

State Exam and entrance exams organized by Institutions of Higher Education or Secondary Educational Institutions.

### Psychologicalmedical-pedagogical examination

The success of the initial stage of education and upbringing of a child with special educational needs is assessed by a complex psychological-medical-pedagogical examination (PMPE) conducted by a regional commission, the results of which lay a foundation for the further education and development of a child.

The procedure for PMPE differs from examinations performed by individual specialists (psychologists. doctors, speech therapists, specialists in mental and physical handicaps) as it is a team operation. Tests elaborated by a team of specialists enable them to identify the level of knowledge, abilities and skills of a child or a teenager. The assessment is made collectively. The report from the PMPE is an obligatory recommendation for pedagogues of educational institutions where a child has been assigned for his own individual course of studies.

Why does one need this examination?

The psychological-medical-pedagogical examination is carried out in a specialized state educational institution, the «Kaliningrad Regional Consulting and Diagnostic Centre for Children and Teenagers»

236000 Kaliningrad, Gostinnaya Street, 7; tel. +7 (4012) 934-291. PMPE was established in order to define educational needs and conditions ensuring development, education, adaptation, social inclusion (integration) of children and teenagers with disabilities on the basis of a comprehensive diagnosis.

### **Objectives of PMPE:**

- Reliable diagnosis of individual features of mental development of a child.
- Elaboration of recommendations for individually-oriented programs for pedagogical, psychological, social and medical support of children; also, special educational conditions and required appropriate psychological and pedagogical, medical and social assistance.
- 8 Ensuring effective psychological pedagogical support of children from one till 18 years.
- Using modern diagnostic methods to select the appropriate educational program.
- 6 Creation of a data base and keeping records of children and teenagers with disabilities
- 6 Comprehensive assistance to family. specialists of educational institutions. consultations with parents (legal representatives), pedagogical and medical staff representing the interests of a child in the family and the educational institution.
- Participation in educational activities aimed at improving the psychological and pedagogical, medical and social culture of the population.
- Facilitation of the process of integration of children with disabilities into society.

PMPE for children is carried out only with the agreement of the parents (or persons replacing them). Children and adults have got the right to refuse the examination. But the reason for a refusal to take the examination should not be concern over the possible circulation of the results, because the procedure of examination is based on the principle of confidentiality. For specialists of PMPE, keeping confidential all the information about the results of the examination and the child's state is compulsory. Nobody has any access to the information designated for parents except officials approved by parents (or persons replacing them) in advance.

Your child and you will be working with the commission that consists of: the chairman of PMPE, chairman's deputy, social pedagogue, teacher-specialist in mental and physical handicaps, teacher-speech therapist, pedagogue-psychologist, doctor-psychiatrist, doctor-neurologist, specialists-consultants: hearing and visual impairment specialists: doctors - audiologist, ophthalmologist, orthopaedic-surgeon who can be invited if there is any necessity. The examination is done by all the specialists and the decision is taken collectively.

### Acceptance procedure and functioning of **PMPE**

The procedure of PMPE can be initiated only by parents (legal representatives) and, with the parents' consent, by pedagogues, specialists of educational institutions and departments. A parental (legal representatives') application is the basis for a comprehensive examination of a child to determine an appropriate program and special conditions for training.

The main parameters for comprehensive examination of a child for PMPE can be specific features of mental and physical development, difficulties in communication and learning.

The acceptance and comprehensive examination for PMPE of children and teenagers is carried out in the presence of parents (legal representatives) or an authorized person having power of attorney which is officially certified by the head of the institution

PMPE is carried out in the form of an educational and practical experiment. If a child experiences



difficulties

with the tasks, the examination is backed up with alternative, safe assessments of mental and physical development, and adequate forms of examination which correspond with the individual and age characteristics of the child.

The initial examination is done before the age of 12. From 12 to 18 the examination is performed in the form of a consultation.

Disabled children and teenagers over 12 can undergo a first PMPE in the following exceptional cases:

- if a child is referred for a secondary PMPE;
- in case of change of domicile arrival from other regions and foreign countries;
- after traumas or long-term treatment;
- in case of the need for an additional examination

A compulsory condition for the comprehensive examination of children over 12, who have applied for PMPE for the first time, is a prior thorough psychological examination of the child's level of intellect.

The results of the collective decision will be presented in the PMPE protocol (hereafter, protocol), which is the basis for providing a child with special conditions and programs of education. The protocol is an official document and kept in a personal file of the pupil.

The representative of the PMPE commission must present a medical report and recommendations to parents (legal representatives) in a comprehensive and understandable form.

Parents (legal representatives) on acceptance of the medical report and recommendations get a written extract of the protocol with the medical report and recommendations.

If the parents (legal representatives) disagree with the decision of the local PMPE commission, the question of appropriate conditions and programs of education will be considered by the federal PMPE commission or by the Institute of Correctional Pedagogies of the Russian Academy of Education.

The original PMPE protocol is transferred to a staff member of the municipal education body (at the child's place of study) for further joint decision on the child's education, made together with the parents (legal representatives).

At the request of municipal management bodies for education and other institutions, the PMPE commission will visit specified groups of children or teenagers to carry out the examination.

Based on the results of the examinations the PMPE commission takes part in determining the need for educational institutions of different types and forms, including institutions for children who are orphans and children left without parental care.



### List of documents required for PMPE:





# Section III. Social protection of your disabled child

Social protection is a system of guaranteed permanent and/or long-term economic, social and legislative measures ensuring the necessary conditions for overcoming, replacing (compensating) disability and aimed at the creation of equal opportunities for life in society.

State policy in the sphere of social protection of disabled persons in the Russian Federation is defined in accordance with the Federal Law «On Social Protection of Disabled Persons in the Russian Federation» of 24.11.1995  $N^{\mbox{\tiny $\Omega$}}$  181-FL.

Such terms as «disabled» and «disabled child» are equivalent (Article 1 of the Federal Law «On social protection of disabled persons in the Russian Federation»). Thus when legislative acts mention a disabled person and the benefits allocated to him they can be referred as well to a disabled child. They both have equal juridical status.

A child is given the status of a disabled child by the State Service of Medical and Social Expertise (hereafter, MSE).

# Medical-social expertise and its procedure

In Kaliningrad Region medical-social expertise for children (under 17 years 11 months 29 days) is practiced in the federal state institution «Head Office of Medical and Social Expertise in the Kaliningrad Region», Branch № 10 (Pediatric Department):

236000 Kaliningrad, Chernychevsky Street, 26. Tel.: +7 (4012) 935-962

#### Powers of the state MSE service:

- ② Specifying degree of disability, its reasons, duration, the time when disability started, the disabled person's needs for different types of social protection.
- Elaboration of individual rehabilitation programs.

- 3 Investigation of level and reasons of disability among the population.
- Participation in creation of comprehensive programs for disability prevention, medical and social rehabilitation and social protection of disabled persons.
- 6 Identification of degree of earning capacity loss for people with work-related injuries or professional illness.
- 6 Identification of cause of disabled person's death if prescribing benefits to the family of the deceased as it is laid down by the legislation of the Russian Federation.

### Making appointment with MSE

After the required diagnostic, treatment and rehabilitation measures have been carried out, providing the data identifying the precise disorder of the functions of the organism caused by an illness resulting from traumas and defects, health care institutions give the appointment. When making an appointment, the health care institution must gather together all information about the child's state of health, its organs and systemic-level dysfunctions, the state

Documents for the FSI «Head Office of Medical and Social **Expertise in the Kaliningrad** Region», Branch Nº 10 (Pediatric Department) are accepted:

> Monday 10.00-14.00, Tuesday 13.00-14.00, Wednesday 10.00-14.00, Friday 11.00-12.00.

of compensatory abilities of the organism, and the results of rehabilitation measures

### **Documents required** for examination at the MSE

- Appointment from a medical institution (with a seal, stamp, signatures of head doctor, head of polyclinic, district pediatrician).
- Outpatient medical record.
- 3 Expanded medical analysis of a specialist, district pediatrician, results of physical examination (on a separate paper).
- Results of examination (in accordance with diagnosis).
- Copies of all extracts for the previous year.
- Individual rehabilitation program (for repeat patients).
- Medical disability certificate (for repeat patients).
- B Copy of child's birth certificate or child's passport.
- Certificate from Housing Office about child's registration (for children who do not have passports).
- Copy of Russian citizenship (extract from internal passport).
- Report from school (pre-school institution), which is written by the class teacher (a pedagogue from PSI) in a narrative format. It should contain information about the level of learning of the educational program and the number of missed classes due to illness. The report must be certified by the head of the educational institution.

The Medical and Social Expertise examination should be carried out in the presence of the child and his legal representative. If a child cannot come to the MSE for reasons of health, which is confirmed by a medical certificate from the health care institution, the examination can be carried out at home, in the hospital where a child is a patient, or without seeing him (in absentia) on the basis of medical documents and with the consent of the child's legal representative. A legal representative at his own expense has the right to invite any specialist in his consultative capacity of expertise.

Specialists of the Medical and Social Expertise study all available information about a child (clinical and functional,

working, psychological and other), conduct a personal examination of the child, evaluate the degree of disability and discuss collectively all the results.

social-domestic, professional and

The decision on whether to give a person the status of a disabled person or not is taken by the full staff of specialists, who are involved in the expert decision, by a simple majority vote. The head of the

institution gives the decision to the child and his legal representatives on the presence of all specialists and provides all necessary explanations.

Depending on the degree of dysfunction of the organism's functions and the limitations of vital functions, a person under 18 is given the status of «a disabled child» for the period of one year, two years or until he reaches 18 years-old, in accordance with the classifications and criteria adopted by the Ministry of Health Care and Social Development.

If a child receives the status of a disabled person his legal representative gets the following documents:

- Certificate of disability from the Medical and Social Expertise (so-called «pink certificate»);
- Individual rehabilitation program.

Follow-up examinations of disabled children are carried out at specified intervals during the period for which the status remains valid. The status of disability is valid until the first day of the month following the month when the repeat examination is to be carried out. A re-examination of a disabled child may be carried out in advance of, but not earlier than two months before, the termination of the status of disability.

## Rehabilitation of your disabled child

The rehabilitation of disabled persons (including disabled children) involves a system and process for the complete or partial restoration of abilities of disabled persons for everyday, social and professional activity.

Rehabilitation of disabled children is aimed at elimination of, or full compensation for, disabilities caused by health deterioration through permanent organic dysfunctions, in order to improve the social adaptation of the disabled, their financial situation and their integration into the society.

In Kaliningrad Region there are three rehabilitation centres for children and teenagers with disabilities, as well as other social institutions specializing in working with disabled children (Attachment 7 of the other publication).

### What are the main elements of the rehabilitation?

- Medical rehabilitation (recovery therapy, reconstructive surgery, prosthetics, sanatorium-resort treatment);
- Professional rehabilitation (identification of appropriate profession, professional training and retraining, assistance in job-seeking, industrial adaptation);



- Social rehabilitation (social and environmental, social and pedagogical, social and psychological, social and cultural rehabilitation, social and domestic adaptation);
- Physical culture, health and fitness activities and sports.

# Individual rehabilitation program

The individual rehabilitation program (IRP) for a disabled person is an amalgam of optimal rehabilitation measures developed in accordance with the decision taken by the State Office of Medical and Social Expertise. This package specifies the separate types, forms, quantities, periods of duration, and the sequence of implementation of medical. professional and other rehabilitation activities aimed at regeneration, compensation of disordered or lost functions of an organism, restoration, and compensation of abilities of a disabled person so he can carry out certain types of activities.

The IRP must include specific measures for all the issues mentioned above.

The individual rehabilitation program of a disabled person is obligatory for the relevant authorities. local government bodies, and all other concerned organizations regardless of their legal organizational forms and types of ownership. The legal representative of a disabled child must always carry the individual rehabilitation program with the designated rehabilitation measures, and request the authorities to record every procedure they carry out, which is listed in the IRP, while attending social protection bodies, the Fund for Social Security, Centre of Employment, and medical and rehabilitation institutions.

The IRP has an advisory nature; you are entitled to decline this or that type, form or quantitative extent of the rehabilitation measures and, indeed, decline to participate in the program itself. A disabled child and/or his parents can make their own decision about the necessity for a specific type of technical

equipment or type of rehabilitation, including cars, wheel-chairs, prosthetic and orthopedic equipment, printed materials with a specific type of print, loudspeaker equipment, signaling devices, video-materials with subtitles and sign language translation and other analogue materials

The IRP includes both rehabilitation activities provided to a disabled person free, in accordance with the federal basic rehabilitation program, and activities paid for by a disabled person or other people or organizations, regardless of the legal organizational forms and types of ownership. This means that rehabilitation activities can be fee-paying as well.

The call-centre within the Ministry for Social Policy in the Kaliningrad Region is:

Tel.: +7 (4012) 531-231

# State support to your family bringing up a disabled child

Designating disabled children within a special category is determined by the necessity for social protection of their families. The legislation provides additional benefits to parents of a disabled child in order to guarantee them proper care of the child. The legislation specifies what benefits are provided for a disabled person (a disabled child), what benefits go to the family with a disabled child and, in the latter case, what benefits are provided for all members of the family living together.

## Disbursements and benefits provided for disabled children and their parents

(as of June 1, 2010 with possible further indexation):

#### Social pension of a disabled person is 5.574.91rubles

(Article 11 of the Federal Law «On state pension provision», 15.12.2001  $N^0$  166-FL»)

## Federal monthly cash payment (MCP) – 1,698.40 rubles, including 705.10 rubles for a package of social services

(Article 28.1 of the Federal Law of 24.11.1995  $N^{\circ}$  181-FL «On social protection of disabled persons in the Russian Federation»)

#### Monthly compensational payment to a non-working able-bodied person looking after a disabled child under 18 years – 1,200 rubles

(Decree of the President of the Russian Federation, 26.12.2006  $N^{o}$  1455 as amended on 13.05.2008  $N^{o}$  774)

#### Monthly allowance for a child – 123 rubles

This is paid to families with an average per capita income lower than the minimum subsistence income per capita of the population in the Kaliningrad Region (Law of the Kaliningrad Region of 14.01.2005 № 487 «On allowances to citizens with children»)

#### Monthly allowance for a disabled child -1,000 rubles

This is paid to families with average per capita income lower than 200% of the minimum subsistence income per capita of the population in the Kaliningrad Region (*The Law of Kaliningrad Region of* 14.01.2005 № 487 «On Allowances to citizens with children»)

#### Emergency targeted support to citizens in a difficult life situation, - up to 2,000 rubles per family once a year

This can be paid to families with income higher than the subsistence minimum if expensive treatment and examination are required (over 500 rubles), and it can also go towards the cost of medicine over 500 rubles

(Resolution of the Kaliningrad Regional Administration of 11.05.2005 № 244 «On providing emergency targeted support to citizens in a difficult life situation»)

For social support of the citizens of the region in the form of payment for examination and treatment in medical institutions with high technological medical aid, the amount of payments is not fixed

but is determined by the actual expenditure on the treatment and the transportation costs to the place of treatment.

(Decree of the Kaliningrad Region Government of 28.12.2007 № 895 «On order of providing social support for the citizens of the Kaliningrad Region in the form of payment for examination and treatment in medical institutions with higher technological tupes of medical aid»)

To get a pension, the MCP (see above) and the benefit allowance for care purposes (1,200 roubles), one should apply to the regional body of the Pension Fund of the Russian Federation at the place of residence.

To get allowances that are provided at the expense of the regional budget one should apply to the «one-stop-shop» at the place of residence (Attachment 7 of the other publication).

#### **Social rights** and benefits

#### Right to rehabilitation

(Article 9 of the Federal Law «On social protection of disabled persons in the Russian Federation» № 181-FL of 24.11.1995, Government order of 30.12.2005)



A disabled child is provided with free rehabilitation activities and technical facilities of rehabilitation and services, including rehabilitation therapy, reconstructive surgery, sanatorium-resort treatment, prosthesis, provision of hearing-aids. All the required child rehabilitation activities as well as technical facilities should be included in the individual rehabilitation program.

#### Right to social service

(Article 5 of the Federal Law «On social services provided for elderly and disabled people» № 122-FL of 02.08.95)

The provision of social services involves social services for social support, social and domestic, social and medical, psychological and pedagogical, social and legal services, financial support, social adaptation and rehabilitation of citizens in a difficult life situation. Children with disabilities, i.e. having deficiencies in physical and mental development, receive social services for free in the amount specified by state standards of social service.

Institutions providing social services to disabled children:

- Centres of social services for the population, including comprehensive service centres
- Centres of social support for a family and children;

 Rehabilitation centres for children with disabilities and teenagers, and other institutions providing social services.

#### **Employment rights**

An employment contract can be signed only by people over 16 years old. If a person has completed compulsory secondary education or abandons it, in accordance with the federal law of the comprehensive institution, an employment contract can be signed by persons from 15 years old. With the agreement of one of the parents (tutor, trustee), or relevant trustees and guardians, a labour contract can be signed by a schoolchild from 14 years old in order to perform light work during time free from study, which does not harm the health and if such work does not interfere with the process of studies (Article 63 of Russian Federation Labour Code). The IRP must contain a record of permitted types of labour activities.

## Right to additional four days-off a month to care for a disabled child

(Article 262 of Russian Federation Labour Code)

These leave-days are granted to a parent on receipt of a written application to an employer. The application is supported by a physical disability certificate and document from the employer of the other parent confirming the number of days-off which were granted (or not granted) to him/her. These additional days-off can be used by one of the parents or divided between them. The payment for every additional day-off is made at the expense of the Social Insurance Fund.

#### Right to take early pension

(Article 28 of the Federal Law «On labour pensions in the Russian Federation»  $N^{\Omega}$  173-FL of 17.12.2001)

One of the parents of a disabled child, up to the age of 8 years-old, is entitled to claim an early pension: men - at the age of 55 years, women - at the age of 50 years, if they have an insured work experience of, respectively, 20 and 15 years.

#### Right to include the period of looking after a disabled child under 18 years to the insured length of employment

(Article 11 of the Federal Law «On labour pensions in the Russian Federation» № 173-FL of 17.12.2001)

This period is included in the insured length of employment if this period was preceded or followed by periods of work for which insurance contributions were paid.

#### Housing and public utilities benefits

(Article 9 of the Federal Law «On social protection of disabled persons in the Russian Federation» № 181-FL of 24.11.1995)

Families with disabled children are entitled to a minimum 50% discount for housing rent (in the housing of state or municipal housing stock) and payment for public utilities (regardless of whom the housing belongs to), and in houses with no central heating - for the cost of fuel purchased within the framework of standards fixed for the population.

From January 1 2010 such measures of social protection are granted in the form of a monthly benefits payment.

#### Right to subsidised travel on city public transport

Disabled children and the persons accompanying them, who reside in Kaliningrad, may get a discount unified season ticket for all types of city public transport except taxis.

#### Right to social service transport (social taxi)

Disabled children and the persons accompanying them may use the services of the social transport service, which operate in all municipal institutions of the region at the comprehensive centres providing social services to the population (Attachment 7 of the other publication).

#### Right to a set of social services (social package) funded through the monthly cash payment (MCP) that is made up of two parts:

1. Additional free medical aid includes the stipulated provision of medicine, articles of medical designation, specialized products of medical nutrition for disabled children according to the prescription of a doctor (medical assistant), and granting a voucher for sanatorium-resort treatment following the doctor's approval.

**2.** Free travel to the place of treatment and back using local train transport as well as the inter-city transport.

Disabled children have the right to a second voucher for a sanatorium-resort and free travel to the place of treatment and back for the accompanying person.

Young people can apply to the social protection institutions for assistance in finding work at their place of residence, or to The Social Service for Young People:

236000 Kaliningrad, Chaykovsky str., 13

Tel.: +7 (4012) 955-542

E-mail: ccm2004@inbox.ru

The right to free travel using local train transport is applicable to the person accompanying a disabled child.



This social package is granted to a citizen at his place of residence the moment his monthly cash payment is determined (an appropriate certificate is issued). A social service package is granted for one calendar year. In order to get free services in applying to the medical treatment preventative institution, and local railway transport booking offices, a legal representative of a disabled child should submit the following documents: Medical and Social Expertise certificate on the

disability of the child, certificate confirming the right to a social package, passport of the accompanying person.

A parent of a disabled child or the child himself, on reaching 14 years, can decline the social package in full or any one of its component services.

An application seeking such a refusal for the next calendar year should be submitted to the regional body of the Pension Fund of the Russian Federation before October 1 of the current year. In cases of declining to avail of any of the services (package of services) sums to be spent on it (them) should be added to the MCP of the disabled child. From June 1, 2010 the

### Right to obtain required information

705.10 rubles.

compensation amount comes to

(Article 14 of the Federal Law «On social protection of disabled persons in the Russian Federation» № 181-FL of 24.11.19950)

Authorized bodies assist disabled people in getting services in sign language, obtaining sign-language translation equipment, and accessing facilities for teaching the blind

## Income tax privileges – standard and social tax deductions (Articles 218, 219 of the Tax Code, Part 2)



# Section IV. Family with a disabled child

Children with a wide range of illnesses and defects, whether inborn or acquired during early development, are assigned to a group of disabled children. These disabilities can be defects and deficiencies of physical development; hereditary illnesses that arise from the genetic level; consequences of different traumas; specific anomalies that are not readily visible from outside. The child's ailment sometimes manifests more physical or physiological symptoms without any practical effect on mental and psychological development. But in some cases it can be vice versa - a child has a retarded mental development but is physically relatively healthy. But no matter what the etiology of the disability, the feelings of the parents of disabled children are the same.

In most cases a disabled child in a family changes the whole way of life and, especially, the psychological climate. All members of the family experience immense stress.

But there is nothing shameful in having a child with disabilities, even if you sometimes feel disgusted and ask why this happened to you. It is normal that you should experience a maelstrom of emotions – which can damage both a mother and a child.

Rebecca Willis – an American psychiatrist – singles out several types of reactions in relation to the birth of a disabled child. The first reaction is denial and shock. It is undeniably difficult for parents to believe what has happened during the first couple of days, weeks and even years. This state is followed by deep sorrow.

Parents feel so helpless and isolated from the outside world. This state of mind leads to disappointment and anger.

Psychologically these are the most difficult moments of life for families with disabled children:

- Discovering there is a development dysfunctionality of the child.
   Emergence of fear; uncertainty over the future upbringing of the child; interminable grief.
- Senior pre-school age. Realization of the fact that the child eventually will not be able to go to ordinary comprehensive school.
- Teenage. Child's awareness of his disability leads to difficulties in establishing contacts with peers and especially with the opposite sex.
   Isolation from society.
- Senior school age. Difficulties with choosing future profession and further job-seeking. Inner conflict.

Parents suffer themselves and often they simply teach their child to suffer as well. In reality it is not the diagnosis itself that makes a child feel inferior, but the attitude to his condition of the people around him. It may be enough simply to acknowledge your own mistaken attitudes in order to assert self-control and eliminate these false attitudes from your heart. Sometimes it is necessary to discuss the problem with some relatives for hours, and sometimes one cannot do anything without the help of a psychologist or neurologist.

There is no doubt that every disability of a disabled child requires specific individual care, as well as certain knowledge and skills. But as far as psychology and general rules of behavior are concerned, there are some universal recommendations of the specialists.

A constructive approach comprises two main elements, which are, first, to bring under control all the life and all the actions of the parents' child in the foreseeable future and, second, to assist in preserving and strengthening the family. First of all, it is necessary to provide proper care for a disabled child, which includes elements dealing with the child's development; to develop skills of self-sufficiency to the maximum; and to encourage his social integration. Secondly, it is necessary to maintain a psychologically healthy atmosphere in the family: not to deprive each other, other children and members of the family of consideration and love: to strive to give every member of the family the possibility for self-development and to live a full life. Complete selfabnegation for the sake of a child is not healthy for the child but in many cases it is actually harmful, From the earliest months of life a child should feel stability and peace in his surroundings.

In no case should parents isolate themselves from the outside world and feel ashamed for their child. Otherwise the chronic stressful situation becomes aggravated, with the mother becoming highly irritable, experiencing a constant feeling of inner agitation, which leads to sleep disturbance, loss of appetite, headaches and other problems with her health. Frequently it can result in neurotic conditions. And while being in such a state of illness a mother can hardly help her child.

The behaviour of the father and other members of the family are also significant for a disabled child. The emotional state of the mother, her emotional balance, greatly depends on the father's behavior. If the father shows self-control, reason, nobility, patience,

and provides constant moral support to the wife and assistance in bringing up the child, family relations will become stronger, which also has its positive effect on the overall medical and correctional work. Here is important advice for friends and relatives: the worst thing you can do is to show your

sympathy to the parents of a disabled child. Saying things like «I'm so sorry about it» can only humiliate a child and parents.

But friends and relatives are not always able to understand the unsettled state that the parents are in. In this case the parents may be supported by others who have a child with similar disability and have succeeded in getting over this difficult period. Parent groups of mutual help are very important, as they help to dispel the feeling of loneliness and despair. In helping each other, parents do not retreat into their own shell of grief

do not retreat into their own shell of grief and thus they find a more constructive way out of their problem.

Scientists suggest looking at the situation from a different angle: here is an opportunity to reconsider one's life, to collect all your strength and will and to love a child the way he is; to live with him, to enjoy life and help other mothers with the same problems to find peace of mind. The parable about Buddha, "A mustard seed," is relevant here.

Once Buddha met an elderly woman. She was crying bitterly because of her difficult life and asked Buddha to help her. He promised to help her if she would bring him a mustard seed from a house which had never experienced any grief. Being encouraged by Buddha the woman started her search for such a seed. And Buddha carried on going his own way. Much later Buddha met this woman again — she was rinsing linen in the river and singing a song. Buddha came up to her and asked if she had found a house where life was happy and undisturbed.

She gave a negative answer and said she would go and look for it a little bit later after she had helped to wash the linen for some people whose grief was far deeper than her own.

We have to understand that life will not stop with the birth of a disabled child, it goes on and one has to keep on living. bringing the child up, loving him the way he is without unnecessary pity. There is an opinion that even the most hopeless child is a bewitched prince living in his own wonderful world. And this world just happens to be a different one.

The American Centre of Early Intervention developed the following list of recommendations for parents of disabled children:

- Never be sympathetic towards a child simply because he is not like everybody else.
- Give a child your love and consideration but do not forget about the other members of the family who also need this as well.



- Organize your life in a way that nobody in the family feels like a «victim», having to give up their own personal life
- Do not shield a child from all obligations and problems. Take decisions together.
- Give a child freedom in his activities and decisions.
- Look after your appearance and behavior. A child should be proud of vou.
- Do not be afraid to deny some child's requests if you consider them unreasonable.
- Talk to the child more often. Remember that neither a TV or radio program can replace you.
- Do not limit the child's communication with peers.
- Do not turn down friends' invitations and invite them to your house.
- Follow the recommendations of pedagogues and psychologists more often.
- Read more and not only specialized literature but fiction as well.
- Get in touch with families who also have disabled children. Share experiences.
- Do not waste your time on selfreproach. It is not your fault that you have a disabled child.
- Remember your child will grow up and have to live his own independent life. Prepare him for his future life. Talk about it.



## **Table 1. Indicators of development of a newborn child**

	Age (months)			
Indicators of development	Mature infants	Premature infants		
		Degree of prematurity		
J T T		I (2,500- 2,001gr)	II (2,000- 1,501gr)	III (1,500- 1,001gr)
1	2	3	4	5
Tries to raise head while lying on stomach	1	1- 2	2-3	3-4
First smile as reaction to adult's speech	1	1-2	2-3	3-4
Watches for a moving toy	2	2-3	3-4	4-5
Lies on stomach with head up resting on forearm	2-3	3-4	4-5	5-6
Expresses happiness by smile, sounds, motion of hands and/or legs, as reaction to adult's speech		3-4	4-5	5-6
Focuses his gaze on stationary objects being in any positions	4	4-5	5-6	6-7
Recognizes his mother	4	4-5	5-6	6-7
Turns his head to a sound	4	4,5	5,5	6
Laughs loudly	4	4,5	5,5	6
Rolls over from his back onto his stomach	4	4,5	5,5	6
Reaches for a hanging toy	4	4,5	5,5	6
«Coos» for a long time	4	4,5	5,5	6
Distinguishes strangers from immediate relatives	5	5,5	6	6,5
Understands the tone being addressed to him	5	5,5	6	6,5
Stands without bending his feet when held under arm-pits	5	6	6,5	7,5
Unmistakably takes a toy that is held over his chest	5	5,5	6	6,5
Rolls over from his back to his stomach and from stomach to his back	5-6	6-6,5	6,5-7	7-7,5
Pronounces separate syllables «ma», «da», etc.	6	6	7,5	8
Easily picks up a toy from any position	6	6,5	7	7,5
Crawls well	7	8,5	9	10,5
Taps a toy against a toy, passes it from one hand to another	7	7-7,5	7,5-8	8,5

Pronounces syllables, babbles a lot	7	9,5	10	11
Finds an object in the right place in response to the question «Where?»	7	8,5	9	10
Drinks from a cup, eats from a spoon	7	7-7,5	7,5-8	8,5
Sits down without adult's help, stands up resting on a support, walks holding a bar	8	9-9,5	10-10,5	11-12
Plays with toys for a long time	8	8,5	9	10
Performs some motions at request of an adult: «give me your hand», «Bye, bye!», pat-a– cake motion	9	9,5	10	11
Repeats familiar and pronounceable by him earlier syllables while imitating adults	9	10,5	11	11,5
Walks well held by two hands	9	9,5	10	11,5
Drinks well from a cup holding it with two hands	9	9	10	11
Does different things with objects – rolls, takes out, puts in	9	9,5	10,5	11,5
Knows its name, chooses objects from the pile of toys	9	10	10,5	11,5
Opens, closes a box, Matryoshka doll, puts one object into another	10	11	11,5	12,5
Imitates an adult, repeats different syllables and sounds after him	10	11,5	12	13,5
Knows the names of the body parts, gives a familiar object at request of an adult	10	10,5-11,5	12-12,5	12-13,5
Stands independently without any support	11	11,5	12	13
Plays with bricks, adds and removes a ring from a pyramid	11	11,5	12	13
Uses first words – names like «kitty-kitty», etc.	11	12,5	13,5	14,5
Carries out some basic requests of adults	11	11,5	12	13
Walks on his own	12	12-13	14	15
Pronounces 8-10 words	12	13-14	15	16
Takes a cup and drinks	12	12-13	14	16

# **Table 2. Scheme of supervision** to evaluate child's neuroand mental development

Age	Movements (motor function)	Accurate movements	Interaction with surroundings	Speech	
1 month	Raises his chin lying on stomach		Keeps his eyes on moving objects	Listens, smiles	
2 months	Raises his head lying on stomach		Focuses his look , turns his head to a sound-180 degrees	Listens to voices, smiles, coos	
3 months	Gets up with the help of his forearms lying on stomach, holds up his head	Stretches his arms spontaneously, trying to reach a toy	Supports social contact, listens to music, smiles	Laughs, «coos»	
6 months	Sits for some periods	Shifts a toy from hand to hand	Prefers his mother, expresses displeasure	Utters polysyllabic sounds	
9 months	Stands up by pulling himself up with arms	Grasps small object with his fingers	Plays with adults, waves goodbye	Imitates sounds	
1 year	Walks held by a hand	Gives an object on request, knows words «you cannot», eats with a spoon	Walks to a call, carries out requests (give/ bring)	Pronounces 2-3 meaningful short words	
1.5 years	Walks up and down a stair with support	Eats with spoon	Imitates adults movements	Pronounces 6 words clearly	
2 years	Runs	Builds a «house» with 6 toy bricks	Plays with others	Says 2-3 word phrases	
2.5 years	Walks up and down the stairs alternating his feet	Builds a «house» with 9 toy bricks	Removes his toys	Knows his name, calls himself «I», «Me»	
3 years	Stands on one foot, rides a three-wheel bicycle	Can draw a circle, cross	Washes hands, goes to the bathroom, helps to get dressed	Knows verses, counts to three objects	

Age	Movements (motor function)	Accurate movements	Interaction with surroundings	Speech
4 years	Jumps on one foot	Builds models with toy bricks	Plays role-games with other children	Tells stories
5 years	Jumps, rides a three-wheel bicycle	Makes a copy of a triangle. Draws. Can do up buttons	Plays with other children, invents different games	Names 4 colours, counts to 10
5-12 years	Rides a two-wheel bicycle, skis, skates. Jumps rope. Can serve and return a ball	Draws, writes	Makes friends with his classmates	Reads poetry. Tells. Knows alphabet
12-18 years	Works on a computer, drives a car, uses household appliances, skis	Draws, sews.	Makes friends of opposite sex, has group communicat- ing skills.	Writes compositions, makes up stories, argues, works with a book.

## Sources of additional information

#### **Books and booklets**

Ask your health visitor or social worker to recommend literature or other information on the physical disability of your child. A library is another place to look for information.

#### Websites of authorities

Websites of regional authorities containing information on services described here and contact details:

www.social.gov39.ru - Ministry of Social Policy of Kaliningrad Region

www.edu.baltinform.ru - Ministry of Education of Kaliningrad Region

www.infomed39.ru - Ministry of Health of Kaliningrad Region

#### Other thematic websites

www.inva.info - a catalogue of sites on physical disability and rehabilitation with a user-friendly search capability

www.invalid.ru - server for disabled persons: chat-rooms, laws, basic concepts, order of conducting of expertise for disability, references to other resources

www.gold-child.ru - a site for parents with disabled children, «Golden City»: books on children's upbringing, books and methodology of rehabilitation, legislative documents

www.apparel.ru - a site for «Apparel» – a Kaliningrad association of disabled young people – useful regional information

www.detiangeli.ru - a site for the parents' community, «Angel Children», concerning children with infantile cerebral paralysis: library, laws and decrees, forum

www.sundeti.ru - a site for a public organization supporting children with Down's Syndrome, «Sunny Children»

www.step-a-head.desc.ru information portal for disabled children and their parents «Make a step!»







A Guide for parents of children with disabilities: help and support

are expecting or already have a

output of a three-year program of Council of Ministers, the three their families. It was initiated by the Nordic Centre for Welfare and

The Guide is available in PDF format at <a href="http://www.norden39.ru">http://www.norden39.ru</a>

The idea of producing the Guide came disabilities in the Kaliningrad Region,



The Ministry of Education of

The Ministry of Health of the



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