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A Study of Special Education in Russia

Report No 3

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Summary: This is the third of six reports from the project that studies special education in Russia, New Zealand and the USA. It consists of two parts. Part one is a study of special education in Russia based on written sources. The second part is an analysis in a series of interviews with teachers, parents and experts in the field. Not surprisingly, the study indicates a state of emergency as regards education for children with special needs. A halting economy and a selective regular school system strongly restricts the possibilities for inclusive practices and tends to force many parents to accept institutional placement for their children with disabilities even if their preferences are different. Even if changes are taking place experts in the field do not recommend any basic changes of the segregated system of special education in the present situation. Basically, special education theory is consonant with the present system - strongly individually oriented and offering little room for the social aspects of disabilities. However, observations within this system indicate a strong element of caring and competence.	
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*Gunnar Stangvik*¹

A STUDY OF SPECIAL EDUCATION in
RUSSIA

Report No. III
from the project:

Special Education at the Bottom Line.
A cross-cultural study of the quality of special education practice²

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² This is the third of six reports from the project. All reports are listed at the end of this report

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PART ONE: A BRIEF OUTLINE OF SPECIAL EDUCATION IN RUSSIA

Aims, design and methods of the project have been described extensively in the first report from this project (Stangvik 2002a). Stangvik (2002b) discusses special education issues and perspectives and is thought of as a theoretical platform for interview studies. A complete list of reports is found at the end of this report.

This report consists of two parts. The first part of the report presents an outline of special education in Russia based on available sources. This outline serves as a background for the analysis of interviews in the second part.

Before this attempt to briefly outline some central issues of special education in Russia some precautions have to be taken. First, due to a low profile of the area in Russia there is a lack of reliable sources. This may have political and historical causes. Secondly, there is the problem of language. I am dependent on sources written in foreign languages. Therefore, the possibility that my conclusions and interpretations might sometimes be too hasty is real. However, this is a risk I have to take when I place a foreign country on my agenda. As things are I judge the risk of not doing this as more detrimental to my understanding of special education.

CONTEXT AND BACKGROUND

Historical accounts of the development of special education in Russia (Csapo 1984; Shipitsina 1996b; Malofeev 1998) indicate that Russia follows a classic pattern. Starting with the deaf (1806) and the blind (1807) the first special school for the retarded was established in 1884. This was followed by assistance to crippled and paralysed children and children with speech disorders. In the aftermath of the revolution a network of state special schools were established - mostly for the mentally retarded.

Rodina (1998) describes the development of special education in the western countries in five stages and compares the development of special education in Russia to these stages. She finds that special education in Russia lags about 20

years behind. While the countries in Western Europe started to integrate students with disabilities from the beginning of the 1970s Russia has during the same period completed a differentiated system of special schools. She concludes that Russia presently is in a period of integration but that special education and integration do not have a legal basis in Russia. Rodina (1998 p 10) draws attention to the fact that a tradition of welfare was broken in 1917 and presently there is still a weak social movement that is not supported by the legal funding. The media, she says, have only recently discovered the problems of disabled children. Vladimir Lubovsky also underscored this last point³. These issues were mainly treated in specialised media. He also pointed out, somewhat mockingly, to me that during the Soviet era there were no such problems in Russia and that even medical doctors lacked training in this area. He underscored that important developments were taking place - primarily in Moscow and Petersburg - especially as regards the severely disabled and the positive role of international organisations.

Until the 1970s there were few establishments for other categories of learning disabilities than those mentioned above. From then on a new network of residential schools, day schools, and remedial classes in regular mainstream schools appeared. From 1992 classes that offer compensatory training for children with specific learning problems have begun to open in mainstream schools. Shipitsina (1996b p. 40) refers to the progressive ideas of prominent Russian special educators in the 1920ies and 30s. For a long time these ideas were replaced by a pedagogy, which regarded the child as a 'subject', and sought to isolate a child with special needs from society. The instrument was a large number of residential special institutions. She asserts that a similar approach is evident today and that special education is brought to a crisis at the present time. This is, she says, a result of a lack of consideration for the rights of children, the absence of legislation which protects the civil rights of the disabled, and the absence of a Special Needs Education Act, coupled with the current economic and political situation in Russia.

³ Dr Lubovsky is a very renown person in Russian special education and a keen observer of what is taking place in the area. I had the opportunity to talk to at CEC congress in Vancouver in 2000.

According to Arnesen (2000) statistical figures indicate that one third of the Russian population live below the poverty level. 44 million people are in need of support, and lots of families are not able to support their children, but have to leave their children to be placed in institutions from the time they are borne. Statistics show that 95 % of children in institutions actually have their parents alive. Rumantseeva (1999)⁴ and Makarova (1999)⁵ gives a bleak description of the situation for handicapped people and the elderly in the Arkhangelsk Region where this interview study was done. Their statistics indicate that over 55 % of families with children have an average income below one half of the survival minimum! Makarova (1999) presents statistics that underscore a number of tendencies. The demographic situation is unfavourable. A decreasing birth rate and increasing mortality rate indicate this. There is a general problem of poverty. In addition poverty is feminised. There is an acute problem of placing orphans in orphanages and other closed institutions and schools (the network of orphanages and other closed institutions keep growing). Criminality, alcoholism and drug addiction rates increase, and there is a growing number of handicapped people. On 1 September 1999 there were over 5000 handicapped children in the Arkhangelsk Region. Comparing with 1996 their number had increased by 9%. The present and future situation of special education in Russia has to be judged with reference to these facts.

The prevalent institutional model of special education is therefore not only a result of rational choice, but also a result of socio-economic constraints. Taking into account the detrimental effects of these institutional environments on development, learning and social interaction Shipitsina (1996b) claims that Russian special education ought to be remodelled to bring it closer to humane values and to support the integration into society for children with disabilities.

Malofeev (1998) traces the impact of economy and political ideology on special education. Due to political ideology testing of cognitive and motor development⁶ was

⁴ Vice - governor of Arkhangelsk Region and responsible for social sector and welfare issues

⁵ Chief of Department of Social welfare and Medical Care, Arkhangelsk

⁶ Csapo (1984 p. 8), however, argues that this decision was due to pseudo-scientific state of the theory and practice of psychometry.

prohibited and debates of related matters banned from media. The Central Committee of the Communist Party even issued a decree that charged educators with looking for "grounds for separating students from the normal school environment in order that an ever increasing number of children could be categorised as retarded or unmanageable. He points out that the existing laws actually reflected the following understanding about such children: They had no right to deviate from their non-disabled peers. For decades, the inherent problems faced by children with disabilities were recognised only by their families and those professionals charged with determining the course of their lives. And he asserts:

The constitutional right to education for children with disabilities was a mere declaration - the State did not provide the needed psychological and pedagogical support. (p. 182).

Korkunov et al (1998) also gives a harsh description of the situation for disabled people in Soviet Russia. Following the 1917 revolution, the Soviet ideology and a vision of a flawless communist society dominated special education. The policy that was established was to maintain the health of communities by removing any "defective" individuals. The primary goal was to use administrative means to perfect the organisational function of the state.

Any child with anomalies was labelled a defective child; the discipline of special education was called "defectology," and teachers with this speciality were referred to as specialist defectologists. Grigorenko (1998) discusses the history and theoretical basis of defectology. He considers defectology to be a functional part of the special school system:

To provide a theoretical and methodological basis for the functioning of special schools, a particular profession, "defectology," was developed, and specialists in anomalous development and special education became known as "defectologists. (p. 194)

The subdivision of defectology into different branches carries over into the special school system. The focus of defectology has traditionally been on handicapped groups ignoring symptoms of light and mild severity. Grigorenko (1998) points out that the Russian educational system and the field of special education are set up to

deal primarily with the most severely disabled groups - that is, children with low-incidence disabilities. He draws attention to the fact that these individuals constitute about 22 % of the so-called school-age population in Russia and asks *how does the state treat the other 78 %?* Grigorenko asserts that the Russian educational system never has officially recognised learning disability as a problem requiring State attention. Students with learning disabilities are piloted through schooling - until the 9th grade - in many creative ways, but their underlying disability is not addressed (Grigorenko 1998 p. 199). The result of this is that there is a relatively large school population whose learning problems have remained undetected.

Thus, society in Russia was clearly divided into "normal" and "abnormal". In spite of its many advances defectology was a part of this division. As regards teaching methods Shipitsina (1996a) notes that it was based on the communist ideology. The textbooks and manuals for defectological faculties of pedagogical institutes, especially in pedagogy, were so politically orientated that whole chapters and sections were devoted to the theory and practice of communist education of children with problems in hearing, speech and other disorders. However, it also ought to be mentioned that the field of Russian psychology is rich with the contributions of eminent Russian psychologists, such as A. R. Luria, A. A. Leontiev, D. B. Elkonin, I. P. Pavlov and others. And not to forget L.S.Vygotsky who has had a positive response in the western countries. His theory of deficiency compensation emphasises the social aspects of defectology (or having a disability) that while the personality of an individual with disabilities is a blend of both biological and social factors, social factors play the primary role. Csapo (1984) discusses specific contributions of Russian researchers in the area of special education. There are reasons to believe that the psychosocial aspects of disability have been strongly underplayed in teaching and care in Russia.

SOME IMPORTANT CHARACTERISTICS OF THE SYSTEM

Several ministries are responsible for special establishments for children with special needs. Children from birth up to three years of age are brought up in establishments run by the Russian Ministry of Health. From their third year, the majority of children move into pre-school and school establishments of the Ministry of Education or the

Ministry of Social Affairs. Older children with deviant, delinquent behaviour are placed in special schools and vocational schools of the Ministry of Education. As pointed out by Shipitsina (1996b)

Interdepartmental barriers interfere with the creation of an integrated, harmonious and effective system of social help and support for the most vulnerable and defenceless section of the population (p 40-41).

She also draws attention to the fact that statistics concerning the numbers of children with developmental problems, for a long time, were unavailable, and that there is no database of all children with problems and the totals undergoing various forms of training. The reason for this is connected with interdepartmental barriers, different approaches to accounting adopted by Ministries, and variation in the classification and categorisation of children's problems. Malofeev (1998) underscores the lack of reliable statistics for the same reason as above. He draws attention to the fact that the statistics only include children who participated in the existing system. Lubovsky and Martsinovskaja (1994) also underscore this. Developmental disabilities are registered according to the indices of children enrolled in special educational institutions. Because the available institutions cannot provide all children in need with education, these indices are much lower than the true number of developmentally disabled children.

THE LEGAL FOUNDATION OF SPECIAL EDUCATION

Lubovsky and Martsinovskaja (1994) say that educational institutions for children with developmental disabilities are a fundamental part of the public education system of the country. Then they continue:

Separate law regulations speak for children and youngsters with physical and mental disabilities preventing them from studying in a regular general school, and stress the need of special educational environments. (p. 262)

According to Korkunov et. al. (1998) probably the greatest shortcoming for teaching exceptional students is the lack of relevant legislation. The only legal document

regulating Russia's special education system is a law that was passed some 70 years ago under the Soviet regime and provided compulsory education for children with handicaps. Malofeev (1998) says there has been no formulation of a uniform governmental policy aimed at resolving the problems of children with special educational needs. There are not yet specific laws addressing the needs of individuals with handicaps or about special education; therefore, legal guarantees about rights to education of this segment of the population are not yet in the place (p.184). According to the same author through the initiative of professionals in the Ministry of Education of the Russian Federation, a group of specialists is now working on formulating a new law addressing special education.

FUNDING MECHANISMS

When I asked my interviewees what they considered to be the most important barrier to improving care and special education for disabled children almost all of them mentioned economy. The financing of education, public health services and other branches of the social services has to be met mainly at the expense of local budgets, which has exacerbated regional variations in quality of life and conditions of children in Russia. The financial assets of a special (remedial) establishment consist of budget assignments, means of the founder, bank credits, means of the sponsors, plus other sources. An establishment has independent control of their budgets and expenditure, though it must have the necessary material base for all educational purposes, including remedial lessons, curative-recovery work, vocational training, day-to-day expenses, and so on and so forth.

DEFINITION, ENTITLEMENT AND IDENTIFICATION

According to the law from 1931 all citizens are entitled to education. But, there is presently no uniform legal definition of special education in Russia. The specific laws, regulations and curricula of different educational institutions define special education. The medical-pedagogical commission makes decisions about special education of a child. In practice this is a decision of placement in an educational institution. According to Shipitsina (1996a p.11) the acceptance of the Law of the Russian Federation 'About Education' (1992) give parents and children an opportunity for

choice among different forms of education (at special schools, at residential schools, in rehabilitation centres, by integrative education in mainstream schools, home education, external education. This freedom of choice seems to be only theoretical for most parents.

For many years in Russia regional medical-pedagogical commissions carried out the selection of children for special establishments. They include representatives of regional education departments, public health and social services, and also physicians, psychologists, and special needs teachers. However, they are being replaced more and more by psychological-pedagogical consulting centres and rehabilitation centres. Theoretically spoken, a psychological-medical-pedagogical consulting centre (PMPCC) is a diagnostic-remedial establishment. PMPCC is an interdepartmental, continuously running structure; in its activities it follows the Convention of United Nations regarding the Rights of the Child and the current legislation of the Russian Federation. The main aims of a PMPCC are to discover, and undertake the complex assessment of developmental disorders in children, and those children who are regarded as being 'at risk'. They also work out individual remedial programs and make recommendations concerning suitable placements of children in certain types of special establishment, and about the upbringing of a child with problems in education or in the family. The PMPCC offer consultative help and methodological guidance to teachers, physicians, psychologists, social workers, and parents on the rehabilitation of children with special needs. The PMPCC is an interdisciplinary regionally located board of expert consultants and based on principles nominated by local authorities. In reality the work of the commissions is seriously hampered by their present workload. Korkunov et al (1998) draws attention to the fact that there is 1 PMPCC per 120,000 children. Because children with special needs make up approximately 8.7% of the population, each PMPCC is responsible for the placement of approximately 10 000 to 11/000 children. Unfortunately, in addition to their extremely heavy workload and the lack of adequate resources, the main task of the PMPCC is placing children in existing special education facilities, not determining the unique learning needs of the children who are brought to them for diagnosis. Vladimir Lubovsky⁷ has recommended lowering the number of children per

⁷ Personal communication with dr. Lubovsky

commission. He thought 10 000 children were a recommended workload for a commission. As a consequence of the workload, he told, there is little of needed consultative work with parents and little professional follow-up. His advice to a committee in the DUMA had not been followed up he told, probably for economic reasons.

CATEGORISATION OF STUDENTS IN NEED OF SPECIAL EDUCATION

Students are categorised and classified according to age levels and according to a rather sophisticated pattern of special establishments. Shipitsina (1996b) and Lubovsky and Martsinovskaja (1994) describe the structure of the special education system in Russia. The following brief summary is based on Shipitsina (1996b):

- i. special remedial educational establishments for students with developmental disorders;
- ii. special establishments for bringing up and educating children and teenagers with deviant behaviour;
- iii. Boarding schools and children's homes for orphans and children not in the care of their parents.

Within the first category and partially also within the third category there is a further branching into eight types of special remedial establishments:

- For deaf children (including classes for mentally retarded children);
- For children who are hard of hearing (including classes for mentally retarded children);
- For blind children (including classes for mentally retarded children);
- For visually impaired children (including classes for mentally retarded children);
- For children with severe speech and language disorders;
- For children with movement disabilities (including classes for mentally retarded children);
- For children with learning disabilities and
- For mentally retarded children (including special classes for severe mentally retarded children and classes for children with multiple and complex disorders).

For children and teenagers with deviant behaviour there exist three kinds of establishment for upbringing and special education:

- Special educational school;
- Special vocational technical school;
- Special remedial comprehensive school and special remedial professional technical school for children and teenagers with problems of development (learning disabilities, mild mental retardation) or with socially dangerous behaviour.

PLACEMENT OF STUDENTS IN NEED OF SPECIAL EDUCATION

Due to a rather complicated administrative structure in Russia statistics concerning special education may be unreliable. However, this may also to a somewhat lesser degree be the case in western countries (OECD 2000). Placement statistics seem to be the most reliable.

According to the last data mentioned in the report of the Minister of Education of the Russian Federation (1995)⁸, there are today about 7.5 million children and teenagers having disorders in the neuro-psychological sphere in Russia⁹. Only 355 thousand of their number are educated by teachers with special training and receive regular qualified help from physicians and psychologists. The majority of children with neuro-psychological problems (more than seven million) are educated at regular, mainstream schools by teachers who do not have special training. From this number, there is a high proportion that is lagging behind academically, who are delinquents, and so on. Material presented by Malofeev (1998) indicates a prevalence of 8.7 % of disabilities in the 6 through 16 age groups This seems to be very similar to the prevalence in the USA. The highest prevalence are found for 'delay in psychological development' (2.40 %), 'speech defects' (2.30 %), and 'mental defects' (2.35 %). These groups represent above 80 % of the total disability population.

⁸ The State Annual Report. Situation of children in the Russian Federation: 1994). Moscow: House.

⁹ Vishnikina (1996) attempts to classify handicapped children in Russia into different etiological groups

Data from the State Statistical Committee of the Russian Federation¹⁰ found 278000 students in 1842 special schools for the eight legal categories of students in 1994/95 and a total 151 000 students (mentally retarded and students with learning disabilities) in special classes in regular schools. In addition 140 000 were in pre-school institutions. The predominant number of schools cater for the mentally retarded (App. 80 % of the schools and app. 80 % of the total special school population). Special classes in regular schools cater mostly for students with learning disabilities (app. two thirds of the students). Statistics show an increase in the number of classes in regular schools for students with learning disabilities and only a moderate increase in the number of children transferred to special schools. According to Malofeev (1998) the number of special classes have increased more than tenfold. With reference to these statistics Shipitsina (1996b) concludes:

These results show that in Russia there is clearly a gradual trend and natural tendency toward integrating the education of children with developmental problems into regular mainstream schools. (p. 47).

I would like to add, however, that this trend is most pronounced for students with learning disabilities. A parallel trend is not well documented by the statistic for the other seven groups of students.

PROCEDURAL SAFEGUARDS

There are certain procedural guarantees:

1. The parents must agree to the evaluation and placement of their child. If the child is sent to a boarding school, it is necessary to obtain written agreement from the parents.
2. The evaluation must be carried out in the child's native language and the results explained to the parents.
3. Tests and tasks should correspond to the family's social-cultural level.

¹⁰ Cited in Shipitsina, 1996b p 46. Cf. Even Malofeev (1998 p. 183)

4. If parents have serious concerns about the qualifications of the staff, they have the right to apply for another consultation.

The referral of children to a special educational establishment by the management bodies in Education follows from the conclusions of a PMPCC, with the consent of parents or guardians, or other substituting person. A referral of students to special classes for mentally retarded children, or for children with multiple complex disorders at special establishments, takes place with consent of parents. Decisions are based on PMPCC conclusions only after it has been ascertained that their poor progress over a period of not less than a year and is caused by mental retardation or multiple disorder. But, according to Korkunov et al (1998) the current delivery system does not provide for any meaningful input by parents about placement or programmatic decisions. Although there are regulations that require that parents give consent to testing and placement, in reality parents have little choice but to agree to the placement in existing programs if their child is to receive any education. They conclude:

In reality, there is little choice in placement or in alternative consultation at this time. As a result parents acquiesce to a system in which little attention is paid to the specific needs the child. (p.189)

The free interplay between parents and professionals as regards decisions may be seriously hampered by the present economic situation. For many parents placement may be considered as a relief of an economic burden. For special schools placement of a child means increased funding. In Russia diagnosis may have a high economic value. But, of course this phenomenon is well known from countries with a much better economy where classification of children into specific diagnostic groups may radically improve the funding for their education.

THE FRAMEWORK FOR EDUCATIONAL PRACTICE

First, it should be underscored that great progress has been done in Russian special education research (Csapo 1984; Korkunov et. al 1998). Results and concepts from this research have also been successfully applied in the West. However, there has

not been established a uniform framework for special education practice as regards goals, curricula, quality criteria, individual programming and transition. The special school curriculum is different from the general curriculum (Lubovsky and Martsinovskaja (1994 p. 268). As pointed out by Shipitsina (1996b):

These establishments try to help the child to find his or her place in the world." To do so a general version of the curriculum is needed and a standard of education in conformity with the demands of society, and its socio-economic conditions. (p. 53-54)

The medical- pedagogical commission mainly makes placement decisions. There is no uniform system for individual planning in Russia. The same is the case with transition planning. However, alongside the traditional types, there is being created a new kind of special establishment; these are called rehabilitation centres. Today in Russia there are more than 110 different centres of rehabilitation, more than 30 of them situated in St. Petersburg alone. These establishments, as a rule, are multifunctional. They include diagnosis, development, remediation and health improvement.

On this background the principle of integration, in the sense of participation of students with learning disabilities in regular classes, is presently not the chosen placement alternative in Russia. However, there is a substantial increase in the number of special classes located in regular schools hosting children with learning disabilities. After a number of years of study children with less severe disabilities may be placed in regular classes.

Teacher training is of course an important factor for improving special education practices. Lubovsky and Martsinovskaja (1994) say that only 13 to 15 % of the teachers in special schools have special training. This may be different for different regions of Russia. Korkunov et. al.(1998) stipulates the proportion of teachers with special training in special schools to be 9 % and the proportion in the Sverdlovsk region to be 30 %. Thus one may conclude that teachers without special training teach most children with disabilities.

FUTURE DIRECTIONS

All authors draw attention to the fact that important changes are taking place in Russia. These changes are characterised by a more humanistic approach to education, adoption of multiple textbooks, decentralisation of the delivery of education and improvement of funding. All of them also look for important changes to be made. The wind of change in Russia is grasped by Shipitsina (1996a) when she says:

In the present period of social-political development of Russia new perspectives for change in the system of special education have opened. They are connected with a new attitude towards children with special needs and with solving the problems of their socialisation and integrative education. (p. 11)

As regards the direction of change most experts seem to find it necessary to preserve a parallel system of special education. Lubovsky and Martsinovskaja (1994) find the idea of educational integration of children with development disabilities attractive for parents and progressive, but they do not think that present conditions in Russia are favourable for widespread introduction of the integration approach. They assert that better provision for children with special needs in the near future should be connected, first of all, with the improvement of the institution (p. 272). They keep the door open for integration, however, by saying that where it is possible to provide developmentally disabled children's education in the general system with qualified staff, such attempts, as an experiment, should be made. It is also most expedient to apply integrated education to such groups that up to now have been pedagogically neglected. These groups are children of an early age and pre-schoolers. Shipitsina supports these views. According to her future development is connected with further completion and perfection of the existing network of remedial schools, with the occurrence of new types of establishment, where there is complex help and support to children with special needs, and also with the integration of these children into regular schools. This preservation of a parallel system is also supported by Korkunov et. al. (1998) who believe that Russian special education could follow one of three different paths: (a) destruction of the present structure and the development of a new one; (b) duplication of one of the Western models; or (c) preservation of the present

special education system while a parallel system is created that would follow Western practice. The authors believe that the third alternative is the most expedient.

Thus one may conclude that extensive application of the principle of integration is not considered to be an alternative in Russia at present. This view ought to be considered in the light of the present economic situation in Russia and the role of institutions catering for persons with development problems by giving them shelter and care. As pointed out by Jones (1994 p. 9) for the mentally retarded there is no alternative to life in institutions. The present concept of defectology that focuses mainly the severe part of the disability population does not seem to give an adequate theoretical foundation for handling the problems of a growing number of individuals with learning disabilities and behaviour problems. This raises at least the demand for diagnosis and prevention of disabilities, rather than mere treatment in rehabilitation of disabilities after they are evident. There is also a need for a restructuring of the educational system in general, and the incorporation of standardised diagnostic methods into the arsenal of school psychologists.

Another factor restricting integration is connected to the Russian school system (cf. Brown, Kaser & Smith (1994). Moss (1997) summarises the development of education in different periods. The basic controversy seems to be the conflict between state control imposing uniformity and conformity and the demand for flexibility and adaptation to student needs. Two factors have been important for this balance: The quest for state control over education and the assumed need for the natural sciences and mathematics in the rebuilding of the Soviet society. Another important factor is related to the role of the social sciences. While the natural sciences have developed the social sciences have been dominated by Marxist-Leninist thinking leaving little room for studying the reality of the society. Now this is changing. Developments in the direction of flexibility and freedom after Gorbachev have, according to Moss (1997), been greatly hampered by lack of resources. In any case there doesn't seem to be sufficient room for integration in Russia today without changes of the present education system. There are four important dimensions of change (Jones 1994): From uniformity to diversification and individualisation; centralisation to decentralisation; from planning bureaucracy to humanism and motivation; and from theoretic to pragmatic.

Grigorenko (1998) draws attention to the fact that the current economic and political changes in Russian society are leading to a huge social differentiation and that the economic stratification of the Russian population is much greater than before. He refers to research that shows that 80% of high-income families support the idea of differentiation of education in Russia. Thus the structural conditions in Russia for an education providing equal opportunities for everyone in an integrated way is seemingly weak at present. With the purposes of unifying the demands within the general system of education in Russia, Shipitsina (1996b) points out that the curriculum of special (remedial) schools of all 8 kinds should be based on a general version of the curriculum. This is necessary in order to create equal educational alternatives to similar categories of children in different alternatives (special school, integrative education in regular school, home education), to help children to become integrated into society and to adapt special education to the needs of society. Lubovsky and Martsinovskaja (1994) also stress this latter point by demanding that the curricula of special schools must be aimed more at the students' socialisation, their practical training for every-day life, and less at the general education level corresponding to the contents of the regular school education. Such work has already started. The traditional model of rendering help through a centralised bureaucracy ought to be replaced by regional special education systems. Laws and funding should support such systems. Other demands mentioned are the creation of a broader number of options for children with disabilities, provisions for disabled children within regular schools and the training of specialists who are able to support children in the process of integration. According to almost all authors cited the most pressing demand is a new law addressing special education and a uniform governmental policy aimed at resolving the problems of children with special educational needs would help to correct existing inequalities.

SOME TENTATIVE CONCLUSIONS

Even if there are some approaches between systems indicated by a growing number of special classes within regular schools Russia has a strict parallel system of education with low level of integration between regular and special education. Literature available to me does not show that the state is adopting any new policy that may change this situation. A rather rigorous distinction between what is normal

and what is abnormal and a halting economy serve to maintain the present situation. This situation seriously constrains the possibility of special education practice. Due to the parallel system and a too heavy workload the medical-pedagogical commissions use most of their time to select and place children in institutions and special schools. The individualising and de-normalising character of the present defectological model on which professional work is based serves as an integral part of the parallel system and by its distinctions between normal and abnormal may serve to maintain the parallel system.

Taking the point of departure in the present state of affairs professionals in the field do not recommend a rapprochement to the western integration model even if they say to support this model. In order to understand their position the context of education has to be taken into account. Conditions for social analysis of disability has not been favourable in Russia. This may have delayed the adoption of social principles into special education as well as critique of the present system. In addition, the centralised character of organisation and curricula of the general education system may have created positive attitudes towards differentiation of students in education and in the general public.

PART TWO: INTERVIEWS IN RUSSIA

Respondents in Russia are listed in the following table.

PERSONS INTERVIEWED IN RUSSIA	
Type of stakeholders	No.
Parents	4
Teachers	4
Directors & Principals	4 ¹¹
Training & Research	1
Executives	0
Psychiatrist	1
Medical doctor	1
Total	15

All interviews were done in the Arkhangelsk region in North Western Russia. I do not claim that the answers given to me in the course of these interviews are representative in the traditional quantitative sense of that word. There are reasons to believe that the biggest differences in Russia are the differences between Moscow and Petersburg on the one side and the Russian periphery on the other side. Asking Grigory - one of my interviewees who is an experienced psychiatrist - about these differences he replies about Moscow *There are other kinds of problems, other kinds of economical situation, other kinds of mental positions and social situations and environment for people.* And then he continues:

Yes, the differences are great between the different parts. Moscow is the country, and Moscow has the president. The only thing we have together is the Russian language. Other things are different.

Well, I can only reflect on what answers I had got to my questions in Moscow and Petersburg. Maybe Grigory gives me a hint by saying that Moscow is close to Great Britain (where he has actually lived). There are most probably more options for

¹¹ Persons classified as directors in Russia are mostly professors (of medicine), medical doctors, or psychologists

disabled people, more flexibility and higher levels of training of professionals - more progressivism. But still the question is if this is typical of Russia?

The project leader at a child development institute that focuses disabled children assisted in the selection of the interviewees and initiated the contacts with them¹². This was necessary because of my lack of sufficient knowledge of the system that would most certainly have hindered me from reaching the right persons. In addition, the language problem ought to be mentioned. Not having command of Russian I needed someone to interpret and to transcribe interviews. This, of course, has social consequences for communication and for the use of time. The tedious process of first raising the questions, translating them into Russian, and then translating the answers to me take time. Due to this interviews in Russia become somewhat abbreviated compared to the other countries as I promised to keep the interview within an hour.

What people told me can of course not be separated from my perceptions. These perceptions are selective and based on my own cognitive organisation of the problems raised in the interviews. Communication is a question of coding and encoding. Therefore, it is necessary to reiterate some of my assumptions about the role of parents and their way of responding to the interview. In the second report of the project (Stangvik 2002b) a number of assumptions were made about the role of stakeholders and their perspectives on special education. The point of departure was that such roles would inflict upon how they judge which qualities should be given priority. These assumptions will be briefly discussed in front of each section of interviews. In the report different knowledge paradigms met in special education are also discussed. This discussion may be said to stage my approach to the interviews.

¹² I am very much obliged to Olga Kagan of the Child Development Institute at the Pomor University for this help.

THE SOCIAL AND PSYCHOLOGICAL CONTEXT

The social context of the interviews has been discussed in the first part of this report. A brief summary may be in place as an introductory note to the interviews as there are characteristic features of that context, which may have a tremendous impact on how people respond to my questions as regards the care and education of disabled people.

SOCIAL AND EDUCATIONAL ASPECTS

A lag of 20 years for special education was stipulated for Russia compared to western countries. Studies of the literature indicated that this developmental lag have many causes. Presently, the primary barrier to development seems to be economy. Families with disabled children often feel themselves compelled to accept offers to have their children placed in institutions and special schools far from home because they are unable to give their children the necessary support. Such placement decisions are also favoured by the lack of public support in terms of a varied educational support system and sufficient disability pensions. Parents may simply feel unable to offer their disabled children proper medicine and clothing. In this situation parents may perceive the institution or the special school like a shelter for their disabled children. If they decide otherwise the home becomes the arena for care and education. The mother staying at home to take care of her child will of course increasingly affect the family economy. This is a particularly vicious circle in a country where statistics may indicate that over half of families with children have as average income below one half of the survival minimum.

However, the situation of the disabled and their families is also affected by other factors. Society and public education seem to have been governed by strong normalising judgements as regards performance and behaviour. Such attitudes towards deviation seem to have been particularly strong in the Soviet era and served to increase the isolation of disabled people from society. As a part of this an institutional archipelago has been built up catering for all kinds of deviating people. Such normalising judgements also seem to have been prominent in the school system defining rather clearly who may pass as a student in the regular schools.

This has not given much room for children with disabilities in these schools. Even if this situation is changing today the principle of integration may seem a little odd in the Russian setting. But, there is still more to it.

The medical-pedagogical commissions became an integral part of this institutional system with the main purpose of selecting children to the different establishments. Having an enormous workload the pedagogical part of the work necessarily suffered and the probability that the commission can do anything substantial about the social situation of the child and the family is low. Still they would have the power to control the situation of the family and their decisions about the future of the child.

Defectology is an important part of this management architecture. Grigorenko (1998) discusses the theoretical foundation of defectology and shows how the social aetiology of disability present in the theories of its founder - Lev Vygotsky - come to play a minor role during the Soviet era. The subdivisions into disability groups came into focus and carried over into the special school system.

To provide a theoretical and methodological basis for the functioning of special schools/ a particular profession, "defectology," was developed, and specialists in anomalous development and special education became known as a 'defectologists." (Grigorenko 1998 p. 194)

Grigorenko (1998) also asserts that when the whole society and the general educational system are undergoing structural and functional changes, special educational services continue to proceed in the "Soviet direction" still ignoring the practices of screening, identification, and prevention.

PSYCHOLOGICAL ASPECTS

To friends and colleagues in Russia I raised the question of trust as I consider trust between people to be a core element in productive communication. One of them wrote to me *that Russians wouldn't tell everything to someone they don't totally trust. They like to have a personal relationship to people.* I find this attitude quite understandable taking history of political oppression into account. In this situation the family may be considered as something of a "safe heaven" in a social turbulent world. What happens then when a family gets a disabled child? When I asked about their situation I am told

Russia has a problem of negative public attitudes towards individuals with disabilities. But now they are becoming "more rightful" members of the society so they are uniting together in organisations and speaking out for their rights.

Further commenting on their situation he says

Before being a handicapped person was a tragedy for a person, but not now, Now it is just that the state does not care about them. Their privileges are very few - they get about 300 rubles a month and are unable to buy medicines and food with that money.

I do not pretend to understand the psychological and psychiatric impact of the social and economic circumstances in Russia. But, it seems reasonable to me that these circumstances must block satisfaction of basic needs related to safety, security and social and economic survival, and one would also expect a strong element of uncertainty about the future.

Grigory is one of my interviewees. He is a psychiatrist. Psychotherapy is his main line of work. Grigory also has a solid experience from Great Britain, Sweden and Norway. When I ask him about the problems he meets in his work he replies:

The situation in Russia is very difficult now. The most important thing in Russia now - not only in Norway - is the very high level of anxiety, and an anxiety higher than in other countries. The next is that every patient who comes to me has a lot of problems.

Anxiety is the basis, he says, on which all other problems grows. *They are rolling up these problems every day and they are not solved, it is not possible to solve them,* he says.

For example problems with the flat, small flats, too small flats. I have some patients who live in one single room, five or seven people, and of course it is a very big problem for them. They meet each other every day and they must do because they have nowhere to go.

What are the consequences of these situations? Grigory draws attention to alcohol problem, aggression, criminal behaviour and suicidal attitudes and behaviour. When I discussed the possibility that the psychic situation in the country might be observed in people's behaviour and hinted that I felt that they had such closed faces when I met them in the streets he replied:

It is not a habit for Russians to smile. Most of them who go along streets think, "How can I live next day?» Where shall I take money to live, what to do with the flat. They have a lot of problems to think about and it is not adequate to smile.

Then he tells me about an event, which is very illustrating. Returning from abroad where he had got used to smiling the staff at the airport took him to be a foreigner.

*"Would you please...." They took me for a foreigner because I smiled!
You can take it as a real feature that proves our psychological position.*

The country is in state of change conveyed by words like glasnost and perestroyka signifying rebuilding of society and the creation of an open public debate as regards the past, present and future of the country. This situation may have vast psychological consequences. Lack of expected economic progress may have turned those words into invalid promises, prolonged feelings of distrust to society and feelings of hopelessness and dissolution.

Grigory uses kindergarten as a metaphor in order to explain the mental changes he tries to foster in his clients.

Our country before perestroyka was as a very big kindergarten, and we were as children because there was dictatorship, and when there is a dictatorship people are children, they cannot live themselves, they must only follow leaders. So we were children and perestroyka opened the door. So it was up to us to go out the door and live, as we liked. But we could not live, as we liked, we had not had the history to do so.

They who were at the top, the komsomol leaders, the communist leaders, were more adults than most of us, Grigory says. Then he continues:

...and they had more speed to move. 99% of the people were like children. Now, we are getting more adults. We are learning to live as adults, and this is the most important thing about before and after the perestroyka.

Grigory expands his metaphor a little more for me by saying that in the kindergarten we have meals 3 times a day, we can be relaxed. We have something to eat and something to wear. Everything is organised. But now, we must think about everything ourselves. So I have all the habits from the past, it is difficult to change them; it is painful to change them. This is particularly difficult for the parent

generation who have more old habits, Grigory says. They say, «it is so difficult to live here now».

WHAT PARENTS TOLD

I have previously asserted (Stangvik 2002b) that the parent perspective is holistic and predominantly personal, life-oriented and social. The source of information of the parent for judgements is the subjectivity of the child exposed in the intimate parent-child interaction in all domains of the life-space and related to the long-range perspective of their relationship. The parent perspective in general is different from the perspectives of teachers, managers and policy-makers. The perspectives of the latter are particularistic and related to their formal roles in the management system. Their perspectives are defined by their role functions and work settings and perceived as complementary to their perception of the function of the system they work in. These definitions and perceptions may seriously restrict the understanding of the educational and developmental needs of individual with disabilities. Consequently this restriction is bound to affect their perception of quality as important areas of support and goal attainment are kept outside their space of action. Attempts to solve this dilemma by means of interdisciplinary organisation have not been very successful (Stangvik 2001).

GALINA

Galina is a teacher in higher education. She is divorced now. Her daughter Larissa has cerebral palsy. Larissa is married and perceived as successfully integrated in society. Hence, Galina's experience covers Larissa's life from birth to adulthood. So, there are all reasons to listen to her story.

Struggling to become normal

The fight for normalcy is an important aspect of Galina's account. It is present in her outline of Larissa's educational career.

1. Galina considered Larissa to be well prepared to start in the first grade. The pedagogical-psychological commission thought differently and Larissa was transferred to a boarding school for children with cerebral palsy. Galina comments

on this decision by saying: *We couldn't avoid the system here and she started in a boarding school for the cerebral palsied*

2. After four years at the boarding school, Larissa herself took the initiative according to Galina to be transferred to an ordinary school. She passed entrance examinations and continued her schooling in ordinary school
3. After the ordinary school she continued her studies at the university

About Larissa's school years Galina says:

To her privilege she succeeded in arousing interest from her classmates. Interested boys and girls surrounded her and when we look at social hierarchy in her class she was a leader

I take this to mean that children should not be judged by their disability alone (as supposedly the pedagogical-psychological commission did when they decided to place Larissa in a boarding school for the cerebral palsied), but one should listen to those who know their personalities.

This quest for normalcy is reiterated many places in Galina's account. Commenting on Larissa's marriage she says:

I would like to underscore that she like all other ordinary people should have all positive things from life, and on August 6 this year she married

This clearly expressed when she talks about how she brought up Larissa.

In Russia the physical condition is often given priority while the psychic condition and health often has no priority. I believe that the most important result I managed to achieve is that she grew up to become a psychologically normal person.

This feeling of having managed with her upbringing of Larissa against all odds is strong in Galina. For a handicapped child schooling and upbringing seems to take place in a rather hostile context. Larissa always has to demonstrate normalcy in order to pass. This is also the case when she is looking for work.

Now at this stage of her development the most important thing is to find a job. It is twice as difficult for her than for other people. Without her physical

defect she would have got every kind of job, but in our society she has to prove that she is a normal human being

When I asked Galina what she meant by using the word normal when she talked about Larissa, she answered *I know that she will never be a cosmonaut, or a ballerina, but she must get from life all the things that so-called "normal" people get from it.*

When I asked Galina what she thought about her daughter's future she said:

I believe my daughter will manage. Since childhood she is used to stand up and fight. I read once that the three most important things for the human personality are engagement, anxiety and volition. She has all the three and that all she needs

What Galina told me is that it is important to be treated as an ordinary person and to live a normal life. This doesn't come easy, however. One has to fight for it.

Society is perceived as a rather hostile place for a mother with a handicapped child. When I ask her directly about attitudes from society she characterises these attitudes as *reserved and aggressive*. Galina, being a strong person, has the ability to step out of her own situation and to take a look at her society. To be treated humanely is not only a problem for Larissa, but for most people with disabilities. She sees the way disabled people are treated in her society as an important indicator of humanity.

I believe that at the brink of the third millennium it is necessary for society to develop an index of humanity "acceptance of children/adults with developmental disabilities". Scientists should develop criteria for such an index. It should be an international concept ... We might compare it to environmental protection which has involved many important people

When I asked Galina if she finds any tendencies in Russia to develop such an index she says *I do not believe there is such a tendency in Russia. Society is not ready.* I take this from Galina to mean that the economic motive tends to suppress humanity.

A pair of good shoes for Larissa

Galina doesn't hold the support system very high when she says

It is a paradox in our society that people who work with these kinds of questions are very far from the problems. I believe most people know that a great part of the economic resources is used to pay bureaucrats who pretend to work to change things, but in reality there is no help to get

She gives several examples to verify this. Being unemployed and staying at home to take care of Larissa she was entitled to 2000 rubles (\$ 100). I contacted the office, she says, in order to get the money. Then she said she had to append documents that verified that her daughter needed specific medical treatment and concludes ...*instead of 2 000 rubles I got 100. Converted to dollars I got \$4 in stead of \$ 100.* Winter is coming soon and Larissa needs a pair of shoes. Because of her condition, Galina says, she needs a special orthopaedic shoe, or a good shoe like Ecco. Such shoes cost 2000 rubels in Russia. Explaining her situation to me Galina says:

It was easier to solve these problems before. I was married and we had a better economy. It is more difficult now. I can't always explain that my daughter needs a special shoe that costs 2000 rubles.

When I asked Galina about what support she had got, she said:

I believe the only one type of help we have got with relatively little humiliation is the pension of 300 rubles (\$ 10) I get. But to get the pension we had to have an assessment each year by a commission that verified that the level of disability hadn't been changed

To raise a handicapped child is a woman's task

Galina tells me about her general experiences of the impact of children with disabilities on the family.

To my experience 80 % of families with a child with developmental disabilities are divorced after the birth of the child or after a time. For 10 % of the families that stay together the father starts to drink. For just a small percent of the cases does the father play a more important (than the mother) role in the habilitation of the child.

This has also been the case for Galina and her family. She feels that she was the only one that really took care of Larissa, taking her to treatment and so on. She did this, she said, to protect her family. She excuses her previous husband from this lack of participation by saying that it was difficult for him to do these things because of heart problems, and that he was able to make a career in his work. Galina just describes their situation and doesn't in any way accuse her previous husband. The

situation even had some merit. *It gave us the possibility to give more to the child, and to be independent of the state, she said.*

But, there was more to it than participation and division of labour.

It is difficult, psychologically, when we two people look at each other and ask who is responsible for this. Society in general, immediate surroundings, and relatives may think that the woman gives birth to the child so she must be the guilty one

Becoming immune: The protective cocoon of a healthy personality

The preceding sections may explain how Galina thinks about Larissa's upbringing. Galina conveys a feeling of having raised Larissa in a rather hostile social context as well as a feeling of her strong need to become independent and to control this context. This may explain why she tried to impute certain qualities in Larissa:

I don't know if I have done this consciously or unconsciously, but I utilised all my capacity in order to develop my child's intellect, and that part of the intellect that we may call humour. Later this has been very useful to her. She has attained an immunity that may protect her from negative reactions from society. This has given her some privileges

In another part of the interview Galina says about the educational situation of Larissa:

Now she has been studying for five years at the university, not due to our present health care and system of rehabilitation. We should rather say it is the other way around: She managed to become a student in spite of this system

As pointed out earlier to achieve psychic normalcy is very important for Galina. She feels she has helped Larissa to achieve this. This is indicative when she reports from Larissa's own account from a trip to Turkey.

Another thing she told was that she surprised people by not having a low self picture, and after a while they began to communicate with her as if she didn't have any defect

SUMMING UP

What Galina conveyed to me, under the restrictions of a short interview done by a foreigner with help of an interpreter, may be taken to express how she organises emotionally and cognitively her experiences of having a child with disabilities.

The interview indicates there may be several antecedents of these thoughts and feelings. The feeling of being confronted with a negatively reacting context that offers little support neither from society nor from partners is one of them. This feeling seems to be coupled with a strong will to master and control this context and against all odds help her child acquire a social and psychological normal role in society. In this situation to help Larissa to develop psychologically seems most important to Galina. To Galina humour, a positive self-concept and optimism seems to be keys to Larissa's mastery of valued social roles. If a girl like Larissa meets all these problems what about children at lower levels of function?

RIMMA

Rimma was interviewed at the location of a class for children with disabilities, which has been established as an adjunct to an institute of child development. Her boy had been approximately one year in the class when I talked to her. He was born in 1991 with cerebral palsy. He was diagnosed with this disability one year after birth. Rimma comments on this by saying *...because of this it was too late.*

Squeezing an elephant through a needle's eye

Asking Rimma what she thinks is the most important thing working with these children she spontaneously replies *...to love them.* And to her the most important things for her son just now are to learn to read and to walk independently. These things are not easy to fulfil.

When I asked about the boy's situation Rimma said:

We have tried to find a place for him in the CP Centre for my child to be educated there, but he was rejected because of his movement problems. This was the centre of Olga Bogdanova. And we came here by

coincidence. I read an announcement in a newspaper about this class. That's why we are here

Asking her about the previous situation she told:

We were first at home. Then we went to a kindergarten for children with developmental problems who didn't have cerebral palsy. The defectologist in the kindergarten told that the kindergarten was not suited for my child and that he had to go to a special centre

She was offered a teacher to teach her boy at home. She comments on this by saying: *But this wouldn't give him any opportunity to communicate with other children*

The special education career of Rimma's boy may be described in the following way:

1. Rejected from a kindergarten for children with development problems by advice of the defectologist
2. Rejected from a centre for children with cerebral palsy because of his movement problems
3. Offered to be taught at home
4. Rimma rejecting this offer because she wanted her son to communicate with other children
5. Finding a place for her boy in a privately established class for two years
6. Future placement undecided

Because of all this Rimma now stays at home to take care of her child.

From this it seems clear that ordinary school has never been an option. To my question about this Rimma replies:

Maybe. I know a lady who has a disabled daughter in ordinary school. She is lucky. The class is friendly to her daughter. But, here we have to talk about funding. Our schools are not suited for these children. There is no special equipment, pools, etc.

At the bottom of the pyramid of needs

To satisfy basic need is primary. The biggest problem for them, Rimma says, is the economy. Rimma told she had to take care of the boy, as the father had to work much. To get medicine and shoes for the boy were problems for the family. Rimma says *it is most difficult to buy shoes as he has cerebral palsy and needs special shoes.*

Previously they were able to take the boy to Crimea where he could have a very good treatment. Now they can't go there anymore as the support has been withdrawn.

The main outside support seems to be given by relatives. When I ask her about the public support she answers *I get 450 rubles (\$ 14). 70 (\$ 2) of them is given to me to take care of my sick child.*

Mother is the playmate

Telling about the boy's social situation Rimma says:

In summer we go to our cottage. There he helps us. Usually. After breakfast we do things together, reading or drawing. After that we take a trip, and we play when we get home

To my question about friends she replies *no he doesn't have any friends here. But, when we go to our relatives he plays with his cousins.*

The future

Rimma is anxious about the future education of her son. What is going to happen when the two-year period has come to an end?

I don't think we have any future. Much depends on the government. Nobody knows what is going to happen to us. What is written down in the law is badly put through.

As regards her son Rimma tells that her husband is doing restoration work at a church. They often take their son there, and she says that maybe he will work there in the future.

SUMMING UP

To Rimma and her husband raising their cerebral palsied son is a private enterprise. The state is almost totally non-existent in her story. When it is present it seems to be there in a negative way by rejecting her son to take part in the public educational system. Her son simply doesn't seem to fit in anywhere as shown by the history of

rejection. It seems very clear to Rimma that love is the basis of her boy's education. The main objectives for him are to learn to read and to walk independently. Both these competencies are important for taking part in society. But, to get her boy into ordinary school is a very distant thought. She knows about a lady who has a daughter. That's all. The lack of a social network of children for the boy indicates that this rejection extends beyond schooling. The family seems to be caught in a trap resulting from a lousy economy and a rejecting society. Rimma's story corroborates seemingly well with Galina's even if the prospects are different.

SVETLANA

Svetlana is the mother of Alyona who is a girl with cerebral palsy. Alyona has been two years by now in a class for children with developmental problems¹³.

Take this, or have nothing

Alyona's public history looks like this:

1. Svetlana got an offer to send Alyona to a public institution
2. She didn't accept this offer because as she says *but I wouldn't do this - she was very nervous and restless*
3. Svetlana took care of the girl herself at home, giving her medicine and massage. *But, she says, I am no pedagogue and I can't teach her the right way*
4. She and her husband travelled to different professors and institutes, but were told that there was nothing to do
5. Now Alyona is in this class, and she is less restless. Previously she destroyed books and toys. She doesn't do that anymore

To my question about what Svetlana thinks is the most important thing for Alyona to learn, she replies: *The most important thing for her is to learn to take care of herself, to dress and to clean up around her.* Then she comments, *now I am helping her, but what is to become of her later on?*

The basics of quality

Svetlana's reply conveys to me the contextual character of quality. To achieve some basic degree of physical and social independence is perceived as the primary objective of education. All other objectives are next to this. What to become of her

¹³ The same class as Rimma's boy.

later on if she doesn't master those basic competencies. This is Svetlana's crucial question.

The family's decision not to accept the offer to institutionalise Alyona is also indicative of their concept of quality. They felt that this would further contribute to Alyona's nervousness and restlessness. I take that to mean that they consider the feeling of being safe and secure as an important qualitative dimension of Alyona's life. As we saw earlier in Rimma's case for her boy to be able to communicate with other children was a so highly preferred quality that the offer to institutionalise him - which from a practical perspective must have been much easier for the family - was rejected.

Mother carries the burden

In this as in other cases the father is a very distant figure in the process of caring for Alyona. Yes, Svetlana says, *I have a husband. But he works very much and he is too shy to take his daughter out.*

Svetlana's situation seems to be the case for these mothers. They stay at home to take care of their disabled children, and their husbands don't seem to be there when they are most urgently needed. One explanation is of course the survival needs of the family. The pension they get for taking care of the child is extremely low as shown by previous interviews. But there is probably more to it. The interviews convey a feeling of guilt having a disabled child and maybe a feeling of being devalued by having such a child in a society that seems to worship the perfect person.

SUMMING UP

Svetlana doesn't want to place her nervous and restless child in an institution. She wants her to feel safe and secure and an institution is not the place for that as she sees it. To achieve this she has to pay the cost, the isolation in the home and always looking for some help and support. The social cost the family has to pay is indicated by the lack of partnership with her husband as regards her daughter. And then there is the uncertainty about the future.

LENA AND ANDREIJ

Lena and Andreij have a son, Oleg, who is deaf. Oleg is a well functioning person who even played the piano to entertain me when I visited him. Andrej and Lena seem to be well off and live in a nice and big apartment. They are both medical doctors. They also work to improve the situation of other parents of deaf children.

The interview took place as an open conversation around an excellent dinner table with all the family around. This situation was not planned and a result of insufficient clarification of the formalities of the interview due to the fact that interviews had to be arranged through middlemen. Their perspectives were summarised after the conversation.

This family, too, was offered a special institution far away from home. They rejected this offer for the following reasons: They wanted Oleg to live an ordinary life and didn't want to place him in any special system. They asserted that it was best for him to live at home and to get his schooling in ordinary school. Oleg didn't get any extra support in ordinary school, but here regarded his situation as good.

The family was very critical about Oleg learning sign language and argued that this would create difficulties for him to become socially integrated into the ordinary society.

This family's judgements about education compared very well with the judgements of Galina. She, too, argued very arduously for her daughter to take the ordinary way through school. All these parents are highly educated and their disabled children are rather well functioning. While other parents have to accept the offer of placement in institutions or keep their children at home better-off-parents may find other paths through the system. Therefore, the conversation told me that in Russia as in other countries there are several factors affecting the educational placement and quality of life of a disabled child. The combination a positive family background and a moderate or high level of functioning of the child improve the parents' control of the life situation of their disabled child.

SUMMING UP

For these parents institutionalisation was not an option. They eagerly wanted their son to take part in normal life in society. They even rejected sign language for their son for this reason. Their success seems to be dependent upon their professional and social setting in society. Lack of extra assistance also indicates the lack of options in ordinary school for children at Oleg's high level of functioning.

SUMMARY

These parents all have one thing in common: They do not accept the offer for education and care for their children offered by society. I take that to mean that they find the present institutional system inadequate for their children. And they pay a high cost for their decision, as there are no other public services for them except a small pension that cannot possibly pay for the things their children need. But the cost for them isn't only of economic nature. Mothers have to stay out of work in order to take care of the children isolated in their homes. There is even more to it. The anxiousness for the future of their children is always there. The interviews also indicate that the caring of the disabled child at home arouse an imbalance in the marital relationship mainly due to a lack of sharing by their husbands. Why do they take this decision with all these costs?

It seems to me that the best explanation is that they want to foster qualities for their disabled children that they perceive cannot be achieved by the present system of education and care. Which are these qualities? To be able to communicate with others in ordinary social settings, to feel safe and secure instead of nervous and restless and to value themselves positively and develop and express humour and temperament. These are all qualities I read from the parents' stories. Their perspectives on education and care seem to verify the introductory assertion that the parent perspective is holistic and predominantly personal, life-oriented and social. They clearly perceive that the option they have been offered for their children do not fit their perspective on the care of their children.

The interviews also tell the story of a non-option selective system of public care for children with disabilities. Commissions and other authorities always seem to vigorously claim that parents verify their survival needs and that the children demonstrate that they are able to pass as normal beings. In such a situation parent feelings of living in a hostile society is understandable.

WHAT TEACHERS TOLD

The teacher's role differs from that of the parent in several ways. These differences are bound to affect their answers differently. The teacher's role is ascribed to her through processes of education and experience and performed within a particular cultural system - the schools. The school system is governed by a particular mandate from society and by historically grounded interpretations of this mandate.

Consequently, the conditions of education isn't only to be found in the student herself, but also in how the function of schooling is interpreted in the school culture. Therefore, generally spoken, teacher response to the child is conditional and related to the particular context of schooling while parent response is unconditional. Which goals and objectives should be achieved? How long time is available to achieve those goals? In this process the teacher doesn't only teach, but she also controls and evaluates. In the process she becomes less involved with the child and more oriented towards the child's behavioural and academic functioning in relation to what is considered to be a good student in the particular context. The teachers in the following interviews teach with different categories of children with disabilities in different locations.

THE CONTEXT OF SPECIAL EDUCATION

Blackboards in the kitchen

Marina expresses the educational situation of disabled children when she replies to my question about the placement of children ...*some are in their family and some are in the institution because their parents want so.* And she continues: *One of my students is a girl of fourteen. She has never been at school at all.*

This lack of alternative educational settings is present in the teacher interviews as well as in the parent interviews. If the family deny sending their disabled children to institutions home education is the only option for most of them. Ludmilla clarifies the conflict between legal rights and actual practice by saying

We have a law of education in Russia where it is written totally clearly that parents themselves choose type of school for their children. And if we are unable to persuade parents that it is the best for their children to go to a

special school and they say their child wants to go to an ordinary school so there is nothing to do but to send the child to a special school.

But, as we have seen, parents may prefer the home to these schools. *You know, Marina says to me, in Russia only children with light mental handicap can start at school. As for deep mentally handicaps the ordinary school does not take them.* Marina captures the stress of the family being forced to accept what they see as a non-viable educational option for their child when she memorises a case:

Yes, her mother was going to give her to some institution. You know, when the mother came to our school she was in such an upset condition, but during the time she stayed with her daughter she felt better all the time, and then she began to think it was a mistake to give the girl to an institution.

Larissa, however, succeeded in being transferred to ordinary school and managed well according to Galina. However, for most of the others home education is the only option. For most families the mothers stay at home to take care of the child. In the present situation this of course is a terrible stroke to the family economy.

Anna describes a typical pattern for those mother who continue to work: The child visits an ordinary kindergarten and the mother goes to work. After lunch she takes the child home and has lessons with the child. In reality this is similar to mother education, as the father seems to become a very distant figure in this education process. However, there are several reasons for this situation. One of these reasons is indicated by Anna when she says: *Frequently the mother takes over all the responsibility for the child in the family, and the father doesn't see any other alternative out of their situation.*

Preserving the specialist role

Teachers do try to support parents in many ways. Anna always gives special tasks to fathers and tells that parents may come to the city for counselling and training in order to educate their children at home. *We work in rather close contact with parents, I would say, Anna tells me. We have courses for parents, and we have a kind of "parents university" where we teach psychology of deafness, methods of communication and other educational methods.*

However, these contacts with parents are often somewhat tense. *It is very difficult to follow the parents' opinions*, Nadezhda says. And when I asked Julia about what kind of difficulties she meets in her work she replies *First, there are parents who make problems, their ways are strange*. For deaf children conflicts have to do with the question of teaching sign language. Many parents resist this training. This was also the case with Andreij and Lena. They didn't want Oleg to be taught sign language arguing that this would create difficulties for him to become socially integrated into the ordinary society. Teachers and parents may have different perspectives. While teachers want to initiate communication in their restricted setting of teaching, parents may be occupied more with long-range goals. Discussing the economic situation in the country with Julia she says *Nowadays parents think how to get a job in the future*, and continues. *Parents want to help their children to become adults, to orient themselves in society*. Learning sign language may, in this situation, be regarded by parents as an introduction to a deaf culture that do not support their deaf children in the process of achieving productive social roles in a society in economic crisis. Such differences indicate that preferences for specific outcome of education may be highly contextual.

To acquire an ordinary role

Commenting on the situation in ordinary school, Marina says:

Maybe, because you know when a teacher in regular school has a child with a little possibility, with aggressive behaviour maybe or some bad behaviour the teacher will try to get rid of this pupil and maybe the teacher will stimulate this situation. That is why we open the faculty (i.e. faculty of special education at the university), and I think the main goal of the faculty will be to prepare specialists and their main goal will be to not stimulate such position of teacher.

This ambition to help children to be integrated into ordinary school is very prominent in many of the teachers, like in Anna. When I ask her about the goal of her teaching, she replies:

I want the children to be prepared to the maximum level for school education. Then, maybe, we may transfer some of the children with "light" hearing problems to ordinary schools, or we may transfer deaf children to special classes in ordinary schools

That these processes really take place is demonstrated by one of the teachers who say that four children who had passed the kindergarten stage went to a special class in ordinary school and the rest went to public schools. In order to stimulate these processes a flexible grouping of children is established. Anna tells me: *If we observe that the deaf child is developing in a positive way we transfer the child to another group.* I take this to mean that to help these children to acquire normal roles in society is an ambition for these teachers. Ludmilla puts it this way:

It is my opinion that social adaptation of children with problems to society is primary. By that that I mean social adoption and integration in society of children with developmental problems.

Like parents the teachers' ambition seem to be to support children in the process of acquiring and maintaining normal social roles. However, the strongly selective character of ordinary schooling very much sets the agenda for special education as regards goals and objectives of the special teaching, especially for teaching children with mild disabilities. They must be trained to become acceptable as students within schools that have no other system adaptation to differences than differentiation of academic tasks within classrooms. Discussing the role of the medical-pedagogical commission in the selection process, Ludmilla says:

One may have different views on the medical-pedagogical commission and my opinion is that after a time the commission will have played out its role. At the present the commission exists as a necessity. The reason for this is our differentiated school system for children with developmental disabilities.

A specialist is a specialist, is a specialist....

How do these teachers perceive the basis of their work? Or, to put it more generally, what paradigm of knowledge seems to be the foundation of their understanding of disability and their strategies?

"Specialist" and "diagnosis" are the two concepts most frequently by the teachers. They seem all of them to have a rather strong belief in a model of change based on knowledge of particular disabilities. Anna's way of arguing is indicative of this line of

reasoning. She actually relates institutionalisation of children to a lack of specialists. When I asked her about the relevance of the family economy for the institutionalisation of their children she replied *It seems to play a certain role, economy is influential. But, also the fact that many districts do not have any specialists.* In another connection she describes the situation:

At that time no deaf pre-school children could get any education here, they were sent to Vychjegodskij. There were no specialists here.

The specialist concept may be closely linked to the concepts of diagnosis and institution. This is clearly the case when Ludmila conveys to me some of her teaching philosophy when training students. *We can never train good specialists at the university without getting them used to life in special institutions,* she says. And, then she explains:

Now we have a unique possibility. After having given a course in diagnosis of the mentally retarded we may go to the first floor to show our students how to make a diagnosis of the mentally retarded in practice, and they will be able to see the teamwork of several specialists - doctors, psychologists and pedagogues.

Here we see how the specialist concept is linked to diagnosis and institutionalisation. However, Ludmila also sees other roles for the specialists. She considers work to change how society looks at the mentally retarded and to prepare society to accept them as equal members of society as important future goals. She complains about what she denotes as a *catastrophic shortage of highly qualified specialists* whom she considers to be the ones to implement the social changes. Marina also points to this role of the specialists:

We need some specialists who can help us to do such work as can open our eyes. You know, in Russia there are lots of problems now, economical, and often there is no time to focus on such problems.

She continues:

That is why we open the faculty, and I think the main goal of the faculty will be to prepare specialists and their main goal will be to not stimulate such position of teacher.

The way these teachers talk to me and the professional terms they use convey a feeling of a diagnostic culture. They fully realise the necessity of changing school and society in order to improve the situation for disabled children. But the knowledge base of this diagnostic culture and its individualisation of disabilities restrict the adoption of the social knowledge, which is necessary to understand the social mechanisms impacting on disabled people and their families. At the practical level the language of this diagnostic culture may serve the present differentiation of children into diagnostic groups for the purpose of institutionalisation, but do not compare well to the problems felt by parents. A generalist role may seem more adequate to the purpose of change and in order to support disabled people and their families to acquire and/or maintain normal roles in society.

SUMMARY

I have talked to well-educated and dedicated teachers. In these talks the presence of an institutional system is very strong and expressed in many ways. At this point they corroborate well with the parent talks. The relationship between parents and teachers becomes symmetrical in many ways. In a system with few non-institutional options a selective group of parents become teachers of their children. Some of the teachers report a strong will to support parents in this educational process. However, taking a personal stand, as regards their children's education these parents may become competitors on the teachers' own arena as they may deem the defectological approach of social and educational management inadequate for supporting their children in achieving ordinary roles. Such a conflict was observed as regards the question of training sign language. The rejection of sign language may be taken to mean that this training serves deviancy-making and does not support their children in the process of normalisation - a process they may regard basic to their survival in the present social and economic situation.

Even if these teachers and parents may disagree on certain points they both seem to support the idea that the scope of the ordinary school and society have to be broadened. There are strong ambitions to train specialists who may assist ordinary schooling in keeping children without striving to have them transferred to institutions and special schools. This training, however, is strongly based on a diagnostic culture

that bases action on individual characteristics. The knowledge paradigm, which is the core of this culture, I judge inadequate to support the disabled in the present situation as well as to develop a broad spectre of services for them.

WHAT LEADERS IN THE FIELD TOLD

It seems reasonable to expect that leaders in the field view things from the perspective of policy, program, rules and regulations. This would be in accordance with their particular responsibilities. Their job is to see to that things work the ways they should.

The leaders I talked with were a director for a newly established research institute at a university, a director of an institution for the mentally retarded, a director of a centre for children with cerebral palsy and a leader of a rehabilitation centre which was a part of the research institute. My approach to these interviews has been to try to find their basic goals and objectives, and to see how they plan to implement those objectives.

IDEOLOGY: PERCEIVING THEMSELVES AS ORDINARY CHILDREN

When I ask Anatoly, the director of an institution with 248 mentally retarded inhabitants about the goals for his institution he spontaneously answers:

My opinion is that the most important goal we think of in our work with children is to achieve results, which we may use later in order to integrate our children in society.

To restructure the relationship between the children and society seems to be a common ambition for all. Tatyana, leader of the rehabilitation unit, puts it somewhat differently by saying: *Our task here is to defend children's interest so that they may perceive themselves as ordinary children.* And Olga, the director of the centre for the cerebral palsied says;

I want to give these children environmental conditions for perceiving themselves as normal and ready to be integrated into society.

They all underscore a different logic when they describe processes which serve to de-normalise their clients, Anatoly tells about the work they do to help their inmates to adapt to society. But there are several barriers, he says:

But we have another problem today. Everything we give the children, all the work we put into them is never used by society. When the child is 18 years of age and is to leave our institution we have the problem of finding a job and a place to live. And that's why we are forced to send most of them to homes for disabled adults.

Anatoly evidently sees the barrier to normalisation in the way the societal system works. He focuses work and housing. Tatyana on the other hand offers another line of reasoning. When I ask her about the segregation of the children she replies:

But everything depends on the degree of difficulties the child has. If there are great difficulties children will not feel well in public schools, and that's why there are special schools for these children.

PROGRAM: INTEGRATION BY SEGREGATION

These different ways of thinking also affect the strategy chosen. Tatyana underscores the importance of the quality of the special environment for stimulating development and restoring parents' belief in their children. *When children come to us, she says, they lack the mother's love. Our task is to create a loving environment for them.* Her strategy could be called developmental and therapeutic. The primary ambition seems to be to foster development and to restore social and psychological distorted relations to the parents. *Parents feel reproach, she says, because other children are normal, good, and their children are special and not normal. Our task, she says, is to co-operate with parents.* The way Olga answers my question about the goals of her work indicates the same therapeutic approach to development. *First of all she says, one must love these children if one wants to work with them. It is very important to be open with these children, They feel if people are false. That's why I always choose people who are sympathetic to handicapped children.* I do not in any way devalue these therapeutic ambitions which I consider to be basic goals for all special education. I just question the adequacy of them.

To Anatoly the scope of co-operation is wider. He offers me a social analysis of the background and future of the inmates of the institution. *If the child is lightly retarded he/she doesn't go to regular school, he tells, but to the special school, If the child doesn't master the special school, and doesn't get a place in an institution it may*

happen that he/she doesn't get any help at all. His description of the situation seems to validate previous reports from parents and teachers.

The functional abilities of children in relation to a number of pre-set norms seem to form the management imperatives of the organisational system. Within this system professionals seem to resort to developmental and therapeutic models of treatment. All seem to believe in normalisation and integration of children in society, but there are few reflections of what really needs to be done in order to implement such principles. To my knowledge a broad interdisciplinary approach incorporating all levels of the social system - professional and non-professional - forms the core of the implementation of normalisation and integration. Specialist is one of the most frequent words used by professionals. Anatoly tells me:

We shall have well-educated specialists, with a new way of thinking. Then we shall start to educate children to develop their physical, mental and other abilities. In order to do this we need a good economy. We think that interdisciplinary co-operation between Russian specialists and professionals from other countries and other professions would be positive.

Segregation becomes a natural part of this "specialism". This was well expressed by Tatyana when she told me:

We segregate a "risk group" which specialists observe. The earlier the work starts the better results. And we arrange such an environment for them that they will have time to prepare. And of course a group is always observed.

This is the core of the developmental model of special education, which has been an important phase in the development of special education. It's diagnosis - treatment thinking adopted from medicine forms the basis for what I have called specialism. To fulfil this medical model all professionals have to be centralised into one institute - the general hospital. Anatoly conveys this thinking when he tells me:

All these structures started to develop as independent units, but we decided to unite them in one institute. We meant that it would be most

rational because here we may have researchers, university teachers who work with students, children, everybody in one institution.

The risk of this kind of institutionalised system is described well by Anatoly. Talking about the lack of functional relationships of the institution to the nearby local society he says:

One may say that we have no relationships to local authorities of Novodvinsk or to the mayor. In some way we are "something of ourselves".

Anatoly indicates the dilemma with this management model when he after having told me the work they are doing says:

We do all this within our institutional system. But when the children are going to leave the institution there is a problem – the problem of integration into society. So what do we do? We try to change societal attitudes to people with retarded development. As an example we try to make sports for the disabled popular and by that change social attitudes. We try to come into contact with local authorities in the cities the children come from and ask them to help the children to find housing for the. We try to teach our children competencies necessary to find a job in Novodvinsk.

The quotation shows the complexity of the special education mandate.

The big question is if the line of thinking prominent in most interviews may form an adequate basis for making Russian children and adult a natural part of society - a goal that all persons interviewed seem to share. Does it lay the ground for changing traditional patterns of selection and schooling, for implementing educational programs for children with disabilities in regular schools, and for preparing the ground for special educators ready to work in interdisciplinary networks in the ordinary society? Based on historical experiences from other European societies I think the answer has to be no. The developmental model may only become effective when it is related to social sciences. Then it may become a functional part of a holistic understanding of the problems confronting disabled children and adults in society.

SUMMARY

The juxtaposition of program and ideology indicates basic conflicts. These leaders in the field clearly share an ambition to support their clients to develop and to live ordinary lives in society. In order to realise these goals conditions that may serve to disable people and to keep them in devalued roles have to be taken fully into account. Progressive work to help them achieve to achieve more valued roles has to be based on social knowledge paradigms. The individual oriented and diagnostic paradigm which I perceive presently forms the basis of knowledge seriously restricts the possibility to implement those changes indicated by other interviews.

CRITICAL ISSUES

It is always risky to draw any conclusions regarding another country. On the other hand, it is also risky not to draw any conclusions at all. This reminds me about the naked king in the fairy tale of H. C. Andersen. Only the child was able to observe that the king really was naked. Maybe I have observed something that needs to be told and discussed. My observations are only a few selective glimpses from a vast and complex society. I claim no general validity for my conclusions, but I dare say they corroborates well with the views of the Russian colleagues who have been cited in the introductory part of this report. What we have seen is a highly segregated system of education for individuals with disabilities. This system is the result of an interplay with a number of factors. The most important of them have been revealed on the preceding pages. Politically conditioned social attitudes to individuals with disabilities, rigid judgements of normalcy, a highly selective public school system and the prominent professional model of defectology are all taking part in the interplay. The institutional model appears very solid, That may be the reason why prominent writers in the field in spite of rhetorical adherence to the integration ideology refrain from recommending structural changes of this system. They only seem to recommend improvements of the present model. The relatively passive role of the State in terms of issuing new laws and new policies is most certainly an explanation. But then, of course, leading politicians may perceive that the present economic and political situation calls for other priorities. This very limited study, however, gives reasons to believe that the present model is not felt legitimate by important stakeholders. Parents want their children to become accepted and to live normal lives in society and experience the present model of special education and care to work contrary to that purpose. The interviews indicate that they actually refrain from utilising its services at a very high cost. This conflict between ideology and present program of management indicates that the present system tends to suffer from a crisis of legitimacy as the study indicates that the system does not deliver services in accordance with preferred goals. The impact of the system is observed in the course of the interviews. Parents pay a high price for fighting the highly selective system and the apparatus, which is, developed to implement the system. Home education, unemployment, a miserable economy and maybe divorce are some consequences for some of the parents who attempts to give their children a better quality of life and

a more humane education than they feel the present institutional system is able to give them. Teachers and leaders in the field seem to share many of the goals of the parents. Some of them make many important efforts to try to implement them. However, the institutional work setting put many constraints on such work. In addition, in order to open society and school for children and adults with disabilities the foundation of work has to be expanded at two levels at least. First, an open social critique of the disabling effects of the institutional system and the unequal and devaluing conditions of individuals with disability in society is necessary to establish new policies. In this process public media play an important role. Improvements would not have been achieved in other, comparable countries without going through this process. Reminiscences from the Soviet era most probably serve to subdue such critique. Still, our experience indicates that it is a precondition for change. Secondly, the present defectological model should be broadened and become a part of a paradigm of knowledge that offers better room for understanding disabling social and psychological conditions in society and the impact of these conditions on personality and for establishing more progressive practices. On this background I distinguish some critical issues

THE CONTEXT OF REGULAR EDUCATION

Presently, many positive developments are taking place in education. Still Russia has a very centralised education system and educational values that offer little room for students with disabilities in regular schools. This is presumably one of the most important reasons why Russia is lagging behind as regards inclusive practices.

CONFLICTING VIEWS ON EDUCATION

There are conflicts between stakeholders. The parents I have met all want to keep their children at home and want their children to have an education in the home environment. This is not presently seen as a viable option or a professional preference. Parental choice seems to have little meaning in this context.

A STATE OF EMERGENCY

Parents seem to be trapped by two negative options. Either they choose the institutionalised option or they may suffer economic breakdown. In such cases

placement of their child in an institution may be perceived as the only viable option. Making this choice may actually serve to maintain the institutional system.

THE KNOWLEDGE PARADIGM

Several macro-social mechanisms serve to create new populations of children with disabilities. To understand these changes the individual is not a sufficient unit of study. Social theory is necessary in order to handle the new challenges. The individual-diagnostic orientation of the defectological model - at least the way it is practised - offers little room for new approaches. This is of course not only an issue in Russia.

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