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AUTHOR Huovinen, Matti

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ABSTRACT

This report discusses a study of the characteristics and needs of children with mental retardation in the Segezha district in the Republic of Carelia in Russia. A training program for professionals and parents of children with mental retardation is also described. As a background for the study, statistical information regarding the populations' social status and health is discussed in Chapters 2-5. Information about the district is compared to similar statistics from Kainuu, Finland. In Chapters 6-9 the regulations concerning the care of people with disabilities in Carelia as well as the services currently available are reviewed. Chapter 10 focuses on the 154 children (0-16) with disabilities residing in Carelia. The study reviews the number of children living at home, the level of development and age of the children, services provided to the children, the tuition of children living in institutions, and family characteristics. Chapter 11 describes the training of the authorities responsible for children with disabilities in Segezha, as well as the training of the children's parents. General recommendations for changes in the care of individuals with disabilities in Segezha are presented in Chapter 12. Appendices include additional statistical information about the Segezha district. (Contains 10 references.) (CR)



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A STUDY OF THE BASIC NEEDS OF THE MENTALLY HANDICAPPED IN THE SEGEZHA DISTRICT

REPORT ON THE TACIS BISTRO PROJECT NR BIS/95/175/030

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Connection addresses

Mr Matti Huovinen, Director of Care of the Mentally Handicapped, Kainuu Central Institution, 87250 Kajaani, Finland. Tel. (358)-86-6156900, fax (358)-86-617 6932.

Mr Anatoly A. Kushnariev, Medical Superintendent of the Segezha Hospital Tel. 2-31-55.

Ms Ludmila Alexandrovna Romanova, Senior Physician of the Segezha Pediatric Policlinic Tel. 2-35-63



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1. INTRODUCTION

The target group of the project are the mentally handicapped children in the Segezha district, especially those living at home. Also other children are shortly discussed in chapter 10.3.

The goal of the project has been to study the relevant factors concerning the handicapped children, their general circumstances, and to define the individual need for services of each child, based on the above-mentioned factors.

As a background for the study, the development of the variables describing the population's social status and health has been discussed in chapters 2-5. The information is mainly based on the annual statistical publication "The Basic Figures of Health Care in the Republic of Carelia". Some pieces of the information were received directly from the health care authorities of the Segezha district and the city of Petrozavodsk.

The statistical practice in Russia differs from that of Finland's. As to a few years, certain figures are missing altogether. Therefore, direct comparisons with the corresponding Finnish figures can only be regarded as guidelines.

In chapters 6-9, the regulations concerning the care of the handicapped in Carelia as well as the services currently available are discussed. The information on the services has been collected by means of a form, enclosed as Appendix Nr 5, and directly from the responsible authorities.

The basic study of the mentally handicapped children in the Segezha district is presented in chapter 10. (In Russia, consequently also in Carelia, the concept "child invalid" is used. It refers to also other than mentally retarded children, as well as to children suffering from chronic illnesses.) As to the children living at home, the evaluation group has collected the information by means of a questionnaire enclosed as Appendix Nr 11 during visits to each home. As to the children living in institutions, the data have been collected by the staff of the particular institution. The information on the children at home and in institutions is partly incomparable, as the staff of the institutions has systematically estimated e.g. the children's level of development and independent initiave to be lower than the estimation given by the evaluation group of the project.

The need for services among those living at home has been estimated by a group consisting of the Russian specialist of the project, Medical Superintendent Anatoly Kushnariev, who during the second phase of the project was replaced by Senior Physician of the pediatric policlinic Ludmila Romanova, Finnish psychologist Jaana Saastamoinen and specially trained physioptherapist Helena Mikkonen as the Finnish specialist of the project, the director of care of the mentally handicapped Matti Huovinen.

The second phase of the project covered the training of the authorities responsible for handicapped children in the Segezha district at two seminars in Finland, as well as the training of the children's parents in Segezha. The goals, contents and participants of the training are discussed in chapter 11. In chapter 12, a general recommendation concerning the most urgent changes in the care of the mentally handicapped in the Segezha district is presented.



1.1. BASIS AND GOALS OF THE PROJECT

An agreement on the development of the health care and social services in the Republic of Carelia and the Segezha district was signed by the Ministry of Health of the Republic of Carelia, the Federation of Kainuu and the Intermunicipal Centre of Health Care and Social Services in Kainuu in 1994. The development of the services for the mentally handicapped was included in the agreement.

In the frame of the Tacis-Bistro Programme of the European Union, an agreement was concluded between the Delegation representing the EU in the Russian Federation and the Intermunicipal Centre of Health Care and Social Affairs in Kainuu (agreement Nr BIS/95/175/030) to carry out a study of the basic needs of the mentally handicapped children in the Segezha district. The agreement was dated in Moscow on the 20th of June, 1995.

The goal of the project is to contribute to the conditions of the mentally handicapped children in the Segezha district by means of studying their current situation and need for services and by training the authorities responsible for the above-mentioned services and the children's parents.

1.2. ORGANIZATION AND EXECUTION OF THE PROJECT

Mr Matti Nissinen has functioned as the project manager.

The project group has consisted of the director of care of the mentally handicapped Matti Huovinen as the group leader, the Medical Superintendent Anatoly Kushnariev 17 July – 19 September, 1995, and after his transfer to another position, the Senior Physician Ludmila Romanova 16 October – 17 December, 1995 and the interpreter Natalya Deryagina from Segezha. The chauffeur of the project has been Roman Gorbunov from Segezha.

The report has been drawn up by the leader of the project group Mr Matti Huovinen.



2. THE SEGEZHA DISTRICT

The area of the Republic of Carelia is 172 200 km².

The area of the Segezha district is 10 723 km² and the density of population is 5,3 inhabitants/km².

The stage of urbanization in the Segezha district is as high as 91,2 %.

In Carelia, there are seven cities subordinated to the Republic of which Segezha is the second largest after Petrozavodsk, the capital. Furthermore, there are six towns subordinated to the districts and four townships.

The Segezha district is, besides the city itself, divided into four other regions, as presented in table Nr 1. There are 22 villages in all, with the average distance from the city of Segezha approximately 60 km. As the table shows, there are 10 villages with less than 100 inhabitants. Several villages lack year-round inhabitants. The communications are presented in Appendix Nr 1.

1) TABLE 1
POPULATION FIGURE BY VILLAGE IN THE SEGEZHA DISTRICT 01.01.1994

REGION	Villages	Distance from the city	Number of population
1. UROSJĀRVI REGION	Popov-koski Bystrjagi Kärkjärvi Ramentsy Rukajärvi Sumerichi Taboi-koski Urosjärvi Jyrkin navolok	70 km 75 km 81 km 73 km 40 km 59 km	420 4 64 24 5 38 88 14 1 total 658
2. MUSTA-KOSKI REGION	Musta-koski Vacha Olenij Pertojärvi	80 km 110 km	649 165 297 312 total 1423
3. VALDAI REGION	Valdai Vozhmovuori Vozhmojärvi Polga	120 km 80 km	1704 248 125 389 total 2466
4. NADVOITSY REGION	Nadvoitsy Kochkoma Hirvikoski Nadvoitskylä Sumskoe Shavan 11. Laivasulku	25 km. 50 km	11400 222 41 95 4 5 36 total 11803
5. SEGEZHA REGION	Segezha Voldoj ärvi Maiguba		36900 296 1 total 37197
	Idel		819

Total in the Segezha district In the city and the township (Nadvoitsy) In the villages 54400 48300 6100

1) Source: The State statistical study 01.01.1994





3. POPULATION

3.1. Population changes and the age structure

The population of Carelia was at its largest in 1992, namely about 800 000. Since then the population figure has been declining, being 789 300 inhabitants on the 1st of January, 1995. The population of the Segezha district was largest in the years 1989-90 (56 600), but has been declining since then. In 1995, the population of the Segezha district numbered 54 400.

The population of Kainuu, Finland, has been steadily declining since the mid-seventies. At the end of 1994, it constituted approximately 95 800. By way of comparison, the population figures of Kainuu are included in the tables given below. The population changes are shown in table Nr 2.

1) TABLE 2 POPULATION

	1970	1990	1991	1992	1993	1994	1.1. 1995
Carelia	713 500	796 100	799 400	800 500	799 600	798 700	789 300
Segezha	-	56 600	56 300	56 100	55 800	55 800	54 400
Kainuu	100 899	96 957	96 689	96 507	96 298	95 814	-

The Kainuu figures on 31.12. and the Carelia figures on 1.1.

The changes in the age structure are presented in table Nr 3. In Carelia, the proportion of the inhabitants under 15 years of age is approximately five percentage units higher than in Kainuu. The proportion of inhabitants of working age has constituted about 58 % in both districts during the 1990's. The proportion of the oldest population (old age pension criteria of Carelia applied) is growing in both districts, but is some 4 % higher in Kainuu than in Carelia. The population figures in the Segezha district by village are shown in table Nr 1 and the number of children under 15 years of age in Appendix Nr 2.

1) TABLE 3 POPULATION CHANGES AND AGE STRUCTURE IN CARELIA, % OF THE POPULATION

0-15 yrs	1970	1980	1990	1992	1993	1994
Carelia	30,8	24,6	25,5	24,9	25,3	
Kainuu	31,5	23,8	21,0	20,3	20,1	19,8
2) 16-59 (54) yrs						
Carelia	58,1	62,3	58,2	57,9	58,0	
Kainuu	55,7	60,2	58,4	58,4	58,2	58,0
over 60 (55) yrs	·					
Carelia	11,1	13,1	16,3	17,2	16,7	
Kainuu	12,9	16,0	20,7	21,3	21,7	22,1

2) In Russia, the women's pensionable age is 55 years

1) Source: The Basic Figures of the Health Care in the Republic of Carelia 1970-1995

The Federation of Kainuu, vital statistics



3.2. INDUSTRIES AND SOCIO-ECONOMIC STATUS OF THE POPULATION

The volume of industrial production in Carelia is presented in table Nr 5. The index representing the total volume of production (in 1990 = 100) was 95 in 1991 and only 74 in 1995. The table shows a considerable decrease of production in all branches of industry, with the exception of the production of electricity.

1) TABLE 5

Index of the volume of industrial production in Carelia (1990 = 100)

	1991	1992
Electricity	104	112
Ferrous metal industry	93	85
Non-ferrous metal industries	87	86
Chemical industry	72	67
Machine construction	96	79
Woodworking and paper industries	98	77
Building materials	99	63
Textile and leather	100	75
Food industry	86	74
TOTAL	95	74

The structure of industry is shown in table Nr 5a. The most remarkable branch of industry in Carelia is wood processing, which constitutes over one third of the total industrial volume. The proportion of metal industry is less than 20 %, the proportion of food industry about 11 %. The largest production units are the Segezha pulp and paper mill and the Nadvoitsy aluminium plant.

1) TABLE 5a

STRUCTURE OF INDUSTRY IN CARELIA

Branches of industry		The consu	mer price index
	%		•
Food	11	1990	100
Energy	7, 8	1991	188,2
Other	2,5	1992	2810,3
Light industry	11,4	(More rece	nt figures not
Building materials	4,5	available.)	•
Woodworking, wood	·	,,	
processing, pulp and paper	39,9		
Machine construction	14,8		
Ferrous metals	13,2		
Non-ferrous metals	5,5		

1) Source: Figures p. 13



As table Nr 6 shows, the number of labour force has increased in one year (1994-1995) by almost 500. In the service sector, the increase is over 500 vacancies, all in state-owned enterprises.

At the same time, the number of people employed in other fields of production has decreased by appr. 200.

1) TABLE 6 LABOUR FORCE IN THE SEGEZHA DISTRICT

Labour force by branch of industry in the Segezha district in 1994-1995

1. Production	1994	1995
Manufacturing	9992	10128
Agriculture	539	548
Forestry	137	147
Public transport	1754	1785
Fishing	26	26
Construction	1494	1263
Trade, food, material technology etc.	2125	2065
Data processing	31	29
Geology and prospecting	103	82
TOTAL	16201	16043
Of the above-mentioned		
In state-own production	2862	2599
In other enterprises	13339	13474
2. Services		
Education, culture, art, science	2759	2827
Health care, social services	1675	1683
Municipal housing	1983	2378
State-owned insurance companies, pension		
funds	195	201
Organizations, courts of law etc.	621	650
Other organizations	1177	1230
TOTAL	8410	8969
Of the above-mentioned		
In state-own enterprises	7900	8466
In other enterprises	510	503
TOTAL	25046	25480

Source: Department of Employment, City of Segezha



The development of wages and salaries in Carelia in 1992-1995 is presented in table Nr 7 and the changes in prices of the most important food stuffs in 1993-1994 in table Nr 8. As table Nr 7 shows, the prices of such basic food stuffs as bread and potatoes has trebled in one year. In December, 1995 bread cost about 2900 roubles/kg and potatoes some 2500 rbl/kg. In other words, the prices of bread and potatoes have grown over tenfold in two years.

1) TABLE 7
DEVELOPMENT OF WAGES IN CARELIA AND THE SEGEZHA DISTRICT IN 1992-1995

Year	Minimum wage	Wage +	Average wage
01.01.199		northern bonus	
1992	342	410	533
1993	2250	2700	23192
1994	14620	17544	187269
1995	20500	26620	424389
July 1995	55000	71500	

Figures describing the general develoment of wages and salaries in Russia are presented in Appendix Nr 3.

2) TABLE 8
PRICES OF FOOD STUFFS/KG IN 1993-1994

PRODUCT	October 1993 Average price rbl/kg	October 1994 Agerage price rbl/kg
Bread	248	1338
Potatoes	249	672
Vegetables	510	1405
Fruit	581	2896
Meat and meat preparations	1936	4480
Milk and milk preparations	258	800
Fish and fish preparations	1180	3612
Eggs	382	1365

The consumption of food products per person in Carelia in 1994-1995 is shown in table 9. The decrease in purchasing power and the deterioration of the nutritional state is described by the fact that the consumption of the most basic food stuffs such as bread and potatoes has decreased most of all.

1) TABLE 9
CONSUMPTION OF FOOD STUFFS KG/PERSON IN CARELIA IN 1994–1995

PRODUCT	January 1994	July 1994	December 1995
Meat and meat preparations	50	77	54
Milk and milk preparations	360	557	205
Fish and fish preparations	67	91	67
Sugar	166	243	126
Potatoes	355	374	307
Vegetables	167	129	176
Fruit and berries	131	103	91
Bread and bakery products	251	361	199

Source: Labour force and Ministry of Labour, Republic of Carelia



4. HEALTH OF THE POPULATION

4.1. BIRTH RATE, MORTALITY AND LIFE EXPECTANCY

During 20 years, the birth rate in Carelia has decreased from approximately 16 live births per 1000 inhabitants (in 1970) to 8,6 per 1000 inhabitants (in 1994). The birth rate in the Segezha district has been somewhat higher than in the rest of Carelia during the late 70's, but has since been falling to the same level, as table Nr 10 shows.

1) TABLE 10

BIRTH RATE: LIVE BIRTHS/1000 INHABITANTS

	1970	1975	1980	1985	1990	1991
Carelia Segezha	15,9	17,4 20,9	16,6 17,1	17,1 -	13,2 13,6	11,2 · 10,6
	1992	1993	1994			
Carelia Segezha	10,0 10,6	8,8 9,2	8,6 8,7			

During the 70's, the mortality increased in Carelia from 7,5/1000 inhabitants to 10/1000 inhabitants, but stayed on the same level in the 80's, as shown in table Nr 11. During the 90's the mortality has increased in a most dramatic way. In 1994, it was 16,8/1000 inhabitants.

The mortality in Segezha followed the general figures in Carelia until the 90's, but since then it has increased even more than in the rest of Carelia. In 1994, the mortality in Segezha was 22,4/1000 inhabitants.

1) TABLE 11 MORTALITY/1000 INHABITANTS

	1970	1975	1980	1985	1990	1991
Carelia Segezha	7,5 -	8,3 8,8	10,0 10,2	10,7 -	10,1 10,1	10,3 10,4
	1992	1993	1994			
Carelia Segezha	12,3 13,6	14,8 16,5	16,8 22,4			

As shown in table Nr 12, the mortality of males was 4,5 percentage units larger than that of females in Carelia and 6,4 percentage units larger than that of females in Segezha in 1993.

1) TABLE 12 MORTALITY/1000 INHABITANTS/SEX IN 1993

	% males	% females
Carelia	17,1	12,6
Segezha	19,9	13,5

Source: The Basic Figures of Health Care



As shown in table Nr 13, over 1100 more males of working age died in Carelia in 1994 than in 1992 (44,6 %). In Segezha, the increase of mortality was as large as 92,4 %.

The amount of the deaths (male and female) of working age increased from 35,2 % to 45 % of the total mortality in Segezha in 1992-1994. The corresponding change in Carelia was only from 32,3 % to 34 %.

1) TABLE 13

MORTALITY OF POPULATION OF WORKING AGE/1000 INHABITANTS

	Males		Males Females		% of total mortality				
	1992	1993	1994	1992	1993	1994	1992	1993	1994
Carelia	2511	3379	3632	615	689	890	32,3	34,4	34,0
Segezha	224	369	431	43	7 9	122	35,2	48,4	45,0

The life expectancy of males born in 1989-1994 in Russia, and by way of comparison also in Finland, is shown in table Nr 14. In Russia, the decrease is 7 years, apparently the most remarkable change discovered anywhere. As concerns Carelia, there is no corresponding data available, but according to Nosova (Nosova et al. 1995), the life expectancy of males in Carelia was less than 55 years in 1993.

2) TABLE 14

LIFE EXPECTANCY OF MALES IN RUSSIA AND IN FINLAND IN 1989-1994

	1989	1990	1991	1992	1993	1994
Russia	64,0	63,8	63,5	62,0	58,9	57,3
Finland	70,1	70,9	71,3	71,7	72,0	72,9

1) Source: The Basic Figures of Health Care

2) Source: Helsingin Sanomat 5.8.1995



4.2. INFANT MORTALITY

The figures in table 15 include the live births of children who died during their first year. In Russia, the deaths that have taken place on the 28th week of pregnancy or later during the first year, are included in the infant mortality. In Finland, the deaths after the 22nd week of pregnancy are also included. This leads to a systematic error in the comparison of the infant mortality figures between the two countries.

It appears from table 15 that infant mortality in Carelia has been around 13 per 1000 live births during the 90's. Thus, it has been considerably lower than in the 70's and 80's. From the late 70's until the late 80's, the infant mortality in Segezha was over 20. In the beginning of the 90's, the infant mortality has distinctly deminished, while in 1993 it has risen up to as many as 27,4 per 1000.

1) TABLE 15
INFANT MORTALITY/1000 LIVE BIRTHS (0 DAYS - 1 YEAR)

	1970	1975	1980	1985	1989	1990
Carelia Segezha	26,1 34,2	20,8 15,6	21,0 19,2	19,2 13,2	12,8 20,5	13,5 18,0
	1991	1992	1993	1994		
Carelia Segezha	13,1 15,7	15,2 11,9	13,2 27,4	13,2 20,5		

The most common causes of death among infants are given in table Nr 16. Diseases of the newborn (such as prolonged hypoxy, congenital anomaly, malformations and intrauterine infections) have caused more than a half of the deaths. The anomalies constituted as much as 27,5 % of all deaths in 1992, but the figure has decreased to about a half (13,2 %) since then. These two groups of causes of death cover almost 2/3 of all infant deaths.

1) TABLE 16

CAUSES OF INFANT DEATHS IN CARELIA IN 1990-1994

	1980	1990	1991	1992	1993	1994
Diseases of respiratory organs	31,6	9,8	9,6	11,8	15.5	8,8
Pneumonia	12,1	5,9	4,8	5,2	6,3	6,6
Influenza	19,5	7,9	4,8	6,3	9,2	2,2
Anomalies	21,8	21,7	20,4	27,5	15,5	13,2
Children's diseases of						•
the newborn	21,5	50,6	47,2	42,5	44,3	51,5
Infections	10,5	5,3	3,2	1,6	3,0	2,2
Accidents, intoxication	6,6	5,9	4,0	5,5	5,2	7,7
Other	7,8	6,5	10,4	11,0	16,5	17,6

1) Source: The Basic Figures of Health Care



4.3. MORBIDITY OF THE POPULATION

The development of the morbidity of the population is presented in table Nr 17. The number of the cases of morbidity which have lead to seeing a doctor has been stable in Carelia. In Segezha, it has decreased by 16 %.

1) TABLE 17

MORBIDITY/1000 INHABITANTS

	1990	1991	1992	1993	1994
Carelia	1083,4	1093,8	1033,3	1037,6	1036,7
Segezha	1209,2	1198,6	1045,5	914,4	1028,2

As table Nr 18 shows, the morbidity of children has decreased 11 % in Carelia and 2,6 % in Segezha in the 90's. This kind of positive development is surprising in comparison with the other factors showing a remarkably poor development in the state of health of the population. The number of contacts with doctors has been stable, as presented in table Nr 19.

1) TABLE 18

MORBIDITY OF CHILDREN/1000 CHILDREN IN 1990-1994

	1991	1992	1993	1994
Carelia	1935,0	1809,9	1910,1	1760,5
Segezha	1751,7	1879,2	1775,3	1706,9

4.4. USE OF HEALTH CARE SERVICES

As shown in Appendix Nr 4, there are 30 physicians, 107 nurses and 125 hospital beds per 10 000 inhabitants in the Segezha district. The number of visits to the policlinics roughly describes the use of the health care services. Table 19 shows that the average number of visits to the policlinics has been 9 both in Segezha and in the rest of Carelia during the 90's. It can thus be concluded that the availability of health care services is fairly good and they are actively used in Carelia and in the Segezha district.

1) TABLE 19

VISITS TO POLICLINICS PER PERSON IN SEGEZHA AND CARELIA IN 1990–1994

	1990	1991	1992	1993	1994
Segezha	9,1	8,2	8,9	9,0	8,8
Carelia	9,8	9,3	9,2	8,9	8,8

Source: The Basic Figures of Health Care



5. RISK FACTORS

5.1. ALCOHOL

As a result of the mother's use of alcohol during pregnancy, the central nervous system of three children out of 1000 is damaged permanently in Finland and the rest of Western Europe. The risk of permanent damage depends on the quantity of alcohol consumed. The risk is highest during the 4th-9th weeks of pregnancy. In addition to the risk of permanent damage, the risk of miscarriage is doubled by the mother's abundant consumption of alcohol during pregnancy.

The disturbance in the child's development can vary a great deal. It may express itself either in the form of severe mental retardation or in the form of learning and concentration problems amongst otherwise normal children. Besides the direct damaging effect on the fetus, the abundant use of alcohol apparently has an indirect negative effect on the children's growth milieu and development. In Russia, 14,2 litres of pure alcohol was consumed per person in 1994, while the alcohol intake was 15,6 litres in Carelia in 1992 (Nosova et al. -95). Judgding from the alcohol psychoses, the consumption in Segezha has even been rising since.

The occurrence of alcoholism and alcohol psychoses per 1000 inhabitants is presented in table Nr 20. According to the statistics, the occurrence has decreased in Carelia by 6 %, but increased in Segezha by almost 21 %.

1) TABLE 20

ALCOHOLISM AND ALCOHOL PSYCHOSES/100 000 INHABITANTS IN 1993-1994 (Number of patients)

	1993	1994	Change, %
Carelia	240,0	225,8	- 5,8
Segezha	213,5	257,3	+ 20,6

5.2. MARRIAGES AND DIVORCES

The dissolution of families, together with the deterioration of the economic situation and abundant use of alcohol, constitute a considerable threat to the healthy development of the children. All the three factors are apparently in strong correlation with each other.

As shown in table Nr 21, the number of both marriages and divorces per 1000 inhabitants has been higher in Segezha than in the rest of Carelia since the early 80's. In Carelia, the number of marriages per 1000 inhabitants has declined by one third from 1980 (10,1) to 1992 (6,8). In Segezha, the corresponding decrease has been 30 % by the year 1994. In Carelia, the number of divorces has increased from 4,2/1000 inhabitants (1980) to 4,7/1000 inhabitants (1992). In Segezha, however, the number of divorces has decreased from 6,3/1000 inhabitants to 3,8/1000 inhabitants by 1990. Since, the number of divorces in Segezha has been rapidly increasing. In 1994, divorces were almost as common as marriages.



1) TABLE 21

MARRIAGES AND DIVORCES PER 1000 INHABITANTS IN CARELIA AND IN SEGEZHA IN 19701992

Marriages	1970	1980	1985	1990	1991
Carelia Segezha	10,1 -	9,9 10,5	9,1 9,9	8,3 8,8	6,8 9,7
	1992	1993	1994		
Carelia	_	_	_		
Segezha	7,5	7,4	7,4		
					•
Divorces	1970	1980	1985	1990	1991
Carelia	2,2	4,2	3,9	3,3	4,7
Segezha	-	6,3	5,0	3,8	5,5
,	1992	1993	1994		
Carelia	_	-	_		
Segezha	6,2	6,6	7,2	•	

MARRIAGES IN THE SEGEZHA DISTRICT IN 1991-1994

	1991	1992	1993	1994
In the cities	385	293	261	280
In the villages	163	129	155	131
Total	548	422	416	411

DIVORCES IN THE SEGEZHA DISTRICT IN 1991-1994

			1991	1992	1993	1994
In the cities	234		2 63	275	291	
In the villages	76	:	85	92	112	
Total			310	348	367	403

Source: The Basic Figures of Health Care



6. REGULATIONS OF THE CARE OF THE DISABLED IN CARELIA

6.1. ORDINANCE OF THE PRESIDENT

In Russia, there is no law concerning the care of the disabled. Instead, the Ordinance of the President Nr 1137 on the 2nd of October 1992, states several benefits. Thus, according to the ordinance, medicines dispensed on prescription are free of charge for all disabled children under 16 years of age. They have also been exempted from sanatorium fees.

The disabled children are entitled to free use of public transport with the exception of taxi, while their parents are entitled to a 50 % reduction of price.

The family of a disabled child is also entitled to a dwelling and a reduction of housing expenses. Aids and facilities, granted by the two institutions mentioned in the ordinance, are free of charge. However, their availability is very poor.

The basic and vocational training of the disabled as well as the tax concessions and pensionary benefits for single parents are also regulated by the Ordinance of the President. According to the ordinance, a disabled child is entitled to both a child benefit and a pension.

6.2. "THE CHILD OF CARELIA" PROGRAMME

On the basis of the federal "The Child of Russia" programme, the President of the Republic of Carelia has given an order to carry out the Child of Carelia programme in 1995–1997. The programme includes measures for the development of the care of the disabled and orphan children. The programme is to be executed by several ministries.

As to the disabled children, the programme includes a decision of founding a data bank for the care of the disabled. Moreover, new departments and classes are to be founded in boarding schools and institutions and temporary hospital beds (15-20) in sanatoria, theatre performances are to be arranged for the children. Consultation and rehabilitation methodics and a system of free transportations are to be developed.

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7. SERVICES FOR THE MENTALLY HANDICAPPED CHILDREN IN THE SEGEZHA DISTRICT

7.1. OPEN CARE SERVICES

The children are examined at the Segezha pediatric policlinic and by the psychological-medical-pedagogical commission, as described in chapter 8. The pediatric policlinic is responsible for the care of the mentally handicapped children until the age of 15.

The kindergarten Nr 4 is responsible for the preschool care and rehabilitation of (slightly) handicapped children in the city of Segezha. There are 38 children in the kindergarten, 18 of which are mentally retarded (Appendix Nr 15). A few handicapped children go to regular kindergartens. In the villages, the handicapped children most commonly go to regular kindergartens, in case they have managed to find a place in daycare at all. After the well-organized preschool care, the slightly retarded children especially are left to get tuition at home or without tuition at all. Classes at home or in institutions – two hours at the most – are given to some of the mentally retarded children, while most of them lack training of any kind. In the city of Segezha, there are no classes at schools for even the most slightly retarded children. However, there are special classes for other handicapped children, six in the city of Segezha and one in Idel. Besides handicapped children, these classes are also attended by children with a socially problematic background. From these classes a student can be transferred both to regular classes and to boarding schools. In Segezha, school Nr 2 has a class for only slightly handicapped children. The children are transferred to different classes by the psychological-medical-pedagogical commission. In Petrozavodsk, there are special diagnostic classes for children whose diagnosis and need for services are especially difficult to determine. The children stay in the diagnostic classes for 3-6 months, during which time the diagnosis is made and the need for services examined. No system with temporary or permanent care in foster families exists.

7.2. INSTITUTION AND BOARDING SCHOOL SERVICES

The network of institutions for the handicapped in Carelia is presented in table Nr 22. Segezha children have been placed in the Ladva children's institution south of Petrozavodsk (10), in the Petrozavodsk boarding school Nr 47 (7), in the Sosnovetsky boarding school Nr 20 and most of all in the Nadvoitsy boarding school Nr 14 (63). Moreover, there is a class for only slightly mentally handicapped children in the Kamennobor orphanage. Detailed information on the Ladva, Petrozavodsk 21 and Nadvoitsy boarding schools is presented in Appendices Nr 6-8. However, most of the students in the boarding schools (except for Ladva) are other than mentally retarded children.



TABLE 22

INSTITUTION	Address	Tel.	Director	Number of children
Kestenga boarding school Nr 11	Louhi district Kestenga village	2-65-94 2-65-92	Georgi Yakovlevich Ivendrik	59
2. Lahdenpohja boarding school Nr 12	Lahdenpohja district Ul.Onezhskogo flota 1 Lahdenpohja	2-26-81	Nina Ivanovna Kopusova	87
3. Nadvoitsy boarding school Nr 14	Segezha district Ul. Lenina 6 Nadvoitsy	3-85-46 3-81-06	Viktor Vasilyevich Vasyra	104
4. Derevyannaya boarding school Nr 16	Prionezhsky district Derevyannoe village	3-93-41	Nadezhda Nikolayevna Yakovleva	63
5. Povenets boarding school Nr 18	Karhumäki district Povenets	4-35-54 4-35-52	Vladimir Pavlovich Borshenkov	130
6. Karhumäki boarding school Nr 4	Karhumāki Ul. Dzerzhinskogo 20	2-23-51	Vladimir Borisovich Rosenfeld	74
7. Salmi boarding school Nr 19	Pitkäranta district Salmi village	2-52-69 2-52-65	Valentin Mihailovich Sheplyakov	90
8. Sosnovets boarding school Nr 20	Belomorsky district Sosnovets village	3-66-87	Valentina Nikolayevna Mesheryakova	68
9. Pudozh boarding school Nr 5	Pudozh Ul. Pionerskaya 69b	2-21-37	Anna Alexandrovna Naumova	112
10. Petrozavodsk boarding school Nr 47	Petrozavodsk UI. Segezhkaya 2	2–63–50 2–61–79	Vladimir Aleksevich Veremeichik	300
11. Petrozavodsk boarding school Nr 21	Petrozavodsk Ul. Scherbakova 21	5-71-19	Leonid Ivanovich Sergin	156
12. Ladva children's institution	Ladva Komsomolskaya 2	3-53-50 3-53-61	Dmitri Arkadevich Kirilchuk	

Source: Deputy Minister V.M. Sinitsina



8. DECISION-MAKING CONCERNING INDIVIDUAL HANDICAPPED PERSONS IN CARELIA

In Carelia, the psychological-medical-pedagogical commission plays a central role when decisions concerning handicapped children are made.

The psychological-medical-pedagogical council, subordinated to the Ministry of Health of the Republic of Carelia, gives an annual ordinance of the functions of separate psychological-medical-pedagogical commissions in various districts of the republic. The ordinance of the year 1994 is presented in Appendix Nr 9. On regional level, the composition and functions of the commission are determined by the director of adult education in the particular district. The decision for the Segezha district in 1994 is presented in Appendix Nr 10. In Segezha, the chairman of the is a children's psychiatrist. Of the seven members three are logopedists. The examination of the commission is preceded by a neurologist's, ophthalmologist's, otologist's and orthopedist's statement whether the child is deaf, blind, a CP child or mentally retarded. The commission must also have the psychiatrist's and the logopedist's reports at its disposal.

As a basis for decision-making, also children's drawings etc. in the kindergarten are used, as well as the staff's observations. The child's parents are obliged to participate in the work of the committee. The examination of the commission is repeated if need be.

As to especially complicated cases, the child can be sent to a so called diagnosis class in Petrozavodsk for additional examinations for 3-6 months.

The future placement, forms of training etc. are based on the examination of the commission.

9. PERFORMANCE OF THE EXAMINATION

The information on the children and their families was collected by means of a questionnaire, presented in Appendix Nr 11. A group consisting of a Russian and a Finnish specialist, an interpreter and a Russian-speaking Finnish psychologist payed a visit to all children registered at the central pediatcic policlinic as mentally retarded.

Each examination took approximately 45 minutes. It was not possible to carry out actual psychological tests, but the psychologis's evaluation was based on a conversation with the children and the parents, on plays, games and drawings. The physiotherapist carried out a regular basic examination. The physician's evaluation on the cause and diagnosis of the handicap was based on documents and a discussion with the parents.

Corresponding data were collected also on the 10 Segezha children living in the Ladva children's institution and the 64 children living in the Nadvoitsy boarding school. As concerns the last-mentioned children, the information was gathered by the staff of the institution. The staff have systematically estimated the children's level of development and independent initiave to be lower than the evaluation group which visited the homes. The observation is based on both an evaluation of the children in the institutions "by eye" and the actual examination of a few of them, also evaluated by the staff.



10. MENTALLY HANDICAPPED CHILDREN IN THE SEGEZHA DISTRICT

10.1. CHILDREN LIVING AT HOME

To begin with, the Segezha central pediatric policlinic had registered 154 handicapped children under 16 years of age, 17 of which were placed in institutions. Of them, 67 were registered as mentally retarded, with 10 living in institutions (at Ladva).

Prior to the examination of the children living at home, four children were found to be dead and three children to be of normal intelligence. Four children were not found due to false address. Five families would not let the examination group in the house. Four children proved to be older than 15 years of age.

Actually, 42 children were examined. Applying Finnish criteria, 34 proved to be mentally retarded or with a slight mental handicap. While this report was already being written, one very severely retarded and motion-handicapped boy was found, who is not included in the following figures. When the 5 verified mentally retarded children placed in institutions are taken into account, the occurrence of either slight or more serious mental handicap appears to be roughly 0,72 children under 16 years of age per 1000 inhabitants. The corresponding figure (children under 18 years of age) in, for example, Kainuu is 0,96 (The Mentally Handicapped in Kainuu in 1993). Supposed all the children who could not be reached actually also are mentally retarded or with a slight mental handicap, the Segezha and Kainuu figures are approximately the same.

Evaluated by means of other variables, the relative amount of the mentally handicapped in the Segezha district should be at least as large as in Kainuu. The surprising result might be explained by the fact that the higher infant mortality in Segezha is especially high amongst handicapped children. Another explanation could be the fact that in Kainuu, thanks to the longer practice, the information available on the mentally handicapped is more extensive and exact than in Segezha.

All children found out to be of normal intelligence during the project were living in the city of Segezha. In the villages, there were five mentally retarded children in all. The total number of the children is presented in table Nr 23, by villages in table Nr 24. The children living at home had a surprising minor handicap. No severely retarded children were found; one child with a serious mental handicap was found. As to the mentally handicapped children (0-17 years) living at home in Kainuu, 8 of them are severely or seriously retarded. In Segezha, the group of youngest children (0-6 years) consisted of 5 children only.



TABLE 23

LEVEL OF DEVELOPMENT AND AGE, THE SEGEZHA DISTRICT, TOTAL

Age	Normal	Slight mental handicap	Minor mental handicap	Medium mental handicap	Major mental handicap	Total
0-6 yrs	2	0	2	1	0	5
7–9 yrs	2	2	5	2	0	11
10-15 yrs	4	6	9	6	1	26
Total	8	8	16	9	1	42

TABLE 23a)

SEX AND LEVEL OF DEVELOPMENT, THE SEGEZHA DISTRICT, TOTAL

LEVEL	Girls	Boys	Total	
Normal	2	6	8	
Slight mental handicap	2	6	8	
Minor mental handicap	5	11	16	
Medium mental handicap	4	5	9	
Serious mental handicap	1	_	1	
Severe mental handicap	-	-	_	
Total	14	28	42	
Of which mentally handicapped	12	22	34	\neg



TABLE 24

LEVEL OF DEVELOPMENT AND AGE BY TOWN/VILLAGE

THE SEGEZHA DISTRICT

Age	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
0-6 yrs	2	0	1	1	0	4
7–9 yrs	2	2	3	1	0	8
10-15 yrs	4	2	8	5	1	20
Total	8	4	12	7	1	32

NADVOITSY

Age	Slight handicap	Minor handicap	Medium handicap	Total
7–9 yrs	0	1	1	2
10-15 yrs .	1	0	0	1
Total	1	1	1	3

VALDAI

Age	Slight handicap	Minor handicap	Medium handicap	Total
0-6 yrs	0	1	0	1
7-9 yrs	0	1	0	1
10-15 yrs	2	0	1	3
Total	2	2	1	5

OLENIJ

Age	Slight handicap	Total
10-15 yrs	1	1
Total	1	1

POPOV-POROG

Age	Minor handicap	Total
10–15 yrs	1	1
Total	1	1



10.1.2. LEVEL OF DEVELOPMENT AND FUNCTIONAL HANDICAP

In this report, functional handicap is considered to consist of deficiencies in independent initiative, communication and motion. As to indicators of independent initiative, the most difficult of them, washing oneself, was chosen. As table 25 shows, of the 42 children 28 manages to wash themselves, 9 needs help and 5 were totally dependent on other people. The last-mentioned all live in the city of Segezha. Of them, two are motion-handicapped children of normal intelligence and two have a major mental handicap. In the light of these figures, the independent initiative of the mentally handicapped in the Segezha district is fairly good.

TABLE 25

LEVEL OF DEVELOPMENT

Town/village	Washing	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	Manages alone	0	1	1	0	0	2
	Needs help	0	0	0	1	0	1
Olenij	Manages alone	0	1	0	0	0	1
Popov-Porog	Needs help	0	0	1	0	0	1
Segezha	Manages alone	6	2	11	3 :	0	22
	Needs help	0	2	1	2	0	5
	Totally dependent on other people	2	0	0	2	1	5
Valdai	Manages alone	0	2	1	0	0	3
	Needs help	0	0	1	1	0	2
Total		8	8	16	9	1	42



25

While the communication ability of the children was being examined, minor errors in pronunciation or other minor deficiencies were not taken into consideration. Of the examined children, 27 had normal or almost normal communication ability. 11 children had problems with their communication and 4 children lacked the ability to communicate altogether. The last-mentioned had a medium or major mental handicap. In general, the children's communication abilities were relatively good.

TABLE 26

LEVEL OF DEVELOPMENT

Town/village	Communi- cation ability	Normal	Slight handicap	Minor handicap	Medium handicap	Major hancicap	Total
Nadvoitsy	Normal	0	1	1	0	0	2
	Problems	0	0	0	1	0	1
Olenij	Normal	0	1	0	0	0	1
Popov-Porog	Problems	0	0	1	0	0	1
Segezha	Normal	8	2	11	1	0	22
	Problems	0	2	1	3	0	6
	Not able to communi-cate	0	0	0	3	1	4
Valdai	Normal	0	2	0	0	0	2
	Problems	0	0	2	1	0	3
Total		8	8	16	9	1	42



As shown in table 27, of the examined children 26 had normal capability of moving. Three had a medium and two a major motion handicap. Of the last-mentioned, one was of normal intelligence and the other severely retarded. The moving capabilities of the examined children were good and had little or no correlation on the degree of the mental handicap. The level of development and sensory handicaps are discussed in Appendix Nr 13.

TABLE 27

LEVEL OF DEVELOPMENT

Town/ village	Motion handicap	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	Normal	0	1	1	1	0	3
Olenij	Normal	0	1	0	0	0	1
Popov- Porog	Normal .	0	0	1	0	0	1
Segezha	Normal	3	3	11	3	0	20
	Minor	3	0	1	4	0	8
	Medium	1	1	0	0	0	2
	Major	1	0	0	0	1	2
Valdai	Normal	0	2	1	1	0	4
	Medium	0	0	1	0	0	1
Total		8	8	16	9	1	42



10.1.3. INTERDEPENDENCE OF FUNCTIONAL HANDICAPS

In tables 28-30, the interdependence of communication, motion handicaps and orientation in familiar surroundings are studied.

Table 28 shows that 21 children, in other words, every other child, had normal communication and capability of moving. Two children lacked communication and, moreover, had a severe motion handicap. One child lacked communication, but had normal capability of moving. Two lacked communication, but had only a minor motion handicap. Two had normal communication, but had a medium motion handicap.

TABLE 28

COMMUNICATION AND MOTION HANDICAP

COMMUNICATION

Town/village	Motion handicap	Normal	Problems	No communication	Total
Nadvoitsy	Normal	2	1	0	3
Olenij	Normal	1	0	0	1
Popov-Porog	Normal	0	1	0	1
Segezha	Normal	16	3	1 .	20
	Minor	4	2	2	8
	Medium	1	1	0	2
	Major	1	0	1	2
Valdai	Normal	2	2	0	4
	Medium	0	1	0	1
Total		27	11	4	42



As presented in table Nr 29, 22 children had normal orientation and capability of moving. Two children were totally dependent on other people in both aspects. Three children had normal orientation but a medium (2) or major (1) motion handicap. As to orientation, two children were totally dependent on other people, while their motion abilities were normal.

TABLE 29
ORIENTATION AND CAPABILITY OF MOVING

ORIENTATION

Town/village	Motion handicap	Manages alone	Needs help	Dependent on other people	Total		
Nadvoitsy	Normal	2	1	0	3		
Olenij	Normal	1	0	0	1		
Popov-Porog	Normal	0	1	0	1		
Segezha	Normal	16	2	2	20		
	Minor	5	2	1	8		
	Medium	2	0	0	2		
	Major	1	0	1	2		
Valdai	Normal	3	1	0	4		
	Medium	1	0	0	1		
Total		31	7	4	42		



Table 30 shows that 25 children were able to orientate well in familiar surroundings and also had normal communication abilities. As to orientation, three children were totally dependent on other people and also totally lacked communication. Four children needed help in orientation and also had problems with communication. Six children had problems with orientation but had normal communication abilities.

As a conclusion, tables 28-30 show that of the 42 children 21-25 are functionally normal and do not need any special rehabilitation.

TABLE 30
ORIENTATION AND COMMUNICATION

ORIENTATION

Town/village	Communication	Manages alone	Needs help	Dependent on other people	Total
Nadvoitsy	Normal	1	1	0	2
	Problems	1	0	0	1
Olenij	Normai	1	0	0	1
Popov-Porog	Problems	0	1	0	1
Segezha	Normal	21	1	0	22
	Problems	3	2	1	6
	No communication	0	1	3	4
Valdai	Normal	2	0	0	2
	Problems	2	1	0	3
Total		31	7	4	42



10.1.4. LEVEL OF DEVELOPMENT, AGE AND RECEIVED SERVICES

Table 31 shows that 5 children of normal intelligence, 4 children with a slight mental handicap and 8 children with a minor mental handicap saw a doctor not less than two times annually. Instead, of the children with a medium handicap 6 only saw a doctor once a year, while the one child with a major mental handicap had no regular doctors' services. Thus, contacts with doctors were clearly concentrated in the group of normal children and the children with only a minor mental handicap.

TABLE 31

LEVEL OF DEVELOPMENT AND CONTACTS WITH DOCTORS

LEVEL OF DEVELOPMENT

Town/ village	Visits to a doctor	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	Once a year	1	0	0	0	0	1
	Twice a year	0	1	1	0	0	2
Olenij	When necessary	1	0	0	0	0	1
Popov- Porog	When necessary	0	0	1	0	0	1
Segezha	Once- twice/month	1	0	5	1	0	7
	Once a year	0	3	1	1	0	5
	Twice a year	2	4	4	5	0	15
	When necessary	1	0	1	1	0	3
	No doctors' services	0	0	1	0	1	3
Valdai	Once a month	1	0	0	0	0	1
	When necessary	1	1	2	0	0	4
Total		8	9	16	8	1	42



Table 32 shows that 5 children over 10 years of age saw a doctor once a month and 10 children over 10 years of age twice a year. Although some appointments only include a renewal of a prescription, the number of doctor's appointments is large. Unexpectedly, most appointments are with oldest group of children.

TABLE 32

AGE AND CONTACTS WITH DOCTORS

AGE

No.						
Town/village	Contacts with doctors	5-6 yrs	7–9 yrs	10-15 yrs	Total	
Nadvoitsy	Twice a year	0	2	0	2	
	At school	0	0	1	1	
Olenij	When necessary	0	0	1	1	
Popov-Porog	When necessary	0	0	1	1	
Segezha	Once-twice a month	1	2	4	7	
	Once a year	0	3	3	6	
	Twice a year	3	1	10	14	
	When necessary	0	2	3	5	
Valdai	Once a month	0	0	1	1	
	When necessary	1	1	2	4	
Total		5	11	26	42	

In general, the contacts with doctors are concentrated on the group of children of normal intelligence or a minor mental handicap, and at the same time, on the oldest children.



22

Table 33 shows that only two children were seeing a logopedist. 13 children needed speech therapy but did not get it. Of them two have a slight mental handicap, seven a minor and four a medium handicap. Seven of the children live in the city of Segezha. In spite of the large number of logopedists, the need for speech therapy is poorly met.

TABLE 33
LEVEL OF DEVELOPMENT AND SPEECH THERAPY

LEVEL OF DEVELOPMENT

Town/ village	Speech therapy	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	Needs but does not get	0	0	1	1	0	2
	Does not need	0	1	0	0	0	1
Olenij	Does not need	0	1	0	0	0	1
Popov- Porog	Needs but does not get	0	0	1	0	0	1
Segezha	Yes	1	0	1	0	0	2
	Needs but does not get	0	2	3	2	0	7
	Does not need	7	2	8	5	1	23
Valdai	Needs but does not get	0	0	2	1	0	3
	Does not need	0	2	0	0	0	2
Total		8	8	16	9	1	42



Table 34 shows that six children were getting physiotherapy. Ten children were in need of physiotherapy but did not get it. All of them live in the city of Segezha. Of them 4 are of normal intelligence. In general, the need for physiotherapy was unexpectedly little.

TABLE 34

LEVEL OF DEVELOPMENT AND PHYSIOTHERAPY

LEVEL OF DEVELOPMENT

Town/ village	Physio- therapy	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	Does not need	0	1	1	1	0	3
Olenij	Does not need	0	1	0	0	0	1
Popov- Porog	Does not need	0	0	1	.0	0	1
Segezha	Yes	1	1	1	1	0	4
	Needs but does not get	4	1	4	0	1	10
	Does not need	3	2	7	. 6	0	18
Valdai	Yes	0	1	1	0	0	2
	Does not need	0	1	1	1	0	3
Total		8	8	16	9	1	42



10.1.5. INTERDEPENDENCE OF RECEIVED SERVICES

In this chapter, the interdependence of the services received by the children is studied. Table Nr 35 shows that of the ten children who did not get physiotherapy in spite of their need for it, only two also lacked speech therapy in spite of their need for it. Thus, as to the examined children, there is hardly any interdependence with physiotherapy and speech therapy.

TABLE 35

NEED AND AVAILABILITY OF PHYSIOTHERAPY AND SPEECH THERAPY

PHYSIOTHERAPY

Town/village	Speech therapy	Yes	Needs but does not get	Does not need	Total
Nadvoitsy	Needs but does not get	0	0	2	2
	Does not need	0	0	1	1
Olenij	Does not need	0	0	1	1
Popov-Porog	Needs but does not get	0	0	1 [1
Segezha	Yes	0	0	2	2
	Needs but does not get	1	2	4	7
	Does not need	3	7	13	23
Valdai	Needs but does not get	1	0	2	3
	Does not need	1	0	1	2
Total		6	10	26	42

As a conclusion, hardly any of the children which needed speech therapy did get it; two thirds of the children which needed physiotherapy did not get it.



35

In tables 36 and 37 need for speech therapy and physiotherapy and use of doctors' services are studied. Table 36 shows that of the 13 children which do not get speech therapy in spite of their need for it, 7 do see a doctor at least once a year.

TABLE 36 SPEECH THERAPY AND CONTACTS WITH DOCTORS

SPEECH THERAPY

Town/village	Contacts with doctors	Yes	Needs but does not get	Does not need	Total
Nadvoitsy	Once a year	0	0	1	1
	Twice a year	0	2	0	2
Olenij	When necessary	0	0	1	1
Popov-Porog	When necessary	0	1	0	1 '
Segezha	Once-twice a month	1	0	6	7
	Once a year	0	2	4	6
	Twice a year	1	3	10	14
	No contacts with doctors	0	0	2	2
	When necessary	0	2	1	3
Valdai	Once a month	0	0	1	1
	When necessary	0	3	1	4
Total		2	13	27	42

Table 37 shows that of the ten children which do not get physiotherapy in spite of their need for it, seven do get to see a doctor at least once a year.

TABLE 37 PHYSIOTHERAPY AND CONTACTS WITH DOCTORS

PHYSIOTHERAPY

Contacts with doctors	Yes	Needs but does not get	Does not need	Total
At least once a month	0	2	6	8
Once a year	0	3	4	7
Twice a year	4	2	10	16
When necessary or no contacts	2	3	6	11
Total	6	10	26	42



10.2. TUITION OF MENTALLY HANDICAPPED CHILDREN

10.2.1. AVAILABILITY OF TUTTION

Amongst the services for the mentally handicapped children living at home in the Segezha district, tuition is the most deficient. Therefore, it is studied separately. It is assumed that all the children living at home do need the services of either a school or day care. Of the 42 examined children 21 – exactly a half – lack all training or tuition whatsoever. Of the mentally handicapped 18 (70%) did not get any kind of tuition and 5 children were given tuition at home. In other words, 23 mentally handicapped children (88 %) were not given tuition in school classes.

Of the 23 children with a slight mental handicap, 3 lacked tuition altogether and 1 child was given lessons at home. Thus, a half of the children with a slight mental handicap were not given tuition in school classes. Of the children with a minor or medium handicap 79 % were not given tuition in school classes. All in all, only 15 children out of 42 (35 %) were given tuition outside their homes. The availability of educational services is shown below, and by the level of development and villages in table Nr 38.

TUITION CURRENTLY GIVEN TO THE HANDICAPPED CHILDREN IN THE SEGEZHA DISTRICT

Examined 42

Of them:

Minor or more serious mental handicap	Slight mental handicap	Normal
26	8	8
No tuition	No tuition	In kindergarten
18	3	3
Tuition at home	Tuition at home	Tuition at home
5	1	2
In kindergarten	In school	In school
1	3	3
In special school	In special school	
2	1	



Table 38 shows that of the children with a slight mental handicap 3 do not get tuition and of the children with a minor mental handicap 10 (63 %) lack tuition. 7 (77 %) of the children with a medium handicap lack tuition.

TABLE 38

LEVEL OF DEVELOPMENT

Town/ village	Tuition	Normal	Slight handicap	Minor handicap	Medium handicap	Major handicap	Total
Nadvoitsy	In special school	0	1	0	0	0	1
·	At home	0	0	0	1	0	1
	No tuition	0	0	1	0	0	1
Olenij	No tuition	0	1	0	0	0	1
Popov- Porog	No tuition	0	0	1	0	0	1
Segezha	In school	3	1	0	0	0	4
	In special school	0	0	1	1	0	2
	In kindergarten	3	0	1	0	0	4
	At home	2	1	4	0	0	7
	No tuition	0	2	6	6	1	15
Valdai	In school	0	2	0	0	0	2
	No tuition	0	0	2	1	0	3
Total		8	8	16	9	1	42



10.2.2. INTERDEPENDENCE OF TUITION AND OTHER SERVICES

In tables Nr 39-41, the interdependence of tuition and other services is discussed. Table Nr 39 shows that of the 21 children which do not get tuition, 11 also lack speech therapy in spite of their need for it. Moreover, one child getting tuition at home and one in a kindergarten do not get speech therapy in spite of their need for it. Table 40 shows that four children lacking tuition also lack physiotherapy in spite of their need for it. Moreover, two children at school do not get physiotherapy in spite of their need for it. Judgding by the information given in tables Nr 39 and 40, the lack of tuition often leads to a lack of rehabilitation services as well.

Table Nr 41 shows that almost all children getting tuition and a half of the children not getting it are seeing a doctor at least once a year. Compared with other services, the use of doctors' services amongst the handicapped children in the Segezha district is active.

TABLE 39
TUITION AND NEED FOR SPEECH THERAPY

TUITION

Town/ village	Physio- therapy	In school	In special school	In kinder- garten	At home	No tuition	Total
Nadvoitsy	Needs but does not get	0	0	0	1	1	2
	Does not need	0	1	0 0		0	1
Olenij	Does not need	0	0	0	0	1	1
Popov- Porog	Needs but does not get	0	0	0	0	1	1
Segezha	Yes	0	1	1	0	0	2
	Needs but does not get	0	0	1	0	6	7
	Does not need	4	1	2	7	9	23
Valdai	Needs but does not get	0	0	0	0	3	3
·	Does not need	2	0	0	0	0	2
Total		6	3	4	8	21	42



39

TABLE 40
TUITION AND NEED FOR PHYSIOTHERAPY

TUITION

Town/ village	Speech therapy	In school In special In school kindergarten		At home	No tuition	Total		
Nadvoitsy	Does not need	0	1	0	1	1 1		
Olenij	Does not need	0	0	0	0	1	1	
Popov-Porog	Does not need	Oces not need 0 0 0		0	1	1		
Segezha	Yes	1	1	2	0	0	4	
	Needs but does not get	2	1	0	3	4	10	
	Does not need	1	0	2	4	11	18	
Valdai	Yes	1	0	0	0	1	2	
	Does not need	1	0	0	0	2	3	
Total		6	3	4	8	21	42	

TABLE 41
TUITION AND USE OF DOCTORS' SERVICES

TUITION

Town/ village	Contacts with doctors	In school	In special school	In kindergarten	At home	No tuition	Total
Nadvoitsy	Once a year	0	0	0	1	1	2
	Twice a year	0	1	0	0	0	1
Olenij	When necessary	0	0	0	0	1	1
Popov-Porog	When necessary	0	0	0	0	1	1
Segezha	Once-twice a month	0	1	1	4	1	7
	Once a year	2	0	0	0	4	6
	Twice a year	2	1	3	2	6	14
	No contacts	0	0	0	0	2	2
_	When necessary	0	0	0	1	2	2
Valdai	Once a month	1	0	0	0	0	1
	When necessary	1	0	0	0	3	4
Total		6	3	4	8	21	42



10.3. FORM OF FAMILY AND PARENTS' WORK OUTSIDE THE HOME

Table 42 shows that in 29 cases (69 %) both parents lived in the family. In seven cases the father and in two cases neither parent lived at home (grandmother was taking care of the children).

TABLE 42

STRUCTURE OF FAMILY

MOTHER

FATHER	Lives in the family	Does not live in the family	Total		
Lives in the family	29	0	29		
Does not live in the family	7	2	9		
Dead	4	0	4		
Total	40	2	42		

Table Nr 43 shows that 26 fathers (62 %) live in the family and work outside the home. Five fathers do not live at home, neither do they work, or information is missing. Three fathers live in the family but do not work outside the home.

TABLE 43

FATHER'S DWELLING AND WORK

FATHER

FATHER	Lives in the family	Does not live in the family	Dead	Total
			4	4
Works outside the home	26	4	0	30
Does not work	3	1	0	4
Information missing	0	4	0	4
Total	29	9	4	42

Table 44 shows that of the mothers 22 (52 %) work outside the home, and with the exception of two mothers, all live in the family.

TABLE 44

MOTHER'S DWELLING AND WORK

MOTHER

MOTHER	Lives in the family	Does not live in the family	Total
Works outside the home	22	0	22
Does not work	18	2	20
Total	40	2	42



AT

10.4. HOUSING CONDITIONS OF THE FAMILIES

The average housing density in the families which were examined was 1,8 persons per room. As shown in table 45, the smallest number of people per dwelling was two and the largest eight persons. In the most crowded dwelling (1), the family had one room for four people and in the least crowded (1) five rooms for four people.

TABLE 45
HOUSING DENSITY

NUMBER OF PERSONS

NUMBER OF ROOMS	2	3	4	5	6	7	8	Total
1	1	4	2	2 0		0 0		7
2	2	4	3	5	1	0	0	15
3	0	2	6	3	4	0	0	15
4	0	0	1	0	0	1	1	3
5	0	0	1	0	0	1	0	2
Total	3	10	13	8	5	2	1	42



Table Nr 46 shows that a little over a half (24) of the families lived in blocks of flats. "Other building" means either a two-storied wooden house where a few families have a flat or a one-family house. Most of the last-mentioned are located in the villages. Nine motion-handicapped children live in blocks of flats, two of them on the first floor.

One block of flats has a lift. Ten dwellings lack piped water installation, three of them in the city of Segezha. Nine dwellings lack a shower or a sauna bath. Of them, eight are situated in the city of Segezha. The houses in the villages usually have a sauna bath, even when there is no water pipe.

TABLE 46

TYPE OF DWELLING AND MOTION HANDICAP

TYPE OF DWELLING

Motion handicap	Block of flats	Other building	Communal dwelling	Total
Normal	15	13	1	29
Minor	6	2	0	28
Medium	1	2	0	3
Major	2	0	0	2
Total	24	· 17	1	42



10.5. HANDICAPPED CHILDREN OUTSIDE THE HOME

As an example, table 46 presents information on the children placed in the Ladva children's institution and Nadvoitsy boarding school Nr 14. Located about 70 km south—west of Petrozavodsk, Ladva is an institution for mentally handicapped children with 450 places. The Nadvoitsy boarding school Nr 14 with 100 places is situated 20 km north of the city of Segezha. Finnish criteria applied, Nadvoitsy is an institution for children with only a slight mental handicap. Detailed information on both institutions is presented in Appendices Nr 6 and 8.

According to the information given by the Segezha pediatric policlinic, five out of the ten children in the Ladva institution are actually mentally handicapped. Due to the deteriorated economic and social situation, also other normal children which lack care have been placed in such institutions. One of the children from the Segezha district has been living in the Ladva institution for over ten years. The others have arrived during the 90's.

In Carelia, a child usually stays in the institution permanently after having been placed there. According to the staff, all the ten children will be living in institutions also in the future. Six children out of ten have never been visited by family, neither have they visited their homes. 3/4 of the children in the Ladva institution goes home for the week-ends and holidays. A few children from the Segezha district may be living in other institutions, but the local authorities have no information on them.

HANDICAPPED CHILDREN OF THE SEGEZHA DISTRICT PLACED IN INSTITUTIONS

	5-6 yrs	5–6 yrs	7–9 yrs	7-9 yrs	10-15 yrs	10-15 yrs	Total
	Boys	Girls	Boys	Girls	Boys	Girls	
Ladva	2	0	0	1	4	3	10
Nadvoitsy	_	_	2	4	32	26	64



11. TRAINING GIVEN DURING THE PROJECT

11.1. TRAINING OF SPECIALISTS

The training for the specialists working with the mentally handicapped children in the Segezha district was organized by means of two seminars 9.10.-12.10.1995 and 21.11.-24.11.1995 in Kajaani, Finland. The first seminar was meant for physicians participating in the examinations and rehabilitation of handicapped children. The second seminar was arranged for teachers and therapists working with mentally hancicapped children. The programmes and lists of participants are enclosed as Appendices Nr 13-16.

The seminar of the physicians was divided into four themes, each of which was dealt with on one day. By the end of the first day, the participants had an overall picture of the services given to mentally handicapped children in Finland. They also were familiar with the most important causes of mental handicaps and with the principles of medical diagnostics and multiprofessional teamwork used in the research and rehabilitation of mentally handicapped children. Moreover, they were given detailed information on physiotherapeutic examinations and rehabilition and on the tasks of special nursing in the field.

As a result of the second day, the participants were familiar with the principles of psychological and pedagogical research and rehabilitation as well as with the principles of guidance given to the parents. The participants also visited the children's neurological policlinic and the children's ward of the Kainuu central hospital.

At the end of the third day, the participants were familiar with the principles of tuition given to children with both a minor and more serious mental handicap. They also visited a school for children with a serious mental handicap.

As a result of the fourth day, the participants are familiar with the main principles of the services and benefits offered to the mentally handicapped children by the Finnish social service system. They also have an overall picture of the developments in the institutional care of the mentally handicapped in Finland and other Nordic countries.



The second seminar arranged for teachers and therapists consisted of four themes, each of which was dealt with on one day.

By the end of the first day the participants had an overall picture of the services given to the mentally handicapped in Finland and of the main principles of the care of the mentally handicapped. They also were familiar with the principles of psychological and pedagogical research and rehabilitation and the multiprofessional cooperation, which plays a most important role in the work with the mentally handicapped. The participants also visited the policlinic of the Kainuu central institution.

As a result of the second day, the participants were familiar with the principles of tuition given to the mentally hancicapped children with both a minor or a more serious handicap. They also visited a school for children with a minor handicap, located in a regular comprehensive school.

By the end of the third day, the participants were familiar with the principles of physiotherapeutic examination and rehabilitation and the significance of the most important aids and instruments. Moreover, they are familiar with the services given to the handicapped children by the Finnish social service system. They had an overall picture of institutional care of the mentally handicapped and the decentralization of such institutions in Finland and other Nordic countries. The participants also visited a school for handicapped children with a medium or major handicap.

As a result of the fourth day, the participants are familiar with the significance of communication in the life and rehabilitation of the mentally handicapped. They know the principles of the research of communication problems and rehabilitation and alternative means of communication. The participants also visited a family guidance centre.



11.2. TRAINING OF PARENTS

A one-day training was arranged for the parents of the handicapped children in the Segezha district on the 2nd of December 1995 at the Cultural centre of Segezha. The programme is enclosed as Appendix Nr 17.

Some 70 parents and officials responsible for handicapped children participated. The training had three goals, the first of which was to study the results and conclusions of the TACIS-BISTRO project from the viewpoint of the children's families. The second goal was to try to contribute to the rehabilitation centre which will begin its work in the near future and to give the parents an opportunity to present their requests as to the development of the services. The third goal was to support and encourage the work of the parents' association in the Segezha district. All the three goals were carried out fairly well.



12. PLAN FOR NEW SERVICES FOR THE MENTALLY HANDICAPPED CHILDREN IN THE SEGEZHA DISTRICT

12.1. THE MENTALLY HANDICAPPED CHILDREN IN NEED OF NEW SERVICES IN THE SEGEZHA DISTRICT

The figures given below are based on the interviews and examinations carried out during the visits to the homes of the mentally handicapped children. They have been given applying the <u>Finnish criteria</u>. Whether the <u>resources</u> do or do not exist at the moment, has <u>not been taken into consideration</u>. The figures only include the children which <u>do not currently receive the particular service</u>.

Three mentally handicapped children in the city of Segezha and two children in the countryside need a place in a kindergarten. Tuition given in schools is needed by 7 children in the city of Segezha, 1 in Nadvoitsy and 1 in Valdai.

The number of mentally handicapped children in the Segezha district is ideal for a special class for children with a slight or minor mental handicap to be founded in one of the schools of Segezha.

13 mentally handicapped children will be needing the services of the rehabilitation centre to be opened in the near future. Of them, 5 would mostly need meaningful activities during the day and 3 actual tuition. As to the rest of them, they should participate both in the activities and tuition.

Four children living in the villages need regular tuition at home.

13 children need speech therapy, 10 children physiotherapy. Here, only the children with serious problems are included.



The current plan contains recommendations on how to organize the services for the mentally handicapped children in the Segezha district. Only the proposals for the most important renewals were included. They have not been put in order of importance or urgency.

12.2. TRAINING IN THE REHABILITATION CENTRE

While the care and rehabilitation of the young children in the kindergartens are well-organized, the children of school age have been left without services, tuition and rehabilitation.

The Segezha Rehabilitation centre currently under construction will constitute an essential improvement in the training of the mentally handicapped children with a medium or major handicap. To give training and tuition for the mentally handicapped children, two groups should be founded in the centre, with altogether 15 places. The first group should have 7–8 places for the children with the most serious handicap. Their training would mainly cover learning the basic skills of independent initiative and functioning in a group. Rehabilitation, based on the indidividual needs of each child (for example, speech therapy and physiotherapy), should also be included in the programme.

The second group would mainly consist of the mentally handicapped children with a medium handicap. Moreover, some of the children with a minor handicap would participate, while some of them would go to regular schools. In this group, the tuition would concentrate on school subjects to a larger extent than in the first group. Naturally, the children would be given rehabilitation services according to their individual needs. Later on, another rehabilitation centre should be founded in Nadvoitsy, utilizing the experiences of the Segezha rehabilitation centre.

An important goal is to give the children an opportunity to go on living at home instead of being transferred to institutions in order to get tuition. In the villages which only have 1-2 handicapped children, the tuition should be arranged in regular schools according to an individually adapted teaching programme and with the support of a personal assistant in the class.



12.3. TUITION AT SCHOOL

As presented in the table on page 33, there are 34 mentally handicapped children in the Segezha district. Of them, 21 lack all training or tuition whatsoever, while 6 are given tuition at home. Only six children go to regular or special schools.

Of the children living at home in the city of Segezha, seven need tuition suited for children with a minor handicap, given in a regular school, either in a group of their own or in a regular classroom with the support of a personal assistent. The rehabilitation services the children need should be given at school. The tuition of the mentally handicapped children organized in this way, the teaching materials, aids, spaces and other resources of the school could be utilized.

12.4. RESEARCH, PLANNING OF REHABILITATION AND FOLLOW-UP

An individual rehabilitation plan, based on the examination by specialists of different fields, should be compiled for each child as soon as possible after the handicap has been discovered. It should contain the particular child's need for services as well as the ways of meeting those needs and the persons responsible for separate measures to be taken. The process of carrying out the care and rehabilitation should be followed and checked by the specialists annually, as to the youngest children and at least every other year, as to the children of school age. The situation should always be revaluated whenever essential changes take place in the child's life, such as starting school and before leaving school. Concerning all new mentally handicapped children, a basic card presented in Appendix Nr 11 should be filled up. New information should be added to all existing cards whenever changes in the child's lives take place.



12.5. GUIDANCE IN HOME CARE

For successful home care of a (mentally or otherwise) handicapped child constant support and guidance is needed, even when the child should go to kindergarten, school or rehabilitation centre. The guidance is especially important in the countryside where few forms of service are available. Naturally, due to the long distances between the villages, the arrangements are especially demanding. The guidance in the homes should be organized by the rehabilitation centre. A vacancy should be opened for a special social worker who would be responsible for the guidance and other social affairs.

12.6. NEED AND ACQUISITION OF AIDS

The need for various aids was determined by the Finnish physiotherapist during the visits to the homes of the handicapped children. Here, the difficulties in the acquisition of the aids are not discussed.

Four children living at home need a wheel-chair. The wheel-chairs should be folding models in order to make it easier to move the chair through doors and carry it on the stairs. One child needs a standing aid and another a special pillow to make sitting more comfortable. One child needs a tricycle and another a roller-walker. Two children need surgical boots and instep supports.

In general, the number of motion-handicapped was unexpectedly low among the mentally handicapped children living at home. There were only a couple with a serious motion handicap.

Probably the need for various aids is essentially larger among the physically handicapped children. In order to get an overall picture, it should be studied as soon as possible. As the aids are expensive and the child will be needing different aids when growing up, all aids should be returned to the rehabilitation centre when not needed any longer. An aid lending system should be created in the rehabilitation centre, which also would maintain and repair the aids. Moreover, it became apparent that the children living at home have hardly any toys. Consequently, also toys should be lent out from the rehabilitation centre.

As a continuation of the current project, a plan should be made to have (second-hand) aids sent from Finland to Segezha. Guidance on their use, maintenance and repair should also be organized.



12.7. INSTITUTIONS

As to institutions and boarding schools, a short-term goal should be not to place new children in the institutions but support their living at home. A long-term goal should be to transfer the children from institutions to their homes, to foster families or small group homes with 5-6 places, whenever the child's situation and living conditions would thus be improved. To begin with, a group home should be founded in Segezha and another in Nadvoitsy.

12.8. TEMPORARY CARE

In order to avoid or postpone permanent placements in institutions, temporary 24-hour care at regular intervals has proved to be an effective method. A unit offering temporary 24-hour care for a period from one day to several weeks should be founded in one of the existing institutions.



13. SUMMARY

The population of Carelia was largest in 1992, namely 800 500 inhabitants. Since then the population has been decreasing by approximately 1000 every year. However, the structure of the population is still relatively young. The proportion of children is larger, that of persons of working age equal and that of pensioners smaller than in Kainuu, Finland.

The economic situation has been constantly deteriorating during the 1990's. The prices have been rising more than wages, salaries and pensions. In 1995, the consumption of such basic food stuffs as bread and potatoes started to deminish.

The figures describing the population's state of health and social conditions show an essential deterioration during the 1990's. The number of live births per 1000 inhabitants has fallen to a half during the 90's, while the mortality has increased by 60 % in Carelia and doubled in Segezha. The mortality of males of working age has been especially large. Currently, their life expectancy is only 55 years. Infant mortality has stayed on the previous level in Carelia, but increased in the Segezha district from 15,7 to 20,5 per 1000 during the 1990's. Consumption of alcohol in Carelia is twofold compared with Finland; in Segezha it is even larger. The number of marriages has decreased by 25 % since 1985, while the number of divorces has risen by 40 %.

During the current project, the number of handicapped children proved to be 134 (instead of the registered 154), while the number of mentally handicapped children living at home proved to be 35 (instead of the registered 57), or approximately 40 including the children which were not reached by the examination group. About a half of the children were functionally independent. Almost all children in need for speech therapy (13) did not get it, while approximately 2/3 of those in need for physiotherapy (10) did not get it either. In two thirds of the cases both parents were living with the rest of the family. The average housing density was 1,8 persons per room.

The most effective way to improve the quality of life of the handicapped children living at home is to reorganize their tuition. One special group for handicapped children should be founded in one of the regular schools and two groups in the rehabilitation centre currently under construction. Services of speech therapy and physiotherapy for the children living at home can without difficulty be guaranteed by utilizing the existing resources. An individual rehabilitation plan must be compiled for each child and a follow-up of the plan carried out. The follow-up can be carried out in the most effective way in cooperation with the psychological-medical-pedagogical commission, the pediatric policlinic and the rehabilitation centre.



14. SOURCES

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- 7. Nosova Tatjana, Simpura Jussi, Gamburg Alexander, Rasnik Irina: Alcohol Policy 2/95
- 8. List of handicapped children, Segezha pediatric policlinic
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Federation of Kainuu, vital statistics



Communications in the Segezha district:

1. Railway traffic (Oktjabrskaya railway)

Stations: Segezha, Nadvoitsy, Idel

Passenger traffic connections:

Moscow-Murmansk 2/day St.Petersburg-Murmansk 3/day

During summer season (May-Sep) additional southbound trains.

2. Waterborne traffic

Industrial use only

3. Motor traffic

Road M18 St.Petersburg-Murmansk

Bus traffic:

Petrozavodsk-Segezha-Kostamuksha (not regularly)

St.Petersburg-Segezha (not regularly)

4. Internal connections

Motor traffic

Petrozavodsk-Kostamuksha (bus)

Segezha-Nadvoitsy (bus)

Segezha-Mustakoski (Olenij, Pertojärvi, Vacha) (bus)

Air traffic

(helicopter, airplane)

Segezha Airport Medical flights Special flights Freight traffic



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-	15 yrs	191	149	32	12	2	٥	٥	0	'n	3	-	9	3	4	-	-	392
	14 yrs	629	201	39	6	12	S	9	0	2	3	1	-	2	0	2	~	917
	13 угз	662	193	34	6	12	01	6	0	5	2	1	1	3	0	-	5	7\$
	12 yrs	654	176	44	19	8	6	10	0	4	3	-	9	3	0	1	و	248
	11 yrs	089	197	67	11	9	6	13	0	3	4	1	0	2	0	0	٠,	996
i	10 yrs	706	223	34	17	12	7	7	0	-	4	1	2	2	0	1	4	1021
	9 yrs	633	270	30	13	16	9	11	3	7	7	1	2	3	0	0	3	1881
	8 yrs	675	203	34	6	13	6	4	9	7	5	2	2	4	2	0	4	9.6
	7 yrs	631	180	33	13		5	3	3	4	S	1		٠. د	0	2	8	\$0\$
	б утѕ	614	154	93	15	9	2	3	4	7	4	0		3	0	0	7	1543
	5 yrs	557	154	24	7	5	4	6	9	2	2	1	0	S	1	1	2	777
	4 yrs	547	148	25	8	8	3	8	2	1	2	0	1	8	.2	0	3	766
1993	3 утs	535	142	38	7	2	9	S	9	4	1	1	4	4	1	0	2	1158
5E 1.12.1993	2 yrs	418	106	22	10	0	4	9	4	2	2	-	1	1	2	2	4	585
LS OF AC	1 уг	403	113	25	4	2	2	5	4	2	2	-	4	3	0	0	3	573
2 16 YEAR	6-12 mths	200	8.	10	4	2	4	2	1	0	3	0	0	1	1	1	3	13104
N UNDE	0-6 mths	156	22	8	3	-	2	2	0	0	0	0	1	2	0	0	-	228
R 2 CHLDRE	Number of children, total	8861	2692	491	170	136	2	103	42	56	52	14	27	58	10	12	65	12876
APPENDIX NR 2 NUMBER OF CHILDREN UNDER 16 YEARS OF AGE		Segezha	Nadvoitsy	Valdai	Musta Koski	Idel	Polga	Popov Koski	Koch- koma	Voldo- järvi	Pertojärvi	Vacha	Vozhmo- järvi	Vozhmo- vuori	Kärkjärvi	Taboj Koski	Olenij	Total
ERIC.																		

WAGES AND SALARIES AND OTHER INCOME PER PERSON IN RUSSIA IN 1991-1995

	1991	1992	1993	1994	1995
WAGES AND SALARIES in roubles (Dec)	1191	1671	141218	354236	
OTHER INCOME, in roubles (Jan)	865	11122	116355	378583	408200

Source: information given by phone from the Bank of Finland.



NDIX NR 4	
APPEN	

The Segezha district	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987	1988	1989	1990	1901
Population (1000 inhabitants) In towns In villages	57,4	57,6	56,9	56,9	57,2	56,8	57,1	56,7	56,7	56,7	57,7	57,4	57,0	56,6	56,3
	49,8	50,0	49,4	49,5	49,9	49,7	50,0	50,4	50,5	50,8	51,3	51,6	51,7	51,6	51,4
	7,6	7,6	7,5	7,4	7,3	7,1	6,8	6,7	6,2	5,9	5,8	5.8	5.3	50	4.9
Births	1154	1029	1004	966	1021	1043	1045	936	974	935	894	783	756	730	1 1 1
Deaths	586	572	573	586	591	591	601	613	516	540	621	615	574	598	
0-1 yrs	28	28	23	16	28	28	27	19	19	19	9	16	15	14	
Marriages	628	643	621	596	597	587	548	580	563	576	546	559	531	498	1 1
Divorces	308	306	313	361	302	291	256	277	287	276	284	240	250	218	
Infant mortality 0-1 yrs	26,8	27	22,6	17,6	20,6	26,8	25,9	5,61	13,34	20,0	6'6	20,4	19,8	19,0	,
Kindergartens Children in them	45 4776	44 4979	44 5066	47 5034	47 4967	47 5035	47 4838	45 4760	45 4725	42	43	42 4721	42	44 4310	- 4117
Doctors/10000 inh.	28,3	29,3	29,5	31,6	32,6	32,7	29,4	30,0	31,0	32,0	32,0	29,1	29,5	30,0	1 1 1
Nurses/10000 inh.	97,0	99,5	103,3	102,3	99,3	114,4	112,9	109,1	109,0	107,0	107,0	116,1	97,0	107,1	
Hospital beds/10000	111,5	111,1	112,5	123,0	125,0	125,4	125,9	125,9	127,5	127,0	127,0	127,0	124,0	125,0	
Pensioners	6472	6746	7082	7384	7669	8012	8353	8672	9032	94 44	79167	10120	10472	10730	11287

THE SEGEZHA PROJECT/CURRENT SERVICES

Date:

05.09.1995

Institution:

Special kindergarten Nr 4

Location:

City of Segezha, Shkolnaya 4

Number of places:

38

Children:

38

Handicapped children

5-15 years of age:

38

	-4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys		22	_	-
girls	-	16	_	-

Of them mentally retarded: 18

	–4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	_	9	_	-
girls	-	9	_	-

Physicians:

_

Speciality:

Physicians:

Speciality:

Nurses, trained:

Nurses, not trained:

4

14uises, not damed.

Other nursing staff, trained:

9

Other nursing staff,

not trained:

Physiotherapists, trained: Physiotherapists, not trained:

Speech therapists, trained:

4

Speech therapists, not trained:

Teachers:

2 teachers + 1 methodologist

3

Other staff: 2 cookers, 1 cleaner, 1 manager, 1 caretaker, 2 doormen

Equipment and aids:

gymnastics equipment

Medication:

epilepsy

5 inmates

psychopharmaceutical drugs

25 inmates

other medication

38 inmates



Other essential information:

- 1) The kindergarten is meant for children 4-8 years of age.
- 2) Pediatrician, neuropathologist and psychiatrist from the pediatric policlinic visit the kindergarten when necessary.
- 3) Three times a year a 20-day rehabilitation period during which the doctors are present.
- 4) The children are divided into four groups:
 - speech therapy group, 6-7 yrs
 - children about to start school, 5-6 yrs
 - CP group, 4-7 yrs
 - mentally handicapped children, 5-7 yrs

Music teacher, pedagogical specialist (teacher), of the four trained nurses one is specialized in physiotherapy, one in massage, one in electric treatments.

The director of the kindergarten is Ms Tamara Alexandrovna Ivanova.



THE SEGEZHA PROJECT/CURRENT SERVICES

Date:

16.08.1995

Institution:

Ladva children's institution

Location:

Prionezhki region, Ladva village,

Ulica Komsomolskaya 4

Number of places:

450

Inmates:

335

Handicapped patients

under 16 yrs of age:

168

over 17 yrs of age:

67

	-4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	-	26	59	14
girls	-	15	43	38

Of them mentally retarded:

	-4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	-	26	59	14
girls		15	43	38

Physicians:

2

Speciality:

Physicians:

Speciality:

Nurses, trained:

20

Nurses, not trained:

Other nursing staff, trained:

Other nursing staff,

not trained:

110

Physiotherapists, trained:

Physiotherapists, not trained:

Speech therapists, trained:

1

Speech therapists, not trained:

Teachers:

42

Other staff:

35

Equipment and aids:

Medication:

epilepsy

psychopharmaceutical drugs

__ inmates inmates

other medication

inmates

Other essential information:

The school of the institution has a dressmaking workshop, a woodworking workshop and a kitchen garden.



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THE SEGEZHA PROJECT/CURRENT SERVICES

Date:

07.09.1995

Institution:

Petrozavodsk boarding school Nr 21

Location:

Petrozavodsk, Ulica Serbakova 21

Number of places:

156

Inmates:

Physicians:

Physicians:

epilepsy

other medication

psychopharmaceutical drugs

130 + 26 students living at home

Handicapped inmates

under 17 yrs of age:

144, of them 26 living at home

	–4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	-	6	47	10
girls		2	42	11 ;

Of them mentally retarded:

	–4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	-	3	12	2
girls	-	1	11	_

5

Speciality:

Speciality:

Nurses, trained: Nurses, not trained:	5
Other nursing staff, trained: Other nursing staff, not trained:	
Physiotherapists, trained: Physiotherapists, not trained:	
Speech therapists, trained:	2
Speech therapists, not trained:	2
Teachers:	42
Other staff:	39 teacher's assistants
Equipment and aids:	keep-fit equipment
Medication:	

11

Other essential information: 11 hospital beds, functions only during school year

Each student has an individual tuition programme in forms 9-12. The goal of the training is to prepare the children and give them facilities for independent life. The school was founded 26 years ago. In the future, it will be made into a rehabilitation centre with a school. The total number of staff is 140. Head physician: Ludmila Viktorovna Strashko.

inmates

inmates

inmates



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THE SEGEZHA PROJECT/CURRENT SERVICES

Date:

03.10.1995

Institution:

Nadvoitsy boarding school Nr 14

Location:

Nadvoitsy, Ulica Lenina 3

Number of places:

108

Inmates:

104

Handicapped inmates

5-15 yrs of age:

90

Handicapped inmates

over 16 yrs of age: 14

	-4 yrs	5-9 yrs	10-15 yrs	16+ yrs
boys	-	5	47	9
girls	-	5	.32	5

Of them mentally retarded: 104

	-4 yrs	5–9 yrs	10-15 yrs	16+ yrs
boys	-	5	47	9
girls	-	5	32	5

Physicians:

1

Speciality:

Psychiatry (visits twice a week)

Physicians:

Speciality:

Nurses, trained:

2

Nurses, not trained:

Other nursing staff, trained:

Other nursing staff,

not trained:

Physiotherapists, trained:

Physiotherapists, not trained:

Speech therapists, trained:

1

Speech therapists, not trained:

Teachers:

39

Other staff:

27

Equipment and aids:

Medication:

epilepsy

2 inmates

psychopharmaceutical drugs

30 inmates

other medication

inmates



Other essential information:

A ten-form school, 9 classes. In forms 1-3 six children/class, in other forms 12 children/class.

The tuition begins at the age of 8-9 years.

The tenth form includes additional work-oriented training such as sewing, woodworking and painting.

2/3 of the students come from the Segezha district, the rest from Belomorsk, Kemi etc.

25 children also spend the week-ends in the school. Each student has an individual tuition programme. A medical examination is carried out in October and a health care programme is planned for them. 25 % of the children are visually handicapped and with impaired hearing. There are no motion-handicapped children. The goal of the training is to give each student a profession.



Ministry of Health, Republic of Carelia

The psychological-medical-pedagogical council of the Republic

DECISION NR 98

31.1.1994

concerning the psychological-medical-pedagogical commission 06.07.1993

It is hereby ordered that

The work of the psychological-medical-pedagogical commission in Carelia must be organized from the 2nd of May 1994 on during the following days:

1420.02.1994
2127.02.1994
28.0205.03.1994
0912.03.1994
1420.03.1994
2126.03.1994
28.0301.04.1994 + 09.0323.03.1994
0409.04.1994
1116.04.1994
1823.04.1994
2330.04.1994
1014.05.1994
1621.05.1994
01.02.–25.05.1994



67

Physicians: a psychiatrist, neurologist, ophthalmologist, orthopedist, otologist and pediatrician examine the child prior to sending him/her to the psychologigal-medical-pedagogical guidance centre.

§ 3

The doctor is to make an entry in the "Children's examination record".

Based on the information given by the kindergartens the physicians, a neurologist, ophthalmologist, otologist and orthopedist are to state in the Record whether the children are deaf, blind, a CP child or mentally retarded.

§ 4

The parents or guardians of the children are to participate in the commission's work and present the following documents:

- 1. The child's examination record
- 2. A psychiatrist's examination certificate
- 3. A logopedist's examination certificate
- 4. A description of the student
- 5. Exercise books, drawings, applications
- 6. Identification card

Director of the psychological-medical-pedagogical guidance centre

Miheeva, G.V.

Minister of Health

Artemjev, A.K.



DECISION NR 30

by the Segezha National Education Department

on organizing the work of the Psychological-medical-pedagogical commission

23.02.1994

Based on the document of the Ministry of National Education of the Republic of Carelia on 11.11.1992 and the decision of the Psychological-medical-pedagogical commission of the Republic Nr 82 on 31.01.1994

I order:

1. To organize the work of the psychological-medical-pedagogical commission of the Segezha district during the period 28.03.-01.04.1994. The location is the Segezha pediatric policlinic.

2. To accept the composition of the guidance centre:

Shmuratko T.E.

Psychiatrist, director of the guidance centre

Martsunova V.I.

Logopedist of the pediatric policlinic, deputy chief of the guidance centre

Shinkevich L.Y.

Logopedist of preschool institutions, secretary of the guidance centre

Korzhova L.S.

School logopedist

Yakovleva L.D.

Specialist of preschool institutions

Gerashenko M.K.

School specialist

Bulaenko I.A.

School specialist

3. The directors of schools and preschool institutions are to in advance organize the medical examination of each child, to inform the parents of the work of the commission and prepare all necessary documents and records. The teachers and nurses are to take part in the work of the guidance centre.

The school specialist Bulaenko is to control the work of the commission.

Director of the National Education Department L.P. Goncharova



THE SEGEZHA PROJECT

BASIC CARD FOR MENTALLY HANDICAPPED CHILDREN Nr:

Date95			
1. Personal data			
Surname and given names:			
day month year Date of birth:	Sex:	female (1) male (2)	
Place of domicile:	Village:		
Father:	Year of b	oirth:	
Lives in the family:	yes (1)	no (2) dead (3)	
Profession:	Works:	yes (1) no (2)	
Mother:	Year of b	oirth:	
Lives in the family:	yes (1)	no (2) dead (3)	
Profession:	Works:	yes (1) no (2)	
Parents' state of health:			
Siblings	brothers	sisters	
Number of: Years of birth: State of health:			
Dead: Years of death:			
2. Handicap (mark the year with X)			
1. LEVEL OF DEVELOPMENT year -95/		2. EYE-SIGHT	
Not yet evaluated 0//_ Normal 1//_ Slight handicap 2//_ Minor handicap 3//_ Medium handicap 4//_ Serious handicap 5//_ Severe handicap 6//		Normal Minor (eye-glasses) Major (blind)	0//_ 1// 2//



3. HEARING		4. COMMUNICATION year 95/
Normal Minor (hearing aid) Major (deaf) Name of assistant	0// 1// 2//	No comm. 2//_
5. MOTION HANDICA	P	6. SPASMODIC FITS
Normal Minor Medium Major (bedridden)	0// 1// 2// 3//	
Name of assistant		Medication:
7. MENTAL ILLNESS (OR DISORDER	8. OTHER HANDICAP OR CHRONIC ILLNESS
None Minor Medium Major	0//_ 1// 2// 3//	None 0// Diabetes 1//_ Asthma 2// CP 3//_ Other, what 4//
NEED FOR AIDS AND	EQUIPMENT:	
		
<u> </u>	,	



dg/ICD9:	
Evaluated Y1995/	
1. Genetic	5. Childhood causes
11 Chromosome mutation	51 Infection
12 Genetic mutation	52 Drugs/toxics
13 Polygenetic	53 Disorders of cerebral
20 1 0.7 go	circulation
2. Malformation/syndrome caused	54 Cerebral tumours
by unknown factor	55 Traumata
2 , 22	56 Lack of oxygen
21 Separate malformation of	57 Psychosis
central nervous system	58 Psycho-social reasons
22 Malformation syndrome	59 Other, what
• • • • • • • • • • • • • • • • • • •	
3. Other prenatal causes	6. Unknown causes
31 Infection	61 Pure, non-familial
32 Drugs/toxics	retardation
33 Disorder of nutrition/	62 Other, what
disturbance of growth	
34 Other, what	
	•
4. Perinatal causes	
41 Infection 42 Problems in delivery 43 Other, what	
4. NEED OF HELP/INDEPENDENT IN	NITIATIVE
1. Dressing	2. Use of toilet
Manages alone 1/	Manages alone 1/
Needs help 2/	Needs help 2/
Dependent on	Dependent on
other people 3/	other people 3/
3. Washing	4. Eating
-	_
Manages alone 1/	Manages alone 1/
Needs help 2/	Needs help 2/
Dependent on	Dependent on
other people 3/	other people 3/

3. PROBABLE CAUSE OF MENTAL HANDICAP



nursing	(e.g. restlessness)	surroundings
	0//	Manages alone 1//
Minor	1//	Dependent on
	2/	other people 3//_
Major		5, <u></u>
	hs and special abilities sicality)	
Need of m	edication	
		

6. Orientation in familiar

5. Characteristic which affects



5. SERVICES AVAILABLE

I. MEDICAL	SERVICES						
2. TUITION	 in school in special sch in kindergart 		4) at h 5) no t	ome, times/week uition			
3. PHYSIOTH	ERAPY 1) yes	2) does not	need	3) needs but does	not get		
4. SPEECH TI	HERAPY 1) yes	2) does not	need	3) needs but does	not get		
5. OTHER	1) yes, what 2) no						
6. HOUSING	CONDITIONS						
1. TYPE OF B	UILDING						
1) block of flat 1st floor other floor lift	3	2) other building) communal d	_				
2. NUMBER C	F ROOMS	·			· ·	-	
3. NUMBER C	F RESIDENTS						
4. KITCHEN			1) yes 2) no				
PIPED WAT	ER INSTALLAT	TON	1) yes 2) no				
5. INDOOR TO	DILET		1) yes 2) no				
SHOWER/SA	AUNA BATH		1) yes 2) no				
7. LOCATION	AND COMMU	NICATIONS					
1. Distance from	n the city of Seg	ezha		_ km			
2. Public transp	ort 1) daily 2 3) none) tim	nes/week				
3. Services:							



8. PERSONS LIVING OUTSIDE THE HOME

1. DWELLING PLACE				
1) institution, what3) other, what	2) school do	rmitory etc.		
2. ARRIVED year 19	from	· · · · · · · · · · · · · · · · · · ·		
3. VISITS TO HOME				
1) once a month	2) less frequently	3) never		
4. VISITED BY PARENTS				
1) once a month	2) less frequently	3) never	•	
5. VISITED BY OTHER VIS	ITORS			
1) once a month	2) less frequently	3) never		
6. FUTURE FORM OF DWE	LLING			
1) current 2) other, what				
7. OTHER ESSENTIAL INFO	DRMATION		·	
				_



75

AGE

Town/village	Communication	5–6	7–8	10-15	Total
Nadvoitsy	Normal Problems	0	1 1	1 0	2 1
Olenij	Normal	0	0	1	1
Popov-Porog	Problems	0	0	1	1
Segezha	Normal Problems No communication	3 0 1	6 2 0	13 4 3	22 6 4
Valdai	Normal Problems	0 1	0 1	2 1	2 3
Total		5	11	26	42

AGE

Town/village	Washing	5-6	7–8	10-15	Total
Nadvoitsy .	Manages alone Needs help	0	1 1	1 0	2 1
Olenij	Manages alone	0	0	1	1
Popov-Porog	Needs help	0	0	1	1
Segezha	Manages alone Needs help Dependent on other people	2 2 0	7 1 0	13 2 5	22 5 5
Valdai	Manages alone Needs help	0	1 0	2 1	3 2
Total		5	11	26	42

AGE

Town/village	Motion handicap	56	7–8	1015	Total
Nadvoitsy	Normal	0	2	1	3
Olenij	Normal	0	0	1	1
Popov-Porog	Normal	0	0	1	1
Segezha	Normal Minor Medium Major	3 1 0 0	6 2 0 0	11 5 2 2	20 8 2 2
Valdai	Normal Medium	1 0	0	3	4 1
Total		5	11	26	42



LEVEL OF DEVELOPMENT

Town/village	Hearing	Normal	Slight handicap	Minor handicap	Medium handicap	Major hancicap	Total
Nadvoitsy	No	0	1	1	1	0	3
Olenij	No	0	1	0	0	0	1
Popov-Porog	No	0	0	1	0	0	1
Segezha	No	8	4	11	6	0	29
	Minor	0	0	1	1	1	3
Valdai	No	0	2	1	1	0	4
	Minor	0	0	1	0	0	1
Total		8	8	16	9	1	42

LEVEL OF DEVELOPMENT

Town/village	Eye- sight	Normal	Slight handicap	Minor handicap	Medium handicap	Major hancicap	Total
Nadvoitsy	No	0	1	1	1	0	3
Olenij	No	0	1	0	0	0	1
Popov-Porog	No	0	0	1	0	0	1
Segezha	No	7	1	8	4	0	20
	Minor	1	3	4	3	0	11
·	Major	0	0	0	0	1	1
Valdai	No	0	1	1	1	0	3
	Minor	0	1	1	0	0	2
Total		8	8	16	9	1	42



LIST OF PARTICIPANTS from the Segezha district

Seminar for physicians

09.-12.10.1995

- 1. Drozdov, Youri Nikolaevich
 Physician-therapist at the children's rehabilitation centre
- Schmuratko, Tamara Enveroyna Children's psychiatrist
- 3. Borzova, Nadezhda Sergeevna
 Senior physician at the pediatric policlinic (group leader)
- 4. Mihailova, Olga Andreevna
 Family doctor at the pediatric policlinic
- Malahova, Galina Ivanovna Children's surgeon-orthopedist
- 6. Turtsevich, Ludmila Petrovna
 Family doctor at the pediatric policlinic (Nadvoitsy)
- 7. Vinkler, Tatiana Antonovna Matron of the pediatric policlinic
- 8. Alyeshina, Tatiana Gennadievna Neuropathologist



SEMINAR FOR THE SEGEZHA PHYSICIANS IN KAJAANI 9.-12.10.1995

PROGRAMME:

Monday 9.10.1995

9.00 Basis of the care of the mentally handicapped and services for mentally handicapped children in

Finland

Director of Care of the Mentally Handicapped Matti Huovinen

10.30 Causes of mental handicap, medical diagnostics and multiprofessional team-work in examination

and rehabilitation of mentally handicapped children

Senior Physician Markus J. Viljanen

12.00 Lunch

Physiotherapeutic examination and rehabilitation of mentally handicapped children

Physiotherapist Helena Mikkonen

18.00 Dinner

Tuesday 10.10.1995

9.00 Psychological and pedagogical research and rehabilitation of the mentally handicapped

Psychologist Jaana Saastamoinen

10.30 First information on child's mental handicap for parents, guidance and consultation

Senior Physician Markus J. Viljanen and psychologist Jaana Saastamoinen

12.00 Lunch

13.30 Visit to the children's ward at the Central Hospital, services for handicapped children at the

Central Hospital

Children's neurologist Anne Hirvasniemi

18.00 Dinner

Wednesday 11.10.1995

9.00 Training of children with a (minor) mental handicap and tuition of persons with a sensory

handicap in Finland

Special teacher Marsa Rantala

10.30 Training of children with a major mental handicap in Finland

Special teacher Marsa Rantala

12.00 Lunch

13.30 Visit to a school for children with a major mental handicap (Väinölä school)

18.00 Dinner: cultural programme



Thursday 12.10.1995

9.00	Social security of the mentally handicapped, home services and family care Director of Care of the Mentally Handicapped Matti Huovinen
11.00	Institutional care of the mentally handicapped; decentralization of institutions in Finland and the Nordic countries Visit to the Kainuu central institution: Director of Care of the Mentally Handicapped Matti Huovinen
12.00	Lunch
13.30	Visit to a school for children with a minor mental handicap
14.30	Final evaluation of the seminar



LIST OF PARTICIPANTS from the Segezha district

Seminar for teachers and therapists

21.-24.11.1995

- 1. Senyukova, Vera Yourevna
 Psychologist of the family and youth department
- 2. Bulaenko, Inna Andreevna Education specialist
- 3. Kurnosova, Valentina Alexandrovna
 Director of the Segezha Rehabilitation centre for handicapped children
- 4. Koivistoinen, Ludmila Vladislavovna
 Specialist of the Segezha Rehabilitation centre for handicapped children
- 5. Makarova, Ludmila Ivanovna Logopedist of kindergarten Nr 4
- Tyleneva, Svetlana Mihailovna Specialist of kindergarten Nr 4
- 7. Fetylina, Svetlana Fedorovna

 Director of school department of the Nadvoitsy boarding school Nr 14
- 8. Vasyra, Viktor Vasilyevich
 Director of the Nadvoitsy boarding school Nr 14



SEMINAR FOR THE SEGEZHA TEACHERS AND THERAPISTS IN KAJAANI 21.-24.11.1995

PROGRAMME:

Tuesday 21.11.1995

9.00	Basis of the care of the mentally handicapped and services for mentally handicapped children in Finland Director of Care of the Mentally Handicapped Matti Huovinen
10.30	Psychological and pedagogical research and rehabilitation of mental handicaps Psychologist Jaana Saastamoinen
12.00	Lunch
13.00	Multiprofessional team-work in examination and rehabilitation of mentally handicapped children Psychologist Jaana Saastamoinen
18.00	Dinner

Wednesday 22.11.1995

9.00	Training of children with a (minor) mental handicap and tuition of persons with a sensory handicap in Finland Psychologist Jaana Saastamoinen
10.30	Training of children with a major mental handicap in Finland Psychologist Jaana Saastamoinen
12.00	Lunch
13.30	Visit to a school for children with a minor mental handicap, located at a regular comprehensive school
18.00	Dinner .

Thursday 23.11.1995

9.00	Physiotherapeutic examination and rehabilitation of mentally handicapped children Physiotherapist Helena Mikkonen
10.30	Social security of the mentally handicapped, home services and family care; decentralization of institutions in Finland and other Nordic countries Director of Care of the Mentally Handicapped Matti Huovinen
12.00	Lunch
13.30	Visit to schools for children with a major mental handicap (special school I and special school II)
18.00	Dinner; cultural programme



9.00 Communicational (logopedical) examination and rehabilitation of mentally handicapped children Logopedist Mirja Hujanen 11.30 Visit to a family guidance centre 12.00 Lunch and conclusion of the seminar



SEMINAR FOR THE PARENTS OF MENTALLY HANDICAPPED CHILDREN IN THE SEGEZHA DISTRICT

2.12.1995 at 10.00

PROGRAMME:

Opening of the seminar, Director of family guidance department Ludmila Andreevna Ublieva

On the causes and forms of mental handicap, Senior physician Ludmila Alexandrovna Romanova

Intermission

Results of the TACIS-BISTRQ project and, in particular, those of family guidance, Director of the project group Matti Huovinen

Results of the TACIS-BISTRO project from a psychological-pedagogical viewpoint, Psychologist, member of the project group Jaana Saastamoinen

Parents' expectations on the services for mentally handicapped children in the Segezha district, Representative of parents Tatiana Vladimirovna Lapina





U.S. Department of Education

Office of Educational Research and Improvement (OERI) Educational Resources Information Center (ERIC)



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Signature:

Joint Municipal Authority for Specialized Health Care and Social Welfare in Kainuu Finland

Printed Name/Position/Title:

Matti Huovinen

Telephone:

FAX:

+358-08-6156900 +358-08-6156932

E-Mail Address: Date:

14.1.1997

