



Graduate School of Development Studies

**Challenges of Caring for Children with Multiple  
Impairments in Russia:  
The Case Study of the Better Practice Boarding-Home  
for Children with Intellectual Impairments in St. Petersburg  
(Russia)**

A Research Paper presented by:

***Ekaterina Evdokimova***

(Russia)

in partial fulfilment of the requirements for obtaining the degree of  
MASTERS OF ARTS IN DEVELOPMENT STUDIES

Specialization:

**Children and Youth Studies  
(CYS)**

Members of the examining committee:

Dr. Mahmood Messkoub

Dr. John Cameron

The Hague, The Netherlands  
November, 2010

***Disclaimer:***

This document represents part of the author's study programme while at the Institute of Social Studies. The views stated therein are those of the author and not necessarily those of the Institute.

***Inquiries:***

Postal address:	Institute of Social Studies P.O. Box 29776 2502 LT The Hague The Netherlands
Location:	Kortenaerkade 12 2518 AX The Hague The Netherlands
Telephone:	+31 70 426 0460
Fax:	+31 70 426 0799

# Contents

<i>Acknowledgments</i>	<i>v</i>
<i>List of Tables</i>	<i>vi</i>
<i>List of Figures</i>	<i>vii</i>
<i>List of Maps</i>	<i>viii</i>
<i>List of Acronyms</i>	<i>viii</i>
<i>Abstract</i>	<i>ix</i>
<i>Relevance to Development Studies</i>	<i>ix</i>
<i>Keywords</i>	<i>x</i>
<i>Glossary</i>	<i>xi</i>
<b>Chapter 1. Introduction</b>	<b>13</b>
1.1 The history of the attitude toward people with impairments	14
1.1.1 The World Experience	14
1.1.2 The case of Russia	15
1.2 Research problem. The situation concerning children with multiple impairments in Russia	17
1.3 Objectives and research question	20
1.4 The scene of the research	21
1.4.1 Statistical data on Disability	21
1.4.2 Geographical settings	23
1.5 The population of the research	24
1.6 Research methodology	24
a. Primary Data	24
b. Secondary Data	24
<b>Chapter 2. Conceptual framework</b>	<b>27</b>
2.1 Children and Childhood	27
2.1.1 The concept of Childhood	27
2.1.2 What do children with multiple impairments need?	28
2.1.3 Institutionalization versus Family Care	30
2.2 Disability – Impairment - Handicap	31
2.2.1 Definition	31
2.2.2 Multiple impairments	32
2.2.3 Russian Terminology	33
2.3 Medical Model of Disability versus Social Model	34
2.3.1. The World Experience	34
2.3.2 The concept of Disability in Russia	36
2.4 Capability Approach	37
2.5 Social Policy and Social Support System	38

2.5.1 Social policy	38
2.5.2 Social Policy toward Children with Impairments in Russia	39
<b>Chapter 3. Fieldwork analysis</b>	<b>42</b>
3.1 Better practice Boarding-Home for Children with Intellectual Impairments	42
3.2 The Implementation of National Guidelines for the Operation of Boarding-Homes	51
3.3 Comparative analysis of the development of the boarding-home in times.	56
3.4 Why the better practice institution can be considered as a better practice	58
<b>Chapter 4. Policy implications</b>	<b>63</b>
<b>Chapter 5. Conclusion</b>	<b>66</b>
<i>Appendix</i>	<i>69</i>
<b>References</b>	<b>80</b>

## Acknowledgments

This paper has been written with the support of my supervisor, second reader, my discussants, CYS convenor, my relatives, friends and colleagues.

I have special gratitude towards my supervisor Mahmood Messcoub for all the support he offered me, and for his readiness to understand my family commitments. His clarity, knowledge and experience helped me to be more precise and clear with the goal of my research.

I am very grateful to John Cameron, who gave me a lot of support beyond his role of second reader. He helped me to stay enthusiastic, find new views on the topic of my paper, and helped me not to get lost during this long process.

I also thank CYS convenor Linda Herrera for giving us clear sessions about the process of our research.

I also appreciate a lot all the help of my discussants David Venn and Suharto for their meaningful and useful comments and our personal discussions on my paper.

Thanks to my friends Ana Maria, Tiina and Alexander for their help with editing process and their support during the whole process of writing.

Special thanks to my son Igor and my mother Ludmila who were patient and conscious about my need to write this paper and complete my master program at ISS.

I am grateful to all people who work at the better-practice boarding-home and conventional boarding-home in St. Petersburg for sharing their feelings and information with me, as well as to the children who live at these boarding-homes and who gave me a lot of love.

Support for this paper was provided (in part) by the Ford Foundation International Fellowships Program. The statements and views expressed herein are those of the author and do not necessarily express the views of the Program or its funders.

## List of Tables

Table 1. The Number of children-invalids at the age before 16 who get welfare payments (after 2000 including children before 18) from 1980 to 2007	22
Table 2. Stationary Institutions of Social Services for children-invalids in Russia from 1970 to 2009	22
Table 3. The picture of the better practice boarding-home for children with intellectual impairments	49
Table 4. The Implementation of social policy at the better practice boarding-home for children with intellectual impairments in St. Petersburg (Russia)	69
Table 5. Comparative analysis of the better practice boarding-home for children with intellectual impairments in St. Petersburg (Russia) in time (1974 - 2010)	75

## List of Figures

Figure 1. Distribution of responsibilities for children among Social and Educational systems at the subjects of the Russian Federation.	40
Figure 2. The Management Structure of the Better Practice Boarding-Home	43

## List of Maps

Map 1. Map of the Russian Federation	23
--------------------------------------	----

## List of Acronyms

PWD – people with disability

PWI – people with impairments

CWI – children with impairments

CWMI – children with multiple impairments

MI – multiple impairments

CWII – children with intellectual impairments

BH – boarding-home

BPBH – better practice boarding-home

ICF - **International Classification of Functioning**

CSPR – Center of Social and Professional Rehabilitation

MD – mercy department

WHO – World Health Organization

UN – United Nations

UNESCO – United Nations Educational, Scientific and Cultural Organization

RF – Russian Federation

NGOs – Non-Governmental Organizations

WWII – The Second World War



## **Abstract**

The achievements and challenges of social care for children with multiple impairments in Russian society are explored in this research paper on the basis of experience of boarding-homes for children with intellectual impairments. The major part of the research takes place at the better practice boarding-home in St. Petersburg. The research considers the model of disability which is used in Russian society, constraint of the caring and legislation systems for children with impairments, and how do children live their lives in these circumstances.

In accordance with the findings at the better practice boarding-home the paper draws recommendations for changing Russian social policy and social care system for children with impairments, namely, subdividing of boarding-homes, combination of social and medical approaches to disability, changes in legislation system and creating new laws which are adequate to the needs and potentials of such children, and all children must be under the care of the Committee of Education, not only Social Committee.

## **Relevance to Development Studies**

There has been a little discussion within the development literature about disability. Maria Kett, Raymond Lang and Jean-Francois Trani argue that disability is one of the under-represented topics in the development area. Although people with impairments have long got international aid, the issue of disability was not widely mainstreamed in the international development. The authors see the reason in “poverty, discrimination and lack of access. However, now the awareness of policy-makers and development practitioners is growing (Trani, J., M. Kett and R. Lang 2009).

People with impairments make up about 10 per cent of the world population and it is assumed that these people and their families form 20 per cent of the poorest population of the world (Elwan 1999). Children and adults with impairments experience social exclusion all over the world and even more in the developing countries. A large number of children with impairments cannot have education and adults cannot be employed on an equal basis with others. As a consequence, there is a high possibility that these people will experience poverty.

Another reason why the topic of impairment and disability is relevant to development studies is that poor people are more vulnerable to get impaired due to the poor circumstances of life and inaccessible health services. And after they get impaired they become even more poor (Trani, J., M. Kett and R. Lang 2009).

This paper aims to raise the awareness of the Russian society as well as the scholars of development studies about one of the most vulnerable group of children – children with multiple impairments.

## **Keywords**

Children, disability, impairment, multiple impairments, social and medical models of disability, boarding-home, social policy, needs, capability, social exclusion, friendly environment

## Glossary

### **Boarding-Home (BH) for children with intellectual impairments (CWII) (детский дом-интернат для детей с отклонением в умственном развитии)**

- if to translate it directly from Russian to English it would sound as *boarding-home*. The word *интернат* means *boarding-school*, and the word *дом* means *home*. However, all colleagues of mine as well as the staff of BH normally call it *an orphanage*. Indeed, some children in these institutions do not have parents and some children have parents, but they abandon the child or parents are deprived of parental rights. Such children are in care of the state. For the purposes of this research we will use the term Boarding-Home. Although it calls the *Boarding-Homes for Children with Intellectual Impairments*, there are children with all kind of impairments. However, all of them have intellectual impairment which is combined with other kinds of impairments. The age of children who live there is from 4 to 18 years.

**Mercy Departments (MD) (Отделения Милосердие)** – common term in Russian BHs for CWII to define the department where children with the most severe impairments live, namely severe mental impairments, chromosome diseases, deafness, blindness, autism, emotional difficulties, physical impairments such as ICP (infantile cerebral paralysis) and absence of some parts of the body.

**Psychoneurologic Boarding-School (Психоневрологический Интернат)** – people over 18 from BHs or families are sent at the *psychoneurologic boarding-school* (Психоневрологический интернат). Although it is called *boarding-school* (интернат) people live there the rest of their lives after the age 18.

**Invalid (Инвалид)** – the word *invalid* was borrowed by Russians from French at the beginning of the 18<sup>th</sup> century and was used originally to define people who were unable to be a soldier due to some physical impairments as well as to define soldiers who got impairments during the war.

**Invalidity (Инвалидность)** – a status which is established by the State Medical and Social Examination Service on the basis of the health state of person. The person who has the status of invalidity can use all the spectrum of social services for invalids in Russia.

**Sickbay (Изолятор)** – the department of the BH where children live separately from other children after they lived outside BH in order to prevent transmission of diseases.

**Inferior (Неполноценный) person** – the word *Неполноценный* means something incomplete, not valued enough and some people and authors in Russia still use this word in regarding to PWI.

Recognizing the special needs of a disabled child (for special care) assistance shall be provided free of charge, wherever possible taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives the education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development...

(UN General Assembly 1989)

## Chapter 1. Introduction

The history of sentiment to people with impairments (PWI) goes hand in hand with such phenomena as exclusion, discrimination and stigmatization. Nowadays there are only a few countries where the majority of buildings, public transport and sidewalks are equipped taking into account the characteristics of PWI. As a result, the majority of them all over the world are not able to access the same services as people without impairments. Consequently, such people are forced to be at home and citizens do not know about them and do not know how to communicate with them. Due to this, when adults and children see people with visible impairments they could be afraid and react inadequately. This stigmatisation and isolations at home and institutions create social exclusion of PWI.

As early as in 1970 Russian authors realized the importance of changing society to meet needs of PWI: Rubinstein argues that biological characteristics of the body influence on the development of the person, but do not predetermine it, while the social circumstances and historical atmosphere influence the development of the person (Rubinstein 1970). Shipicina (2005) underlines the need to explore the topic more in order to improve care systems, to meet the needs of children with impairments (CWI) and to develop their potentials. Specialists of the Center for Curative Pedagogics in Moscow analyze the Russian legislation system and find the system needed reformulation and restructuring (Center for Curative Pedagogics 2006). However, there is insufficient literature and research on children with multiple impairments (CWMI), social policy and systems of care for them in Russia.

The present research explores the practical experience of caring for CWMI who live in the boarding-homes (BHs) for children with intellectual impairments (CWII) and examines regulations regarding CWMI in the Russian Federation (RF). The case of the study is BHs in St. Petersburg, one of which is considered as a better practice BH (BPBH).

The paper argues that in order to meet needs of all groups of CWI, to give them opportunity to use their capabilities and to create friendly and save society, Russian legislation system in the area of social policy must be reviewed. Moreover, the social care framework and institutions for CWI must be reorganized.

This paper firstly describes the history of attitudes to the PWI and establishes the problem of the research and its research question and objectives. It is followed by description of the scene of the research, population of the research and methodology which was used to explore the problem. The second chapter describes conceptual and theoretical framework to help reader to understand terms and models which are used in the research. In particular the medical and social models of disability will be considered as well as the model using in Russian BHs. The third chapter presents field data and data analysis. The fourth chapter draws policy lessons which can be learned from the experience of BHs in St. Petersburg. Finally, the fifth chapter concludes the results of the research.

The terminology concerning disability is a complicated one and it was difficult to figure out how to better define the population of the research using existing terminology. Considering differencing between the meaning of the words “disability” and “impairment” (see chapter 2.2) I will use the terms “children with impairments” and “children with multiple impairments” to define the group of children who have some difficulties with physical, sensory, mental and/or emotional development. However, I will also consider the concept of disability as used in the socially constructed environment around PWI.

## **1.1 The history of the attitude toward people with impairments**

### *1.1.1 The World Experience*

PWI existed at all times. However, there is no clear understanding up to now how to treat such people in the best way and how to harmonize the society where PWI live to give them opportunity to use their capabilities. To

enable the inclusion it is crucial to define what disability and impairment means. The perception of the phenomenon of disability has changed during the history of mankind. Consequently, the attitude toward PWI differs in times, cultures and countries. It has been changed from abruption to acceptance, from perception of PWI as children of devil to perception them as people of God. The treatment of them distinguished depending on it as well. For instance, in the Middle Ages children with some kinds of impairments such as dwarfism, blindness, infant cerebral paralysis often were called “people for entertainment” and were subjected to the mockery, jeering and derision (Metzler 2006). In Sparta children with noticeable impairments were killed as soon as they were born, while now in the majority of countries doctors try to keep the lives of such children as long as possible.

Helander states that it is difficult to draw “the clear line between disabled and non-disabled people”. He underlines the cultural aspect of the perception of the phenomenon of disability and PWI. He argues that the same person can be considered as disabled in one society and as non-disabled in another. For instance, in Northern Mali the main focus is on the appearance and the most disabled are ugly women, while in Somalia the main focus is on unusual behaviour, and refusing of unwilling marriage can be considered as inadequate and lead to perception of the person as mentally handicapped (Helander 1993).

Next subchapter considers the history of attitude and contemporary perception of PWI in Russian society.

### ***1.1.2 The case of Russia***

The formation of social protection for PWI begins on the foundation of special institutions - alms-houses (богаделен) for people who were unable to work (elderly people, PWI). However, it existed thanks to the personal donations, and participation of the state was insignificant. The next step was made by Peter the First in 1712 who ordered to found alms-houses in each province and provided food and financial compensation to these houses. However, the aim of that was not to protect people who were not able to

earn themselves, but to remove beggars and “lame” people from the streets. At the end of the 19<sup>th</sup> and the beginning of 20<sup>th</sup> century significant changes were made by the Opened Movement of Public Assistance (Открытое Движение Общественного Призрения). The network of the institutions for bringing up and educating of children and youth with impairments was created. In these institutions pupils learnt reading and writing and some kinds of handicraft trade. After the age 21 young people lived in “the best family of the village”, and state paid to this family a small salary. In 1930<sup>th</sup> the majority of institutions of social assistance were called “Houses of invalids”. During the Second World War (WWII) a lot of new people came to these houses. It was elderly people who lost their relatives during the war and also children and adults who got impairments as a result of the war (Shipicina 2005).

After the WWII such institutions were called Hospitals for Chronic Patients, because people got professional treatment there. In 1960<sup>th</sup> these institutions were divided into the different types depending on the age and type of impairments of pupils, namely BHs for CWII, psychoneurologic boarding-school and homes for elderly people and invalids. This subdivision exists till now (Shipicina 2005).

Nowadays Russian society is developing in the positive way in terms of treating the issue of socialization and integration of PWI: information awareness increases, new public organizations protecting the rights of PWI are founded, new programs for such children are created and implemented and legal framework is changing and improving to meet needs of PWI (Shipicina 2005).

There is a change in the perception of such children by Russian society. CWMI are more visible now; there are more literature and information in the mass media about them. The reaction of people without impairments on the streets when they see CWI is more often adequate than negative, signaling that PWI are less stigmatised now (Shipicina 2005).



However, there is still a big room for improvement, and a lot of children and adults with impairments in Russia are out of social life and do not have possibilities to fully use their capabilities.

## **1.2 Research problem. The situation concerning children with multiple impairments in Russia**

Michael Mednick (2002) underlines the influence of the atmosphere and emotional state of the child on his/her physical state:

Many CWMI have either hypotonia (floppiness) or hypertonia (stiffness), which is the most common problem. However, like us, the flexibility of their body is related to their emotional and behavioral state. If we are anxious, our movements become more hypertonic. Hypotonic are more prevalent when we are tired. This is also true for these children, and their movements can become more difficult to control when they are tired or anxious (Mednick 2002).

Nowadays in Russia the majority of children with multiple severe impairments are out of social life due to different reasons such as inaccessible buildings and transport, as well as stigmatization and unpreparedness of the staff of special institutions such as special schools, orphanages, boarding schools and boarding-homes, day care centers, and society as a whole to meet needs of CWI. CWMI are even more excluded than other CWI due to the severity of their impairments which cannot be managed by contemporary Russian society (Center for Curative Pedagogics 2006). Using the words of Colin Barnes and Geof Mercer one can say that CWMI are “minority within a minority” (Barnes, C. and G. Mercer 2008).

Additionally, the majority of people without impairments in Russia do not know how to communicate with such children and some of them even do not know that CWMI exist. Consequently, the community cannot fully participate in the process of creating a safe and accessible environment for CWI.

One of the big issues is that CWMI are offered access to preschool institutions, but they are not offered special schools or access to the mainstream schools. It means that children aged three to seven can attend preschool (special kindergartens or special groups for CWI in mainstream

kindergartens), take a part in social life and education, and their parents can work. However, this is not inclusion – it is just a postponement of exclusion, because after the age of seven there is no place for such children. One of the parents has to leave the job and stay at home to care for the child. According to the information provided by the principal of the BPBH, often such families break, because the financial situation in the family deteriorates, the tension rises and conflicts appear. Moreover, very often families where a child with multiple impairments is born brake very soon after the birth of the child due to the stress, shock, a complete change in lifestyle. Single parents are usually not able to work and care for the child at the same time. Consequently, parents have to put their children at the BHs for CWI to have possibility to work. It is a big stress for both – parents and child. Usually the process of adaptation goes very slow, children may lose part of their skills and be depressed.

Moreover, placing CWMI in the BH for CWI does not mean that the children will get education and some level of socialization. In one of such institution where the researcher worked there were no teachers in some groups, because children were considered as uneducable and had only one nurse for 12-13 children. The nurse must feed, wash and change children three-four times every day. The majority of children almost could not move, some of them were heavy and had contractions<sup>1</sup>. This is low-paid, but physically and emotionally hard work. The professional burnout is a wide spread phenomenon in such BHs. At the beginning the nurses tried to communicate with children, but after several years the majority of them made their job mechanical as if the children were inanimate objects. And, taking into consideration the working conditions, one cannot blame them for that.

In some groups, where children were considered as teachable, additionally to the position of nurse there existed a position for one teacher per group. The teacher's duty was to write an individual plan of development of

---

<sup>1</sup>Contraction - when the muscles are always tensed

every child and provide respective lessons for all children in the group. This situation was much better for children in terms of attention, care, emotional contact, development of different skills, communication and socialization. However, one teacher cannot reach significant results with all children, because every CWMI needs individual program of development, individual support and very intensive process of communication and studying. It is important to take into consideration that the “significant result” in the case of CWMI can be insignificant in term of “normal” development. For example, the teacher can work several months to teach the child to use the spoon and it would be a great achievement.

On the other hand, even if parents can leave CWMI over seven at home, such children could have a lack of education and socialization, because the majority of them cannot attend any educational institution. There are some institutions for CWMI such as day care centers, but places are limited (Federal State Statistics Service 2010). Additionally, parents often do not know about services which they can use.

..it is difficult ... for parents to maintain an accurate and up-to-date knowledge of the multiplicity of funding sources and the constantly evolving range of programs at a federal, state and local government level (Hollingsworth 1992).

Another difficulty in both cases – BHs and preschool for children with severe impairments – is that teachers who work with CWMI in Russia have to follow general instructions for all CWI which often are not suitable for CWMI. This generalization creates a great problem in terms of programming, planning and reporting about the results of the work. As it has been mentioned before, the progress of such children is very slow and it is very difficult to create the correct program at the beginning of the year. Usually the program changes throughout the year. Moreover, such children are highly susceptible to illnesses and sometimes unable to attend lessons for months. Additionally, the group can be closed because of quarantine, and it can be forbidden to take the child from the group for the lesson. All these factors can impede a program.

Lastly, CWMI in Russia are often practically orphans from the birth, because parents renounce them. Till now some doctors in the maternity hospitals try to persuade parents of such children to leave them in order to guarantee the parents a “normal” life. In such cases, children are placed in infant homes for children of ages between zero and four. In these institutions, children get only medical support. Until quite recently there was no position of educator in such institutions (Shipicina 2005).

The next subchapter considers objectives of the research taking into consideration the above-raised issues.

### **1.3 Objectives and research question**

#### **Objectives of the research:**

- To analyze what do CWMI need as a special group of CWI and what do they have in Russia
- To understand why the experience at the BPBH for CWII is successful and why it is not implemented at other institutions for CWI in St. Petersburg

#### **Research question:**

1. What is done and what more can be done to fulfill the needs of CWMI in Russia?

#### **Sub-questions:**

- Which model of disability is being used in Russia?
- What do CWMI in Russia need?
- What can be learned from the practice of BPBH for CWII in Russia (St. Petersburg)?
  - a. What model of disability is used in this institution?
  - b. What challenges are still faced in this institution?
  - c. How sustainable the success of this institution is?
  - d. Can this practice be widely replicated in Russia?

## 1.4 The scene of the research

### *1.4.1 Statistical data on Disability*

Nowadays between 500 and 650 million people or 10% of the world population are estimated to live with significant impairments. About 10 % of children and young people all over the world have physical, intellectual, sensory or mental impairments (UNICEF 2007). It is difficult to tell the exact number of children who have impairment, because of the differences in defining what impairment is in different contexts. For example, in some countries children who have learning difficulties are not included in the list of CWI and in other countries they are included (Dowling, M., J. Foy and G. Fajth 2005).

Another reason is that there are children who have impairments, but they are not registered as children with disabilities due to different factors, for example, thanks to the high level of adaptation or specific context. For instance, children can live in areas where nobody registers CWI or children do not attend the school and some light impairments are not publicly visible. One of the ways to count how many CWI live in the particular area is to count all the children who receive welfare payments or other financial support from the government and children who study in special institutions for CWI. However, the rate of the CWI in this case can be very different from the medical observation on the rate of the CWI.

Table 1 shows that the number of CWI receiving welfare payments in Russia was increasing before 2000 and decreasing after that. However, the number of CWI per 10,000 children grew till 2003, after which it fell slightly, because of declining fertility rate after 2000. The number of CWI in Russia in August 2009 was 545,000.

**Table 1. The Number of children-invalids<sup>2</sup> at the age before 16 who get welfare payments (after 2000 including children before 18) from 1980 to 2007<sup>3</sup>**

	1980	1990	1995	2000	2001	2002	2003	2004	2005	2006	2007
Total, thousands	53	155	454	675	658	642	624	593	573	554	529
Per 10 000 children	16,5	38,6	119,3	201,7	203,7	205,9	207,1	204,2	205,0	205,0	200,2

Nowadays in Russia there are 148 stationary institutions of social services for CWI there 22,000 CWI live (see table 2). In St. Petersburg 14 056 CWI live and there are 35 state institutions for CWI and four BHs there about 1050 CWI live (Federal State Statistics Service 2010).

**Table 2. Stationary Institutions of Social Services for children-invalids in Russia from 1970 to 2009<sup>4</sup>**

	1970	1980	1990	1995	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
The number of Institutions	168	156	160	159	156	155	152	152	152	153	157	151	146	148
The number of places (thousands)	27	34	38	35	33	33	32	32	32	31	30	29	29	28
The number of living children (thousands)	...	34	36	31	29	29	29	29	29	29	27	25	23	22

<sup>2</sup> Direct translation of the term from Russian to English

<sup>3</sup>Source: <http://www.gks.ru/wps/portal/english>

<sup>4</sup>Source: <http://www.gks.ru/wps/portal/english>

## 1.4.2 Geographical settings

Map 1. Map of the Russian Federation<sup>5</sup>



Russia is a big country which has a wide range of diversity within it in terms of standards of living and culture. It covers 17.1 million square kilometres in North Eurasia. The population of Russia on September 10th 2010 is approximately 142,011,363 people (Federal State Statistics Service 2010). There are 88 administrative territorial divisions called federal subjects. The city St. Petersburg also has a status of federal subject. There is a big difference between the well-being of people in different subjects as well as between big cities and rural areas within one subject. The case of this research is St. Petersburg, the North-West region of Russia. In comparison with other regions it is one of the economically successful regions of Russia.

<sup>5</sup> Source: <http://www.infoplease.com/atlas/country/russia.html>

## 1.5 The population of the research

CWMI who live in the BHs for CWII and the staff who work with them have been chosen for the purposes of the research, because in this case one can see the pure implementation of government policy almost without any help of parents. Children who live there are aged from four to eighteen years and have different kinds of impairments such as physical, intellectual, communicational, sensory and emotional impairments.

The staff who works with children include care-nurses<sup>6</sup>, sick-nurses<sup>7</sup>, teachers, educators, doctors, principal and vice-principal of the BHs.

## 1.6 Research methodology

### *a. Primary Data*

1. Participant Observation:
  - a. Boarding-Homes for children with intellectual impairments in St. Petersburg (Russia)
2. Semi-structured interview:
  - a. Staff of Boarding-Homes for children with intellectual impairments in St. Petersburg (Russia)

### *b. Secondary Data*

- Literature Review:
  - a. Literature review policy analysis
  - b. Literature about disability and impairments and multiple disabilities and impairments in Russia and worldwide

The significant part of the research is literature review, which includes investigation of the literature about disability and impairments and multiple disabilities and impairments in the world theory and practice as well as in Russia. Moreover, this research has ex-

---

<sup>6</sup>do not have special education and their duties are washing, feeding, changing children in the group

<sup>7</sup>medical attendants



plored the documents which are produced by Ministry of Public Health and Social Development of the RF and Ministry of Education of the RF.

As the primary data the participant observations in two BHs for CWII (conventional BH and BPBH) and semi-structured interviewing of the staff of these institutions have been used.

The participant observation is one of the methods which allow to get an in depth view of social conditions and processes and to see the real situation on the field, because the researcher is a part of the team and is perceived as a colleague by the people who are observed and interviewed. Additionally, the method of observation leaves space for new finding which were not expected by the researcher. The administration of the BPBH kindly allowed me to work there as a volunteer at the Mercy department (MD). Thanks to that I had possibility to come, observe and communicate with the staff and help them to care about children by myself during the whole month. I have worked at the ordinary BH for 2 years and have a lot of observations there. That is why I have spent the majority of time at the better practice institution.

Semi-structured interview is flexible type of research and allows new questions to be raised during the interview depending on what respondent says, what in turn allows us to get more diverse information and do not limit respondents in what they want to tell. The framework of themes was thought about in advance (see appendix).

For the interviewing I purposefully sampled among the different groups of staff of the BHs. I have made eight interviews at the BPBH (principal, vice-principal, educator, the head of the MD (a doctor), two care-nurses, parent of one of the children and one person who has lived at the BPBH when she was a child) and four interviews at the ordinary BH (principal, physiotherapist, educator and care-nurse).

My first intention was to make a comparative analysis of the conventional BH and the BPBH as well as the analysis of the progress of each BH in time. However, due to the ethical reasons I have decided to describe only better practice institution. The information which I have got at the conventional institution is used among other information while I am talking about the general situation in Russia. These ethical reasons were that the information which I was allowed to provide by the interviewees was not highly reliable and the other information I was not allowed to include in this paper.

During data collection I faced some other difficulties, namely that some people from the staff of BHs did not want to show negative sides of the work and tried to create a good impression about their institution. In these cases they provided only general and positive information. There is a big concern among the staff of the institutions that they will have some punishment from administration if the negative information about the institution will arise.

## Chapter 2. Conceptual framework

This chapter will familiarize the reader with main concepts and theory which were used at the present research. These concepts are children and childhood, institutionalization, disability and impairment, multiple impairment, social versus medical models of disability, and social policy. The theory which is used is the capability approach based on the work of Amartya Sen.

### 2.1 Children and Childhood

#### *2.1.1 The concept of Childhood*

Childhood is a period of life between infancy and adulthood, nevertheless there is no way to fix when childhood ends and adulthood begins without the social context. Age-based criteria cannot be used in many societies. For example, in some African counties children have to work and become mature much earlier. For certain Christian groups life begins at conception, but in the Middle Ages parents were indifferent to babies till the age about seven, because of high level of mortality (Montgomery, H. and M. Woodhead 2003). Nowadays there is generally accepted age range according to which childhood finishes at 17, and adulthood starts at 20. There are also two stages in between which are intersecting: adolescent (10-19) and teenager (13-19). However, it is important to remember that indeed the range varies from one culture to another (Montgomery, H. and M. Woodhead 2003).

There are some universal features which are attributed to the stage of childhood, such as biological immaturity and dependence, physical and cognitive subordination. However, there is no universal definition of childhood, because this term varies according to particular times, places and cultures. Moreover, it differs depending on social groups, ethnicity, income, gender and ability or disability. For instance, in Japan children are viewed as an extension of their parents. In medieval Europe children were perceived as small adults, and concept of childhood did not exist and was not consid-

ered as a separate stage from adulthood (Montgomery, H. and M. Woodhead 2003). A child with impairments usually reaches maturity and independence later than other children (and in some cases never).

There is also a criterion of puberty, which is considered as the end of childhood in some cultures. However, in some countries puberty could not be considered as maturity, because of cognitive infantilism and legal regulations.

There are two main opposed trends in the understanding of children as main actors of childhood in the process of socialization. The first one is to comprehend children as a passive participant of the process of socialization. Children are viewed as incomplete and incompetent half-person, a-political, a-sexual, vulnerable, passive and economically useless. They are born without contents and parents have to put it in them. The second trend is considering children as an agency, active learners of culture, and active participators in social life. They interpret, create and change the world around them. Having different kinds of impairments often leads to the perception of the child as a passive participant of the life and to the social exclusion (Montgomery, H. and M. Woodhead 2003). Even adults with impairments in many cases are considered as a-sexual, incompetent, vulnerable, and economically useless. While positive practices demonstrate that PWI can at least partly earn themselves if they have an appropriate social support (Metzler 2006).

In the case of our research children at the age from 4 to 18 years old will be considered, because this is the age when children live in BHs for CWII.

### ***2.1.2 What do children with multiple impairments need?***

To explore needs of CWMI David Werner (1988) suggests that the person who work with child with multiple impairments should: 1) observe the child with his/her interaction with relatives and/or other specialists who are involved in the process of habilitation of the child; 2) ask the relatives and specialists as well as the child (if possible) about the history of the child's

development; 3) to examine the strengths, weaknesses of the body and mind of the child and ask the child (if possible) what does s/he need.

Taking all this information into consideration the specialists can build adequate system of habilitation for the child and can request special services, equipment, treatment and the way of learning which are most appropriate for the child. The starting point is child's characteristics and social policy should be designed on the bottom-up principle to address needs of every child (Werner 1988).

The issues faced by a child with impairments will affect the whole family (Sloper, P., R. Webb, V. Greco and J. Beecham 2008). Probably that is one of the reasons why there is a lack of information in the literature concerning CWI about what children need, while there is a lot of information which services families need. Other reasons could be that it is challenging to get the clear response about the needs from the CWMI themselves.

J. Hollingsworth (1992) defines the following services as services needed by families of children and adults with impairments:

- help with household chores
- respite care
- education (special or inclusive)
- transportation available for PWI
- accommodation where PWI could live for a while and their relatives could have a rest from the daily care
- access to the information resources
- financial support
- special equipment (for free or for low prices)
- medical services
- therapy (physiotherapy, speech and occupational therapy)

Elaine Maag (2009) adds such services as:

- social worker
- recreational therapist

### *2.1.3 Institutionalization versus Family Care*

Russia is one of the countries where institutionalization is a significant part of the social care about CWI. UNICEF specialists suppose that it is the heritage of the communism which held the belief that the state can care about children better than parents do and should be a caretaker of all people in the country (Dowling, M., J. Foy and G. Fajth 2005).

There are a lot of different reasons why parents put their children in special institutions such as BHs for CWI. “This can be result of social values and individual beliefs, knowledge and training, or a gap in material and economic support” (Dowling, M., J. Foy and G. Fajth 2005). Parents might be unable to provide the appropriate care at home due to economic conditions, lack of appropriate nursing skills, or the imperfections of the system of social protection. Parents of CWI do not have or have a little of support from the state. For example, some parents think that their children will have better nutrition and will be taught better at the institution than at home. Other reason can be the stigmatization of PWI in society. “Another key challenge is the labelling of children, especially those with developmental disabilities, as “uneducable.” Such a labelling is ethically questionable and effectively prevents such children from receiving any educational support and access” (UNICEF 2007). Finally, a lot of parents do not believe that there is a chance that such a child can be integrated into society. Parents of CWI also lack information about how to defend their children’s rights (UNICEF 2007).

Institutionalization has both positive and negative aspects. Children can find friends who can understand them, their problems, fears, and needs at the institutions. The staff is ready to meet their needs on the level which is possible in this society, and to perceive them like they are. Some children mention that “it was only in institutions that they feel safe and understood” (Dowling, M., J. Foy and G. Fajth 2005). Additionally, for children who experienced malnutrition at home the food at the institutions can be more appropriate and nutritious. However, the negative impacts are too serious to think that institutionalization is an appropriate kind of care for CWI. Such

negative effects can be social and emotional deprivation, losing part of the skills which the child had before institutionalization, low self-esteem, poor health status, retardation of physical, mental and emotional development.

Institutionalisation is also psychologically difficult for parents who put their children in the BH, because they were not able to care about children at home. In Russia there are very strict rules for parents and they cannot visit their children any time they want. For instance, at the BPBH the visiting time is every Sunday from 10 am to 1.30 pm. Parents have to be on time at the institution, otherwise they will not be allowed in. They can also come on the birthday of the child. According to an interview with one parent, parents see this system as a prison. Parents can take their children home for several days, but when they bring them back, children will be put at the sickbay (изолятор) for few days. Thus, parents do not want to take children home for weekends because of the negative impact of the isolation that follows.

The ideal situation for any child is to live in a family among people who love and care about him/her, help him/her to fully use their capabilities and adapt in society. Institutionalization even at the best institutions has its negative impacts on the child. "There is no such thing as a good institution" (Dowling, M., J. Foy and G. Fajth 2005). However, the society should be ready to support families with CWI. Nowadays in Russia, there are no possibilities for very big number of parents of CWI to keep their children at home. Thus, the institutions where CWI live will remain there for a long time. Nowadays the aim is to analyse the situation at the institutions in order to improve it and to provide better life conditions and opportunity for development for CWI.

## **2.2 Disability – Impairment - Handicap**

### ***2.2.1 Definition***

Nowadays the definition of disability by United Nations (UN) accepted in the majority of the countries all over the world. United Nations distinguishes the phenomena of Disability and Impairment.

*Impairment* is a loss or limitation of physical, mental or sensory function on a long-term or permanent basis (UNICEF 2007).

*Disability* is the condition whereby physical and/or social barriers prevent a person with the impairment from taking part in the normal life of the community on an equal footing with others (UNICEF 2007).

Thus, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN General Assembly 2006).

WHO emphasizes the third phenomenon – Handicap, which is disadvantage from Impairment and/or Disability.

*Handicap* – the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Sendege 1998).

For example, the impairment can be deafness, which leads to the incapacity to hear and communicate in a usual way (disability), which in turn leads to the difficulties with the participation in social life (handicap).

### ***2.2.2 Multiple impairments***

Multiple impairments (MI) are a particular case of impairment. MI mean two or more impairments occurring at the same time, which may include physical, intellectual, communication, sensory and emotional difficulties (Mednick 2002), the combination of which causes complex of secondary impairments. For example, the combination of two primary impairments - deafness and intellectual impairments will lead to the difficulties in communication, retardation of development of logical thinking, learning difficulties and will make mental impairment deeper.

Michael Mednick (2002) states that among CWMI

..no two children are alike. They vary in their abilities, temperament, interests and needs... Indeed we cannot talk of a typical handicapped child.

Although CWMI differ among them by their impairments and abilities, the majority of them have some common characteristics. For example, the



majority of children have hypotonia or hypertonia, poor social and communication skills in a meaningful way for all other people. Some of the communication methods can be breathing patterns, hand, arm and head movements, way of using objects and vocal signals. Many CWMI are uninformed about the parts of their bodies and cannot relate themselves to that. CWMI also could have poor self-esteem as a result of often failures. Poor sensory and cognitive skills are also commonly occurring characteristics of CWMI. Additionally, these children often need some long term medical treatment. Finally, CWMI often have eating problems such as anorexia or reflux. Some children take food through gastronomy tubes (Mednick 2002). As the result, they all need support to fulfill their basic needs, in some cases during the whole life.

### *2.2.3 Russian Terminology*

In Russia, as well as probably all over the world, the terminology in the area of disability differs depending on who is using it. People who do not work with PWI in the majority of cases will use the word “invalids” to define such people, while professionals in this field will use such set of terms as “people with developmental disorders” (люди с нарушениями развития), “special child” (особый ребенок) or people/children with special needs (люди/дети с особыми потребностями). Although till now in some professional literature one can find the term “invalid” and “child-invalid” or even inferior (неполноценный) person. This reflects the perception of the person as incapable instead of differently able.

The word *invalid* means *not valid*. Initially the term was used to define people who were not able to do military service. So, the term underlines only inability to do something. In Russia till now in order to get welfare payment from the government person with impairments should get status of *invalidity* which is appropriated by the State Medical and Social Examination Service.

## 2.3 Medical Model of Disability versus Social Model

Nowadays the attitude toward disability has been moving from a needs-based approach to a right-based approach and perception of disability has been changing from medical or charitable model to social model and holistic approach (*Disability, Inclusion and Development* 2005).

### 2.3.1. *The World Experience*

Although PWI have existed at all times, only since 1960s did impairment become a social and political concern. In the early 1970s, the critic of the medical understanding of the phenomenon of disability appeared and “the focus of attention shifted away from their impairment to the inherent structural, legal, social and economic factors which systematically exclude persons with” impairments (Trani, J., M. Kett and R. Lang 2009).

In the world practice there are two main approaches toward PWI:

- *Medical or Individual model*: person with impairments cannot fully participate in social life due to his or her biological differences from people without impairments. Person with impairments faces difficulties in the society where s/he lives due to his/her impairments, physical, or mental incapacities. S/he is unable to follow the rules and norms of the society. According to this approach PWI get medical support, and all effort are aimed at the attempts to cure them and to make them as “normal” as possible (Barnes, C. and G. Mercer 2008).
- *Social model*: Disability is considered a socially constructed phenomenon rather than biological differences. According to this approach PWI experience severities in the society where they live due to the inadequate social care system, stigmatization, inaccessible buildings and transport, inappropriate system of education and employment. In respect to this approach the efforts are aimed on the socialization of PWI and changing the society in such a way that it would be suitable for all members of the society (Priestley 2003).

The social model is important not only for PWI, but also for people without impairments. Firstly, such an attitude helps people to develop the sense of

tolerance and respect to the differences between people. Secondly, some people who have impairments and do not have disability could have it in different social circumstances. For example, people who have low vision and hearing can use glasses or hearing aid and fully participate in social life. In spite of the fact that these people have an impairment, one cannot consider them as people with disability.

“Disability in degree and impact can vary greatly depending not only on physical health or care opportunities but on how supportive and enabling society is” (Dowling, M., J. Foy and G. Fajth 2005).

Sophie Mitra (2006) mentions two more models of disability:

*The Nagi model* is also called the *functional limitation paradigm*. Nagi starts the model from pathology, which leads to the impairment, which in turn leads to disability. Nagi develops the relativistic view of disability – the same impairment can lead and can do not lead to disability depending on the social, political and economic context.

*The International Classification of Functioning (ICF) model*, which is sometimes termed as the biopsychosocial model, was developed by WHO and presents the synthesis of social and medical models. ICF aims to provide the complex view of “health from a biological, individual and social perspectives” (Mitra 2006: 238). According to ICF the impairment gives rise to the limitations of activity and then to the participation restrictions. As well as the Nagi model, ICF model underlines the importance of the context, but it also includes the individual factors such as personal characteristics of people with impairments. The way how the person communicates with the community and how s/he uses the opportunities which s/he has depend a lot on the character of the person. It has a great influence on the development, adaptation and socialization of the person with impairment (Mitra 2006).

This research will analyze what model or combination of models is more appropriate for CWMI in Russia.

### *2.3.2 The concept of Disability in Russia*

In the official documents of the RF, such as the *Constitution of the RF* ('Constitution of the Russian Federation'. 1993), federal laws *Concerning the Social Protection for Invalids in the RF* (The State Duma of the Russian Federation 1995b), *Concerning the Social Service for Elder Public and Invalids* (The State Duma of the Russian Federation 1995a) the social approach toward PWI is reflected.

For example, the federal law *Concerning the Social Protection for Invalids in the RF* states that “the rehabilitation of invalids must be done in three main directions: medical, professional and social” (1995). The main organization which evaluates the capabilities of PWI in Russia is the State Medical and Social Examination Service<sup>8</sup>, which considers both medical and social aspects. The emphasis is on the holistic approach toward PWI – their clinical, functional, social, professional, working and psychological capacities. There is also the distinction between impairment and disability.

The necessity to adapt the society to the needs of a PWI, to provide access to the information, education, professional training, buildings and transport is emphasized. Shipicina (2005) shows social model as improving of the society, medical model as influence of the society on the person, and active participation of the person in his/her socialization as a third aspect.

However, in spite of the fact that one can consider the model of disability in these documents as a social model, definition of PWI as “invalids” demonstrates that PWI are considered as “incapable” instead of being considered as “differently able”. Shipicina (2005) argues that the process of adaptation of PWI is widely used and developed in Russia, while the process of adaptation of society to the needs of PWI is incipient.

---

<sup>8</sup>State Medical and Social Examination Service is one of the institutions of social protection of Russian Federation. It is subordinated to the Government of Russian Federation and establishes the status of invalidity, its extent and the program of rehabilitation for people with impairments.

## 2.4 Capability Approach

One of the theories which are connected with the concept of Disability is the Capability Approach, which was developed by Sen as:

(...) a framework to analyze different concepts in welfare economics, including standards of living, personal well-being, quality of life, and poverty (Mitra 2006).

Sen adheres to the liberal trend of thinking, which supposes that increasing freedoms and opportunities of people is most important in the development of a society. Sen says that people should be able to live lives valuable for them, and confirms that freedom of development for each person would lead to the development of the whole society. For example, the social provision of a good education system for everyone would improve not only literacy of several people, but also literacy of the society as a whole.

Sen emphasizes two main concepts in the approach which are the functioning and capability, where functioning is real activity of the person, while capability is the potential of the person (Gasper 2006). Sen's capability approach includes a wide range of functionings from basic ones such as nutrition, shelter, sanitation, and health, to complex ones such as self-respect and happiness. Sen has not limited the list of functionings, pointing out that the list will vary depending on the context. Sen considers impairment as one of the personal characteristics which can influence the well-being of the person with impairments. He analyses disability as a denial of capabilities and as a lack of choice of functionings (Mitra 2006).

This theory is very helpful in order to understand the inadequate standards of living of PWI in Russia and to demonstrate that PWI could have more capacities in different environment. Moreover, it underlines the importance of development of capabilities, which in the case of CWMI mainly applies to education. Educational processes for them mainly include the development of self-service skills (eating, walking, washing), as well as communicative and other social skills.

The ICF model of Disability is the closest model to the capability approach as it considers people with impairments in terms of their capacities and their real activity (Mitra 2006).

## **2.5 Social Policy and Social Support System**

### ***2.5.1 Social policy***

David Werner (1998) argues that social policy designs must be created to meet the needs of PWI and must be adapted to local social and environmental situation, economic limitations, and available resources.

Mkandawire (2001) defines social policy as

collective interventions directly affecting transformation in social welfare, social institutions and social relations. Social welfare encompasses access to adequate and secure livelihoods and income. Social relations range from the micro to the global levels, encompassing intra-household relations of class, community, ethnicity, gender, etc. Social institutions are the humanly devised constraints that shape human interaction or the rules of the game in a society (Mkandawire 2001).

This research is based at the social institutions, while the main concern is social relations and social welfare as a consequence.

Social support systems is one of the areas of social policy that provide assistance and back-up to the members of the society and can be formal or informal. Formal support is institutional support that can include such institutions as school, kindergartens, day care centers, social services, church, orphanages, boarding schools, BHs, social centers and supporting groups. Informal social support is provided by friends, families, relatives, or peers and community (Medical Dictionary 1998). Although the case study of this research is the BHs, it is important to take into account the wider context of social services. Moreover, it impossible to analyze one type of services and ignore another as they are intersected and interrelated. For example, the BHs have connection with infant homes and psychoneurologic boarding-schools for adults. CWMI who are in the care of the state from the birth to age four live in the infant home, over four to 18 at the BH, and over 18 at the psy-

choneurologic boarding-school for adults. In case of serious disease they are sent in the hospitals and come back after recovering.

### ***2.5.2 Social Policy toward Children with Impairments in Russia***

The implementation of the policy toward CWI differs among different regions of Russia in spite of the fact that the policy is unique for the whole country. However, constituents of the RF can establish local laws which are not in the conflict with the Federal laws. The case of this research is St. Petersburg, the North-West region of Russia.

Now all CWI who have invalidity<sup>9</sup> (*инвалидность*) get the social welfare payments (see tables 1, 4). Additionally, there some social services for CWI and their families, namely social taxi, social worker, free travel at the public transportation and free equipment for children who need it.

Accordingly to the federal law *Concerning the Social Protection for Invalids in the RF* (1995) the individual plan of the development of PWI who has a status of invalidity is worked out by the State Medical and Social Examination Service and includes all services which the person needs, and any rehabilitation organization can provide these services.

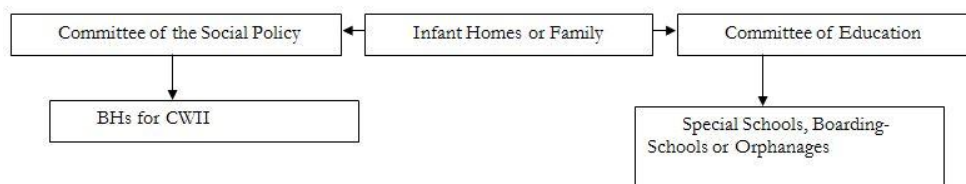
However, specialists of the Center for Curative Pedagogics (2006) in their analysis of social policy of the RF state that Russian legislation is imperfective and often is in contradiction with International conventions. Moreover, often some Russian laws are in contradiction to themselves. For example, the law *Concerning the Education* (The State Duma of the Russian Federation 1992) establishes in the first article that every child has a right to education regardless gender, race, nationality, language, citizenship, religion, state of health, social status, etc. However, further in the same article it is stated that CWI have to get their education at special institutions, and the

---

<sup>9</sup>The status of invalidity (*инвалидность*) is appropriated by the committee of the State Medical and Social Examination Service

Psycho-Medico-Pedagogical Committee is the Committee which takes the decision about who will get the education at these institutions. CWI experience discrimination from the early age. After infant homes after completing kinder gardens, children are distributed between educational and social services (see graph 1). For children who were sent into the social institutions it is very difficult to get to the educational system.

**Figure 1. Distribution of responsibilities for children among Social and Educational systems at the subjects of the Russian Federation.**



There are also laws which are discriminatory by nature, namely the order of the Health Committee and Committee of Education: *Indications and Contra Indications for Acceptance of Children at the Special Schools for CWI*. Children who are not accepted will stay out of the educational system (Center for Curative Pedagogics 2006).

There are orders establishing the guidelines for the activity of BHs for CWI:

- BHs for CWI are medico-social institutions
- The number of staff is the same as in the hospitals (per 25 people: one doctor, seven medical-nurses, ten care-nurses)
- There must be rooms for medical, social and hygienic procedures
- Education (if needed) must take place in the rooms of children
- No more than 12 children per group (Ministry of Social Protection for the Public of the Russian Federation 1993)



However, the Ministry of Labor of the RF recommends to increase the number of care-nurses and medical-nurses for children at the MDs to 22 and to reduce the number of children to 5 per group (Ministry of Labor and Social Development of the Russian Federation 2002).

These guidelines limit the educational process for children and prove the lack of the staff who work with CWMI. The chapter three of this research will consider how BPBH follows these guidelines.

The main negative consequences of inadequate legislation are that children with severe impairments are out of the education system, which is segregated, and these children do not have good supporting system for development; there is no continuation of education for the majority of CWMI; there is no information exchange between the specialists who work with children and specialists of Psycho-Medico-Pedagogical Committee and State Medical and Social Examination Service (Center for Curative Pedagogics. 2006). The identification of needs and the design of interventions tend to be top-down and state-led what leads to a gap between the actual needs of PWI and services provided. Moreover, the capacity of PWI and their families to access these services is often limited (Werner 1998).

Thus, CWI in Russia have their right to enjoy all human rights and freedoms, the realization of which is responsibility of the state. However, it is difficult for CWMI and their families to enjoy these rights because of bureaucracy and inadequacies of the social support system.

## Chapter 3. Fieldwork analysis

This chapter analyses data collected during fieldwork in St. Petersburg. To answer the main research question, the chapter will firstly describe the system of care, structure, policy, and the way how children live their lives and develop their capabilities at the BPBH. Secondly, the picture of BPBH will be considered in terms of the implementation of national guidelines for BHs for CWII. Then, on the basis of interviews with staff the changes at the BPBH over time since its founding in 1974 will be analysed. The final subchapter concludes why the BPBH is considered a better practice.

As one can see from the previous chapters, the main challenges which are faced at the BHs for CWII in Russia are:

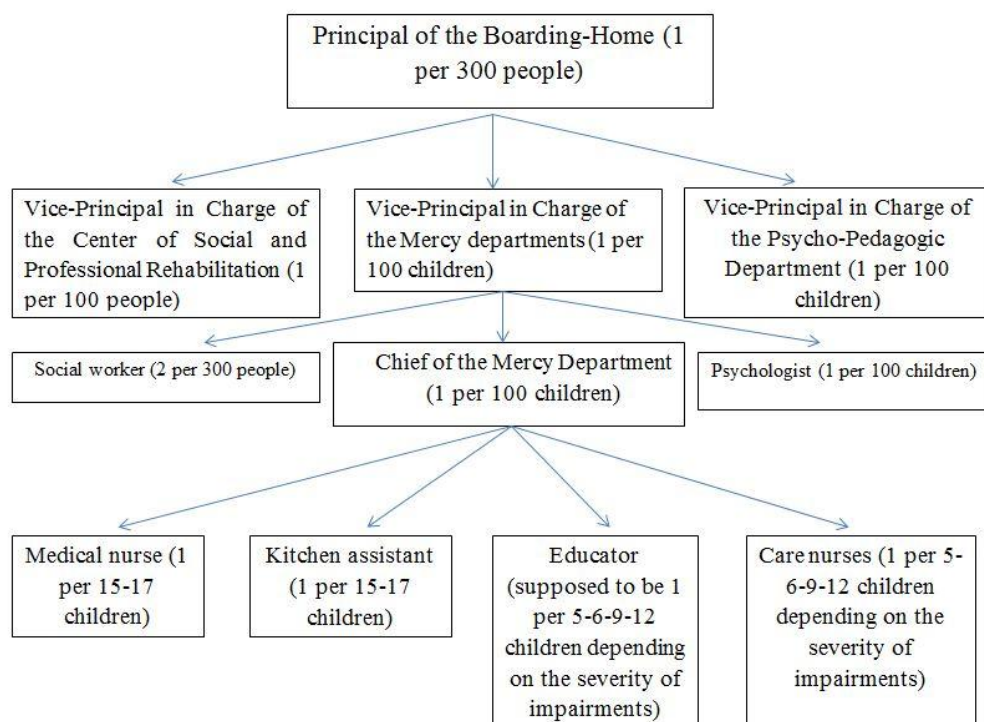
1. Lack of the access to the services, limited understanding of the needs of children and lack of support of the BHs by the government
2. Lack of the information about PWD
3. Limited understanding of the needs of CWMI by the staff of BHs
4. Low budget of BHs
5. The problem of continuation of support for CWI
6. Medical model is still the priority in the majority of BHs
7. Buildings of BHs are often inaccessible for CWMI
8. Too big institution and group size

### 3.1 Better practice Boarding-Home for Children with Intellectual Impairments

The research took place at the MD where one hundred CWMI live. The majority of children cannot eat by themselves, walk, speak and serve themselves.

This subchapter will provide the information about the BPBH which was collected mostly through observation, but also by interviewing. Figure 1 shows the main structure and subordination at the BPBH.

**Figure 2. The Management Structure of the Better Practice Boarding-Home**



There are several significant differences at this BH in comparison with the situation at some other BHs in Russia especially concerning the care of CWMI.

One of the advantages of this BH is that it is big and well equipped. It creates the impression of a school or holiday hotel more than a hospital. The large number of playgrounds and sport fields tell us that children here can develop wide range of their capabilities. As the result one can see the high level of the functioning. For instance, since 1991 children from the BH have participated in the Special Olympics Movement. In such sports as swimming, hockey, alpine skiing, snowboarding, the Russian team is 50-60% formed by children of this BH. They have got a lot of high prizes in different countries of the world.

The total number of people who live in the BH is about three hundred people. There are one hundred people over 18 years who live at the Center of Social and Professional Rehabilitation (CSPR). Children with different

kinds and severity of impairments compose two hundred of total number of children. This number of people is too big to provide appropriate care and conditions of life in one BH, and the institution still needs to be subdivided. However, in comparison with some other institutions of the same type in Russia where about 600 children live, this BH is relatively small. Thanks to the large area it was possible to build a new building for the C SPR, to subdivide the MDs and create small groups for children.

The continuation of care is one of the crucial factors in the physical, emotional, psychological and intellectual development of children. It is very important to support skills which the child has developed, because CWI tend to lose their skills very fast without maintaining. One of the concerns of the principals of the BHs in Russia is the future of the pupils over 18. Normally if the person can care for him/herself s/he gets a flat and can live independently. However, it is difficult to adapt in society because Russian care systems are not ready to provide the appropriate support. It is difficult to find a job and to participate in the social life. One of the first barriers for PWI will be inaccessible buildings and transportation. These factors among others prevent such people from fully use their capabilities.

The principal of the BPBH has founded the C SPR to solve this problem. People at the centre can live and work at the BH and have circumstances to be social active, to make some sports, to earn themselves (at least partly) and to acquire new skills. For people who decided to live independently there is a project which called *Social Flat* and which allows PWI to understand if they are ready to leave the BH. Five people over 18 live there independently, but on the territory of the BH. They always can ask for help and receive social and psychological support. This project helps them to learn how to live in the society, how to cook and how to organize themselves. These people also work and should wake up on time and come to their job on time. They live at the flat for 1 year and after that they get their own flat from the government and live completely independently. After this training people chose more consciously whether they want to leave the BH or whether they would like to stay at the C SPR. One of the girls who has lived

there for one year abandoned to leave the BH and has stayed at the Center. Thus, one can see here the implementation of the social model of disability when PWI are considered not as patients, but as differently able people who need to be in a friendly environment to be able to use their capabilities.

However, for people who cannot serve themselves the issue of continuation still exists. After they reach the age 18 they are sent to the psychoneurological boarding-school for adults. At the psychoneurological boarding-school in which the majority of children from the BPBH are sent 1000 people live and it is hardly possible to provide individual attention to all of them. They live in the rooms for 6-12 people and they live there for the rest of their lives. There is also a lack of care, because there is not enough staff who work with them. The following set of specialists work there: 16 doctors (psychiatrists), five doctors of other specializations, one massage therapist, one physiotherapist, two psychologists, one medical worker, one lawyer, one educator, eight labour instructors, 160 medical and care nurses for about 1000 people (Sander, M., K. Stengler, O. Pospelov and A. Iljin 2007). Thus, PWI do not have individual space and appropriate care as well as possibility to fully develop their capabilities. In such circumstances they can completely or partly lose the skills they have acquired before.

Another issue in terms of continuation is the process of replacing children from the infant homes to the BHs. So far, it is made by the Psycho-Medico-Pedagogical Committee, and the opinion of the staff of the BHs and infant homes is not taken into consideration. Parents can ask to send their children at the particular BH, but if the child does not have parents or parents do not care about the child s/he will be placed according to the decision of the committee. However, there are some connections between the BHs and infant homes which could be supported. For instance, the staff of the BPBH prefer to accept children from the certain infant home, because the results of the work with children from this infant home are visible. People who worked with children at the infant home visit children at the BH and the staff of the BH try to maintain the skills which children have and to provide further development for them. At the end children benefit from such

kind of continuation and these connections could be considered by the committee.

The BPBH has a wide range of partnership both in Russia and abroad (see appendix) what has allowed to implement a lot of projects such as subdividing of MDs, founding of the Social Flat and CSPR, buying expensive equipment for other projects.

The state financing of all BHs for CWII in St. Petersburg is the same. The difference is in the other activities which produce a profit such as different projects with sponsors and workshops (see table 3). There are such workshops as ceramics, millwork, painting, tailoring, ornamental art, metalwork, and greenhouses. Some of the products are used at the BH, some of them are sold. It gives to the BH the possibility to provide some additional services for children.

One of the aspects which should be considered is that the principal of the BPBH has an education at the pedagogical and psychological fields, while in the wide range of others institutions of that type the principals have only medical education and working experience at the medical sphere. The education and experience influence a lot on the model how the person will organize the work with children and which priorities s/he will have. The person with only medical experience more likely will implement the medical model of disability while the person with pedagogical, psychological and other social-oriented educations could be more ready to implement the social model of disability.

The Chiefs of the MDs are doctors. However, one should remember that children with severe impairments need both medical and social care.

One of the most significant achievements at the BPBH is subdividing of the MDs into the smaller groups depending on the severity of the impairments. When children live in smaller groups they get more support and individual care. The atmosphere in such groups is more friendly and home-like. Although the majority of children cannot speak, one can see their reaction and interaction with staff through the body-language and face impression. For, instance than the care-nurse enters the room children start

smiling or screaming trying to attract her attention. It means that children know that they can communicate with the nurse in a positive way and the nurse will pay some attention to them. However, there are still big groups at some MDs which need to be subdivided as well.

At the majority of the conventional BHs for CWII one group contains 12-13 children and only one care-nurse cares about them. For example, in one of the conventional BHs at the MDs children live 13 children per group (does not depend on the severity of the impairments), and one care-nurse cares about them. There are also doctors (one for 50 children), medical nurses (one for 25 – 40 children), and educator in some groups (one per 13 children). This number of specialists is not enough to maintain physical, intellectual and emotional development of children and to provide them the opportunity to fully use their capabilities.

The day plan of children is strongly connected with how many people work with them. For example, to be able to take all CWMI from their groups outside for the walk a lot of adults are needed to put them in the wheel-chairs or baby-carriages. This is one of the reasons why at some conventional BHs children stay in their rooms for months and do not go out. At the MDs of the BPBH it is possible to provide walking outside for all children every day (if the weather is good), because the staff can manage to take all children outside. If the staff have some difficulties they can request additional help from the administration of the BPBH and people from the CSPR will come every morning and help to lift heavy children. Both staff and children benefit from it.

There is a wide range of additional services for children who live at the BPBH (see table 3). Some of them aim to cure children, to make them more healthy while others aim to help children to socialize, to develop their communicative, learning and speaking skills. It shows that children are considered not only as people who need some medical support, but also as members of the society who have their rights to play, to learn and to enjoy their lives in the way which they can. While at some conventional BHs at the

MDs there are only medical services such as massage, physiotherapy and speech therapy only for some children.

The next important point is the process of feeding. Children eat at least four times per day and it takes a lot of time in their life. Consequently, the way they eat influences their perception of people around them, of the process of eating itself and the children's health.

The eating environment needs to be happy, relaxed, safe and conducive to good practice and communication... Lunchtime should be an interactive and social experience and not rushed. Children should be allowed quality time to eat and communicate with others, including their support worker. However, sometimes it is necessary for the support worker to help the child to eat as quickly as possible in order to be free to help other children...Lunchtime may then become the most stressful time of the day rather than a relaxing and enjoyable experience (Mednick 2002).

Additionally, some children can learn how to eat by themselves and, according to the Sen's theory, develop their capabilities of self-service. However, it needs a lot of time. In some BHs at St. Petersburg one nurse has to feed 12-13 CWMI several times per day and s/he tries to do it as fast as possible. Consequently, the atmosphere during feeding is high-pressure and tense. However, if the nurse has to feed only two or three children s/he can do it slowly, communicating with the children. The educator can teach children how to use a spoon and eat by themselves. Nevertheless, at the BPBH the situation is not that ideal. There are a lot of children who could eat by themselves, but are fed, because of the lack of educators.

The table 3 shows the picture of the BPBH in details.



**Table 3. The picture of the better practice boarding-home for children with intellectual impairments**

<b>Boarding-Home (better practice)</b>	
<b>I. General information about the Boarding-Home</b>	
Territory	The territory is very big with a lot of playgrounds, football, volleyball and basketball fields
The number of people living in the BH	Total: 300 people 3 departments: 1. Center of Social and Professional Rehabilitation(100 people over 18) 2. Psycho-pedagogic department (100 children) 3. Mercy department: (100 children)
Continuation	Children arrive from infant homes (at the age 4) or families (any age from 4 to 18) and are sent to the psychoneurological boarding-school for adults after they got 18. Some of the children can stay at the CSPR; more socialized children can start independent life outside institutions. The decision is made on the basis of the personal willing of the child and on the basis of the decision of psycho-medico-pedagogical committee. The staff of the BH try to support people who decided to live independently: help them to buy furniture and household appliances. Some of PWI work at the BH
Partnership	BPBH has more than 17 partners in Russia and abroad (see appendix)
Financing	<p><b>I. Income</b></p> <ol style="list-style-type: none"> <li>1. Government financing</li> <li>2. Fee for the hospital service (75% of the welfare payments of the children who have parents). For orphans and people over 18 years who cannot care about themselves and do not have a family 100% of the welfare payments is saved for themselves and the tutorship and guardianship authorities care about spending it for the benefit of the person)</li> <li>3. Other activities which produce a profit (sponsors and workshops)</li> </ol> <p>Points 1 and 2 are the same for all BHs for CWII in St. Petersburg. However, the point 3 can differ depending on how successful other activities are.</p> <p><b>II. Expenses</b></p> <ol style="list-style-type: none"> <li>1. Salary of the staff</li> <li>2. Taxes</li> <li>3. Public services (gas, water, electricity, heating)</li> <li>4. Communications services</li> <li>5. Food for children (202,7 rub/ child/day = 5 euro)</li> <li>6. Medicine (15,2 rub/child/day = 0.35 euro)</li> <li>7. Sanitary and hygienic accessory (1,5 piece of soap, 1 toilet roll, 1 tube of toothpaste/child/month)</li> <li>8. Cleaning agents</li> </ol> <p style="text-align: center;"><i>Other expenses according to the demand:</i></p> <ol style="list-style-type: none"> <li>9. Trash pickup</li> <li>10. Disinfection of the buildings</li> <li>11. Technical maintenance</li> <li>12. Security</li> <li>13. Expendable materials</li> <li>14. Renovating</li> </ol>

	<p>15. Medical inspection</p> <p>During the year 2010 it is supposed to spend 162,495,700 rub = 4,062,392.5 euros) for 301 people who live at the BH now. It is about 37 euros /child/day</p>
<b>II. Specific information about the field of the research</b>	
Field of the re-search	The Mercy departments (100 children)
The number of children with severe impairments in the group	<p>Children who have severest impairments live five children per group (15 children at one MD). They have one room for sleeping and eating for five children and one playing room for the whole department (15 children).</p> <p>Other groups have 6-9-12 children depending on the severity of impairments. 25 children at each MD. They have one room for sleeping, one for eating and one playing room</p>
Staff who works at the MD	<ul style="list-style-type: none"> <li>• two-three care-nurses for/children</li> <li>• one educator for/children (in reality one/15 children)</li> <li>• one medical nurse/25 children</li> <li>• one doctor (a chief of department)/children</li> <li>• one kitchen assistant/25 children</li> </ul>
Additional services for children from the MD	<ul style="list-style-type: none"> <li>• Massage (1 per week)</li> <li>• Physiotherapist</li> <li>• Music therapist (once per week)</li> <li>• Aroma therapist (once per week or more often)</li> <li>• Psychologist (1 per 100 children)</li> <li>• Sensory therapist (according to the individual plan of the child)</li> <li>• Speech therapist (according to the individual plan of the child)</li> <li>• Water therapy (1 course per year)</li> <li>• Phototherapy (3-4 courses per year)</li> <li>• Electrotherapy</li> <li>• Phytotherapy</li> <li>• Thermotherapy</li> <li>• Orthopedic alignment</li> <li>• Art-therapy</li> <li>• Montessori class</li> <li>• Dentist</li> <li>• Psychiatrist</li> <li>• Department of functional diagnostics</li> <li>• Mechanical treatment</li> </ul>
Day plan	<ul style="list-style-type: none"> <li>• Children stay in their beds only during the night and nap time. The rest of the time they seat in their wheelchairs or play on the floor</li> <li>• All children walk outside every day. During the summer period they walk twice per day for 2.5 hours (5 hours per day)</li> <li>• If the weather is not good, children walk in the hall of the department while their rooms are ventilated and the quartz lamps are on</li> </ul>
Equipment of the MD	<ul style="list-style-type: none"> <li>• Carpet at the each room</li> <li>• Small amount of toys in the room, but a lot of toys in the playing room</li> <li>• There are a lot of good clothes. Every child has his/her own shelf in the cupboard. The Committee of the Social Policy of St. Petersburg establishes which company will supply the clothes and it is the same for all institutions. But at this BH if the clothes does not compliant with standards they do not accept it</li> <li>• There are one-use bibs and diapers (3-4 stuck per child per day)</li> </ul>
Care	<b>Food:</b> each care-nurse has to feed 2-6 children (depending on the dif-

	ferent MDs). Children can eat slowly. Some nurses speak with children during feeding. If the food is cold the kitchen assistant warms it up. Each MD has its microwave. <b>Clothes:</b> they change clothes even if the child perspires
Atmosphere	The atmosphere of home. The care-nurses are relaxed; they have enough time to care about children properly. The salary is the same low at all BHs), but at the BPBH care-nurses have less number of children and better circumstances of work

### 3.2 The Implementation of National Guidelines for the Operation of Boarding-Homes

This subchapter will analyse the data from participant observation and interviewing, and the implementation of national guidelines at the BPBH (see subchapter 2.5.2). The criteria of the assessment are human resources, other resources (money, equipment, etc.), the policy of the government of the RF and of the administration of BPBH toward CWMI and, finally, the attitude of the staff and the administration toward such children. The analysis is subdivided on the positive and negative finding, although some of them can be considered as both positive and negative as well as neither positive nor negative (see table 4).

Firstly, considering human resources issues, there is a lack of staff at the MDs of the BPBH. Especially more educators and physiotherapists are needed. As consequences of this shortage children do not have opportunities to fully develop their capabilities. CWMI target for the development, but it is limited due to the lack of staff. For instance, one boy can walk by himself, but needs somebody to hold him by hand. Every time he sees that somebody approaches him the boy gives his hand asking (nonverbally) to walk with the person. However, care-nurses do not have time to do it and ask others do not to do it, because otherwise next time the boy will cry if nobody has time to walk with him. This example demonstrates how the using of capabilities is limited because of the imperfect system of social care for CWMI.

All educators are forced to go to the departments where children have less severe impairments. It is understandable, because one of the main purposes of the principal of the BH is to give to as many children as possi-

ble the opportunity to get education, work and move from the social protection system to the education system.

The vice-principal of the BH tells:

We have a lot of different services which some children cannot use due to the severity of their impairments...maybe it would be better to place the weakest children at special institutions for them, because they cannot use all the services and stronger children could take their places and have a good development. We can give them more here at our boarding-home...

Thus, children with severe impairments have to be considered a special group within the whole group of CWI. The gap in Russian social policy is that the need of children with the severest impairments to have more attention is not taken into consideration. Such children cannot fully develop their capabilities in groups for 12-13 children. The places occupied at the MDs at the BPBH are maintained by the internal budget which is not enough to provide all educators with a good salary, because it is counted on the basis that one nurse and one educator work with 12-13 children. Consequently it is very difficult to organize such departments, and principals of the conventional BHs do not have possibilities or willing to do it, because all the responsibility is on the principal in this case.

The level of care is good – children at the MDs have one care-nurse for five-six-nine children depending on the severity of the impairments. However, there is a lack of educators and physiotherapist. CWMI need to have comfortable chairs, wheel-chairs, baby-carriages in order to be able to perceive the information from the outside. They also need to learn how to control their bodies, how to move, walk, or crawl. Thus, the lack of physiotherapy plays a crucial role in the development of their capabilities.

The vice-principle of the BPBH tells:

We are expecting more people soon, because the big residential complex is built near our BH. The BH is situated in the countryside and it is difficult for people to come every day that far. However, for new residents of this complex it will be a good opportunity to work near their home.

Secondly, all interviewees among the biggest challenges mentioned the lack of money and different equipment. The budget of BHs for CWII is not big enough to provide all children with services they need. However, thanks

to the initiative of the principal, his participation at different projects and permanent contacts with the government of St. Petersburg and sponsors, there are a lot of additional services, good equipment, good clothes and enough child care supplies at the BPBH. It was even possible to build new building for the CSPR, to equip the school for children from Psycho-Pedagogic Department, to renovate old buildings, to create Social Flat and to subdivide MDs with support of government and sponsors. The principal of the BH tells:

It is only the first step to buy the equipment. You have to maintain it in working condition, to find specialists who can work with it, to care about that.. otherwise you would waste the money. The more you work the more you need. We are always in the process of search and fight...

However, even at the BPBH children lack some special devices and devices which they have not always fit children's body. The wheel-chairs must be fit up to the shape of the child's body. At the BPBH a lot of CWMI do not have comfortable chairs. That means that they cannot relax, because they have to control their body. In these circumstances it is impossible to teach them. One of the boys at the MD has walking-frame and very often he looks at care-nurse and shows by sounds and eyes impression that he wants the care-nurse puts him in the walking-frame. Using this device he can keep vertical position of body, he can move and explore the environment around him. In other words, he can use his capabilities.

Next, the most important issue of the government policy is the top-down design of the social policy which is implemented in Russia. Namely, programs, plans, requirements are set from the top without clear understanding what children need. Additionally, children are distributed between different institutions on the basis of the decision of psycho-medico-pedagogical committee and without taking into consideration the circumstances of the institution and the opinion of the specialists who work with children. The vice-principal of the BPBH tells:

Nobody asks our opinion about children and about what is better for who of them..

During last decade more children with severe impairments appeared. However, the administration of the BH requires more now from the educator and other specialists who work with them. It is both positive and negative, because on the one hand, the educator and other members of the team are trying to work better, but, on the other hand the circumstances of the work do not allow to have such a high results (there is no enough educators, the lack of the equipment, etc.). Although the administration of the BH supports the staff there are a lot of things which are lack. For example, the staff of the MD can request for the everyday help in moving heavy children and boys from the CSPR will come and help. But at the same time care-nurses are not completely satisfied. One of the care-nurses tells:

This child needs different kind of the chair, because it is not comfortable for him to eat and it is difficult for us to feed him in this chair. But nobody cares about that.

Another aspect of the administration policy is understanding of the social needs of children not only while they live at the BH, but also after that. As has been mentioned before, there are two projects, namely CSPR and Social Flat, which aim to socialize PWI at the appropriate environment and to give them the opportunity to adapt in Russian society. Another indicator of using social model apart from medical model is creating of individual plans of development for each child with participation of the set of specialists including doctor (paediatrician and psychiatrist), educator, speech therapists, resource specialist, psychologist, physiotherapist, massage therapist, and the teacher from the school.

In spite of the fact that the administration realizes the importance of the continuation of the educational, socialization and bringing-up processes, it is not completely implemented yet at the BH. The educator of the MD tells:

These is no system of continuation – we had 7 educators at our department, but they were replaced to the different departments for children with less severe impairments. Our children now are losing their skills, because nobody can maintain it...

However, one can see that the level of care about children at BPBH is relatively high. Children have good clothes, they are clean, fed and they

do not stay in their beds all the time. As has been mentioned before, it differs at some other BHs. For instance, the provider of the clothes is established by the government and it is the same for all BHs in St. Petersburg, but at the BPBH they do not accept the clothes which they do not like and ask to change it.

Now let us turn to the policy of the government which has direct influence on the policy of the BH and children's lives. The vice-principle of the BH tells:

The RF has ratified, but not signed up CRC so far, because the whole legislation system is not ready yet to that. There are a lot of contradiction in our law system and it has negative consequences. One of the big difficulties for the BH now is that we are under the supervision of the Committee of Social Policy. It means that we do not have education license and cannot teach children. We have a wonderful school, fully equipped and professional teachers, but we cannot graduate our students. There is a possibility to bring them every day to the special school, but it is far and it is hard for both – children and staff. Such children must have opportunity to study near their houses.

The social policy in this case is not appropriate for CWMI and is not ready to meet their educational needs. Specific needs of CWMI are not taking into consideration.

Another issue is that the staff of the BHs has low salary and together with hard work it leads to the lack of the staff.

Also, there is no good system of controlling money which children get as welfare payments. Mothers of some children are getting part of these payments, but some of them visit their children only one per 3 months to keep getting the money and do not care about children. Otherwise the administration of the BH can take them to court to deprive of parental rights. In this case the whole payment would be spent for the child's needs.

One of the biggest challenges for both parents and staff who work with children is that the caregivers have to fight for the social services which exist in the RF. There is no system of control that CWI get the services which they have to get. The principal of the BH tells:

Sometimes I have to ask, sometimes to argue, sometimes to cry...

Finally, there is a gap between the model of disability from the perspective of the principal which is social and from the perspective of the junior labour (care-nurses, medical nurses, etc.) which often is still medical. Although the principal understands well that children need to live at the appropriate environment to be able to develop their capabilities, the majority of the junior labour still see their roles in some technical actions which are the same at the hospitals, even though the quality of the care at this institution is much higher than it is at the majority of the conventional institutions in Russia. The atmosphere is very gentle and quiet, but there is not enough attention to the socializing and development of children from the side of the personnel. However, thanks to the principal's and other people's understanding the whole system is moving to the combining of the medical model with social model.

Thus, BPBH follows recommendations of the Ministry of Labor of the RF in terms of completeness of the groups and number of staff who work with children, and makes step forward in terms of providing education for children who can attend the school at the BH. However, children with severest impairment still lack education at this institution.

### **3.3 Comparative analysis of the development of the boarding-home in times.**

The girl with impairments who lived at the BPBH ten years ago tells:

Everything has been changed! Now they work with children. They make everything for children. They love children. People who work there must love children and then children will want to live there. When I was a child we were brought up by the punishments... it made us stronger, but we needed love..

This subchapter will compare the progress in terms of care about CWMI at the BPBH and Russian social policy in times. The considered period of time is last 36 years from 1974 when the BPBH was founded to 2010. Some people who were interviewed during the present research have worked there since the beginning (the principal of the BH and the educator). The same criteria are used as at the previous subchapter: human resources, other resources (money, equipment), policy of the administration toward CWMI, and the attitude of the staff and of the administration toward such children.



To demonstrate some positive changes the principal of the BPBH tells:

There is a big progress at the perception of our children by the people who live in the neighbourhood of the boarding-home. Ten years ago people called to the Committee of the Social Policy of St. Petersburg<sup>10</sup> and told that they have bad mood when they see children with impairments walking at the park and asked to not allow them to go out at least during the weekends. Now it does not happen anymore.

PWI are getting more known in Russia now, consequently the extent of the stigmatization is getting lower. The Russian society now is more aware about these people and about the quality of life they live. For example, one of the Public Charity Organizations of St. Petersburg which work at the BH for CWII was celebrating one year ago the fact that the percentage of the financing by Russian sponsors is more than 50 % now, while 10 years ago the majority of the financing was from the foreign sponsors.

Let us turn now to the comparative analysis of the changes in details.

The table 5 (see appendix) illustrates a big improvement of the circumstances of the life of CWMI at the BPBH and Russian social policy in details. There is a considerable progress at the understanding of the basic needs of CWI and the ways of developing their capabilities. Firstly, the system of care for such children at the BH as well as at the society is better organized. Namely, there is a significant social aid to CWI from the government and there are a lot of additional services at the BPBH which aim fully development of children capabilities. One of the most important changes is the understanding that children from the MD need not only medical, but also pedagogical, psychological and social support.

Secondly, there is a positive changing at the perception of such children by Russian society. CWMI are more visible now; there are more literature and information in the mass media about them. The reaction of people without impairments outside BH when they see CWI is more often adequate

---

<sup>10</sup> That time the Committee of Social Policy was called The Committee of Labor and Social Protection

than negative. The contacts with foreign specialists help to get new knowledge and to improve the level of the life of children.

Finally, the BH is fit up better with equipment and although it is done with the help of foreign sponsors, there is also a big support from the Russian government.

### **3.4 Why the better practice institution can be considered as a better practice**

This subchapter shows how the principal and staff of the BPBH have achieved such results and why there are still a lot of difficulties which they face. The eight main challenges which are faced by the BHs for CWII and which were mentioned at the beginning of this chapter will be followed:

1. *Lack of the access to the services, limited understanding of the needs of children and lack of the support of the BH by the government.*

As has been mentioned before, although nowadays there are a lot of social services in Russia it is difficult for children both at home and at the institutions to get them, because of bureaucracy, lack of information about the services, inappropriate conditions of giving the services. To get these services parents or other care-givers have to find it by themselves, to fill in a lot of documents, to be in the waiting lists for a long time, etc. However, at the BPBH children have a lot of additional services which can be hardly got by them even at home. These services give children opportunity to use and develop their capabilities.

How have they got to this stage? The initiative and persistence of the care-giver in Russian society is a crucial factor if s/he wants to achieve the goal. The care-giver is often the one who has to explain to the government what children need and to implement the bottom-up design of the social support rather than top-down one.

The vice-principal of the BH tells:

Our principal is a very special one. He spends a lot of time to find out the way how to get the best for children. He spends every single kopeck for the benefit of children. He is always in the search of new opportunities...

2. *Lack of the information about PWI*

The team of the BPBH considers their role not only in care about children, but also in creating more inclusive environment for PWI in Russian society. For that they organize seminars, lectures, workshops, invite mass media, take parts in the broadcasts, have a website of the BH, CDs and printed information about the BH. In some others BH one can see such activities mostly as an initiative of NGOs and charity organizations, while at the BPBH it is built in at the institutional system of the state.

3. *Limited understanding of the needs of CWMI by the staff of BHs*

The education and experience of the principal and other administration staff have a big influence on the understanding of what children need and how to develop their capabilities. The principal of the BH has worked at this institution since the beginning. He realized that he did not have enough knowledge to work with CWMI and he got second high education at the pedagogical institution on the defectology department. After that he could understand better that children with severe impairments need not only medical treatment, but also social adaptation and education, and how to organize the environment to make it possible. He also understood that it is very important to work with the personnel correctly in order to make them following his policy and to create a good atmosphere at the BH. That is why he got the third high education – psychological one.

The team of the BPBH understands that CWMI have not only basic and medical needs, but also educational needs. As this paper considers education as a development of capabilities, the following example can support the statement:

The educator tells:

Every child can be taught even if it will not be visible for a long time. The child should not stay alone on the bed. I try to do at least something with

every child when I am here – to teach how to eat, to walk, how to show what you want...

Additionally, children must be at the comfortable atmosphere and must be heard if they need something. At the BPBH it is more possible than in many others BH, because groups are smaller.

#### 4. *Low budget*

One of the important things at the management of such big institutions as Russian BHs is distribution of resources. The team of the BPBH tries not only to find some external sources (long-term relationships with sponsors, different kind of workshops...), but also distribute the internal budget in such a way that allows subdivision of the MD into smaller group with bigger number of care-nurses and educators.

#### 5. *The problem of continuation of support for CWI*

The continuation of the help is seeing by the principal of the BPBH and his team as a crucial factor for development of the child and his/her future life. To make the help meaningful it is important to support the skills which the child has developed and to think how to support it at the next stage of his/her life.

To implement this approach the CSPR and Social Flat for people after 18 years old were built as parts of the BH. Moreover, the staff of the BH have contact with people who live independently after they left BH, as well as with the staff of other institutions where people with severest impairments can live.

Additionally, the staff of the BPBH gets information about children from the places where children lived before BH, namely families and infant-homes.

Mother of one of the children from the MD tells:

The head of the MD called me every day after my son was accepted at the BH. She asked everything about him: about his eating habits, playing with him, how to make him calm, and many other things. It made me happier, although I still was crying all the time.

6. *Medical model is still the priority at the majority of the BHs*  
CWMI have medical as well as social needs. Some of them cannot live without medical support. However, it does not mean that they are sick. It is the state of their body in which they live all their lives. That in turn means that they must live at Home rather than at Hospital. The capabilities of CWI must be recognized and individual plans of development must be built on the basis of their capabilities rather than on their limitations. The team of the BPBH tries to avoid the hospital atmosphere at the BH and to provide to the CWMI not only medical services, but also services which are associated with normal children's life, such as playing, doing sports, walking outside, being not on the bed during the day time, etc. For these purposes the individual plan of development is created for each child by the wide set of specialists including medical as well as social and pedagogical staff.

7. *Buildings of the BHs are often inaccessible for CWMI*

The team of the BPBH realizes that if the building of BH is inaccessible the CWMI will not be able to participate in some events, to walk outside, and will have a lot of limitations with movement. It also would create big challenges for the staff. That is why the building was reconstructed and has a big ramp from the second floor to the ground floor. Moreover, children with the most severe impairments live on the ground floor. That makes everyday walks possible for them.

8. *Too big institutions and groups for CWMI*

The team of the BPBH realizes that it is hardly possible to meet children needs in such big groups as groups for 12-13 children and only one care-nurse working with them. The decision at the BPBH was in subdividing of the groups at the MDs into smaller groups for five-six-nine children.

Steps forward are made at the BPBH. However, this progress is not sustainable if the whole system in the RF is not ready to maintain these achievements.

## Chapter 4. Policy implications

This chapter will conclude on the basis of the literature review, field data and data analysis what policy lessons can be learned from the experience of BPBH and what must be done to implement better practice at other BHs for CWII in Russia and to further improve the picture of BPBH especially for children with the most severe impairments.

Firstly, the main lesson which can be learned is that an “ideal” society will not need such institutions as BHs for CWII. The system of social care must be able to support families which have CWI and help them to bring up such children at home. However, this stage is hardly achievable for the RF in the near future. Thus, this chapter will consider first steps which could be made in order to improve the lives of CWMI at the existing circumstances.

Secondly, the legislation system must be changed in order to meet needs of CWI and CWMI. Internal contradictions as well as contradictions with international conventions should be eradicated. CWMI must be considered as a special group of CWI with special needs which must be met along with the needs of all other groups of CWI. In order to create an adequate law system, specialists who work with CWI, caregivers, family members, PWI and CWI should be involved in the process of formulating these needs and potentials. Laws of the constituents of the RF must be created to ensure that federal laws are implemented correctly and cannot be in contradiction with them.

Thirdly, there should not be children who are out of the educational system. Thus, the procedure of dividing children between Social and Educational institutions must be abolished. All children have to have equal opportunities to get education. In order to make education accessible the institutions where CWMI live must have schools which are easy to reach every day for every child. The easiest option is to allow to the schools which already exist at the majority of BHs to graduate students and to have license for teaching activity. Additionally, it is important that the principal of the

BHs has pedagogical education, as s/he works with children who need education and full development of their capabilities.

Then, the subdividing of the BHs and the departments at the BH is one of the most vital measures which should be done in the area of care about CWI and CWMI. The bigger the institution the harder it is to provide an individual approach to the children who live there. And taking into consideration that all CWI are very different, the individual approach is necessary to create a convenient program of development for each child. Moreover, it is easier to manage smaller institutions and to create the appropriate environment for a lesser number of children.

Next, the continuation of the care and educational processes during the whole lives of CWI must be a concern of the state institutions and organizations such as Psychology-Medico-Pedagogical Commission and State Medical and Social Examination Service and others. The decision about the BH, school or other kind of institution which is better for the child must be taken on the basis of the child state and opinion of caregivers and specialists who work with the child as well as who work at these institutions. In other words, the social policy must be built on the bottom-up principle rather than top-down principle.

Another important point is that PWI, as equal members of society, must be more visible in order to participate actively in social life, to let other people know about themselves, about their capabilities and their needs and to involve people without impairments in the process of creating an appropriate environment for PWI. The crucial measure to reach that would be reconstruction of inaccessible buildings and transportation, creating social events where PWI could take part and involving Mass Media.

The issues of caring for CWI should not be considered a low priority issue and must have higher budget to fill in all rates at the BHs, to provide good circumstances of live for children and work for the staff. It also would allow to subdivide BHs and to equip it better. Moreover, higher welfare payments would prevent a lot of children from living at the BHs, because their parents could live them at home.



Lastly, it is not enough just to create social services for children. Children and their families must have access to these services. For that it is important to provide parents with detailed information about all services which exist and to update this information. One of the ways to do it could be through paediatricians who work with children. Another measure is to improve the system of social work with children. The duties and the time which social workers spend for every child must be increased. The social worker can be a person who checks if children get all services which are determined to them.

In the picture of the BH one can see the metaphor of the whole society in terms that the new approaches more easily come from the up to the down. Thus, the sooner the Russian government will be ready to take into consideration needs of children with CWI the sooner the society will be more tolerant and will be ready to accept PWI as equal.

## Chapter 5. Conclusion

This paper shows the system of social care in the RF and how it is implemented in one of the better practice examples of BHs for children with severe impairments in St. Petersburg. On the basis of the literature review as well as observation, interviewing and data analysis, one could see that the issue of caring for CWI is topical one and there are a lot of children in the RF who do not have opportunity to develop their capacities and are excluded from the social life.

There are positive changes in the caring system for CWI in the RF. PWI are more known now in Russia than they were decades ago. Some buildings are reconstructed and there are new buses which are accessible for wheel-chair users. More children and adults with impairments have welfare payments and can access social services. Additionally, there are positive changes at some institutions for such children. For example, at the BPBH for CWII children have both medical and social support, a lot of additional services, live in better circumstances and at the calm atmosphere.

However, there are still a lot of challenges which specialists who work with children, families and children themselves face. For example, BHs for CWII have a lack of staff and money and CWMI are often left out of the educational process. Children with severe impairments are considered as not having capabilities to get educated and to participate in the social life. Instead of being considered as differently capable they are considered as incapable. Such attitude influences the whole lives which CWMI live starting from the everyday curriculum to the opportunities to socialise and to be employed. Next, families are not able to support children with severe impairment at home, some social services are hardly accessible for all families, a lot of buildings and public transports still need reconstruction to meet needs of PWI. Moreover, PWI are still stigmatized and some parents do not want to show with their children in public places because of inadequate reaction of PWI. Additionally, the legislation system is inadequate and often

in contradiction with international laws and with itself, there is no system of continuation of the help, and BHs as well as departments and groups at these BHs are too big. These challenges mostly result from the inadequate system of social care in the RF and from limited understanding of needs of CWI and CWMI by the government and some specialists who work with children. CWI and especially CWMI are still considered as people who need to be cured and cannot participate in social activities due to their health conditions.

All these challenges make the success of the BPBH unsustainable till the whole system of social care in Russia will be ready to maintain better practices. To meet needs of CWMI, to implement positive experience of BPBH and to improve the social care system in Russia following measures must be taken.

The legislation system must be changed to meet needs of all different groups of CWI and to create an appropriate environment for them; PWI must be involved in the decision-making process; all children must be under the supervision of Committee of Education and have equal opportunity to get education and to use their capabilities; BHs, departments and groups at these BHs must be subdivided; the united system of care during the whole life of the CWI must be created in order to provide the continuation of the care; PWI must have equal opportunity to enter transport, buildings and as a consequence they will be more visible; the budget for BHs, social services must be bigger, and, lastly, the information about these services must be distributed among parents and these services must be easy accessible for all families with CWI and for children themselves. To implement these changes Russian society should move forward from using medical model of disability.

Medical approach alone is not enough for CWMI as it is hardly possible to cure them. However, the majority of CWMI need some kind of medical treatment during the whole life and they cannot live without medical support. Moreover, CWMI are a very diverse group within them in terms of different kinds of impairments and consequences of these impairments. Thus,

it is difficult to create an adequate plan of social support without taking into consideration differences and limitations which children face due to their body conditions. Nevertheless, medical model is limited in terms of perception of CWMI as equal members of society having their strengths. Social model is needed to create friendly and evolutive environment for CWI. Thus, neither medical no social model alone are enough to understand and analyze the complexity of the case of CWMI. Regarding to the present research the ICF model is the most appropriate one, because it mentions both social and physical conditions, and also individual characteristics of PWI which must be taken into consideration to meet their needs and to use their capabilities. CWI must be considered as having different capabilities which can be realized in the appropriate environment.

In order to implement these changes in my further researches I would explore in details needs of CWMI. I would involve in this process children themselves, specialists who work with them and family members. Additionally, I would investigate the Russian legal system in details to find out the possibilities to change it in order to meet those needs and to create an appropriate environment for all children.

To conclude, it is important to remember that even best BH is worse than family care. The main aim of the social care system should be creating a society where BHs are not needed and all children live at home.

## Appendix

**Table 4. The Implementation of social policy at the better practice boarding-home for children with intellectual impairments in St. Petersburg (Russia)**

Criteria	Positive	Negative
Human resources	<ul style="list-style-type: none"> <li>• There is a problem with human resources, but not catastrophic</li> <li>• The administration is expecting more people will come to work, because new buildings are built near the BH</li> <li>• Children who have severest impairments live 5 children per group (15 children at one MD). They have two or three care-nurses at one department</li> </ul>	<ul style="list-style-type: none"> <li>• There are not enough people who want to work at the BH and the principal decided to put all educators in the groups where children have higher level of development. So, the weakest children do not have educators in the group, or have only two times per week. There are a lot of children who could eat by themselves and walk, but nobody has time to teach them</li> <li>• There is a lack of physiotherapist service – the wheelchairs and baby carriages are not always suitable for the child who is sitting there. This equipment needs to be fixed up by physiotherapist</li> <li>• The only educator who worked on one of the MDs is an elderly woman who worked before with children with less severe impairments and she does not know well how to work with children at the MDs. All younger educators were forced to go to the different departments</li> <li>• Some people from the staff have left, because it is difficult to work and salary is low</li> </ul>

<p>Other resources (money, equipment, etc.)</p>	<ul style="list-style-type: none"> <li>• The principal of the BPBH is not afraid to take money from government, to take a part in new projects. He knows how to use money properly and how to save the result</li> <li>• There is school at the BPBH with a lot of new facilities and professional specialists</li> <li>• The new building for the C SPR was built and a lot of PWI over 18 were replaced there. Consequently the free space for other children appeared</li> <li>• MD where children with severest impairments live (5 children per group) was created with sponsor's help 10 years ago. However, now it is supported by the internal budget. The weakest children live in this department in the rooms for 5 children</li> <li>• There are a lot of additional services for children (see table 3)</li> <li>• There are enough clothes and staff care about the condition of the clothes. Every child has his/her own shelf in the cupboard</li> <li>• Some bathrooms are equipped with special lifting tools which help to lift heavy children and put them in the bath</li> </ul>	<ul style="list-style-type: none"> <li>• There is a lack of physiotherapist service – the wheelchairs and baby carriages are not always suitable for the child who is seating there. This equipment needs to be fit up by physiotherapist</li> <li>• The budget is not enough to provide all children with everything what they need</li> </ul>	
<p>Policy</p>	<p>3.1 BH</p>	<ul style="list-style-type: none"> <li>• The staff who works on the MDs have support from administration: they can ask for help to move wheelchair users or other heavy children from the group outside and men from the C SPR will come every</li> </ul>	<ul style="list-style-type: none"> <li>• Children have more severe impairments. Consequently it's getting harder to work. For example, eight years ago the bigger percentage of children could speak, walk and eat by themselves. But the</li> </ul>

		<p>day and help</p> <ul style="list-style-type: none"> <li>• The principal of the BPBH is not afraid to take money from government, to take a part in new projects</li> <li>• Children have more severe impairments. Consequently it's getting harder to work. For example, 8 years ago the bigger percentage of children could speak, walk and eat by themselves. But the principal and vice- principal ask more now than they asked 8 years ago. Educators need to reach results which are difficult to reach with such children.</li> <li>• New building for the CSPR was built</li> <li>• Each child has his or her individual plan of development which is created at the beginning of the year by the set of specialists: doctor (paediatrician and psychiatrist), educator, speech therapists, resource specialist, psychologist, physiotherapist, massage therapist, and the teacher from the school.</li> <li>• The staff and administration care about the assessment of their job by parents of children</li> <li>• The provider of the clothes is established by the government and it is the same for all BHs in St. Petersburg, but at the BPBH they do not accept the clothes which they do not like and ask to change it</li> <li>• The "Social Flat" was built in 2005. Five people over 18 live there independently, but they live on the territory of the BH and always can ask for help. This project helps them to learn how to live in the socie-</li> </ul>	<p>principal and vice-principal ask more now than they asked eight years ago. Educators need to reach some results which are difficult to reach with such children.</p> <ul style="list-style-type: none"> <li>• All young educators were forced to go to the different departments where children have less severe impairments</li> <li>• There is no system and continuity – the educators are replaced on the other department, consequently children lose part of their skill which they learn with educators</li> <li>• Care-nurses are not always satisfied with the administration of the BPBH, because they have some difficulties (for example it's difficult to feed some children and they need some special equipment to make it easier) and the administration of the BH does not pay enough attention to these problems (from the nurses point of view)</li> </ul>
--	--	--	--

		<p>ty, how to cook, how to organize themselves. They also work and should wake up on time, come to their job on time. People there got social and psychological support</p> <ul style="list-style-type: none"> <li>• In 2007 the C SPR in the BH was opened. 100 PWI after the age 18 live there, they work (cleaning, washing, cooking, gardening in the BH, etc.), learn new profession, and learn how to use computer. They live in the rooms for two people; have common kitchen, sport hall and concert hall, workroom, gym and art studio</li> </ul>	
	3.2 Government	<ul style="list-style-type: none"> <li>• The last year they took exams by extern and 14 children got the certificate that they have finished special school</li> <li>• In the case of this particular BH government reacts fast on the requests. For instance, one boy who lived here in the BH told to the mayor of St. Petersburg that the road near the MD is very bad, children with severe impairments often need the urgent medical help and the emergency ambulance cannot come close to the building. On the next day the road was fixed</li> </ul>	<ul style="list-style-type: none"> <li>• Russia has not signed up CRC so far. The whole law system should be ready to that</li> <li>• The BHs for CWII in Russia are under the supervision of the Committee of Social Policy. Consequently they cannot teach, because they do not have educational license. They have school, but cannot grade exams</li> <li>• There is no separated policy for CWMI</li> <li>• Some staff has left because it is difficult to work and salary is low</li> <li>• There are more services in the BH than weak children can use. From the point of view of some workers of the BH it would be better to accept at this institute children with less severe impairments who could use all the spectrum of services. However, it is not taken into consideration</li> </ul>



			<p>by the government. Children are placed at BHs by the psychology-medico-pedagogical commission and they do not ask the opinion of the staff and administration of BHs</p> <ul style="list-style-type: none"> <li>• Mothers of some children are getting their welfare payments, but some of them visit their children only once per three months to keep getting welfare payments. Otherwise the administration of the BH can take them to court to deprive of parental rights</li> <li>• In Russia caregivers have to fight for services which CWI have right to get, nobody will come and give them to children and their families</li> </ul>
Attitude toward children	4.1 Staff	<ul style="list-style-type: none"> <li>• During the walk outside if some child is crying care-nurses sometimes will walk with the child. The educator always plays or walks with children</li> <li>• Care-nurses change the body position of children several times per day, reseat them from their beds to the wheelchairs or to the play pens</li> <li>• Care-nurses and other staff go to the child if he/she is crying</li> <li>• Care-nurses and other staff speak with children gently the majority of the time</li> <li>• No one child is on the bed during the day</li> </ul>	<ul style="list-style-type: none"> <li>• The care-nurses during the walk just seat and talk with each other the majority of time and do not pay attention to the children who are seating in wheelchairs or baby carriage</li> </ul>
	4.2 Administration	<ul style="list-style-type: none"> <li>• Each child has his or her individual plan of development which is created at the beginning of the year</li> </ul>	<ul style="list-style-type: none"> <li>• The rules for parents who want to visit their children are very strict. They can come only</li> </ul>

		<p>by the set of specialists: doctor (paediatrician and psychiatrist), educator, speech therapists, resource specialist, psychologist, physiotherapist, massage therapist, the teacher from the school, etc. At the end of the year the plan is compared with results and is analysed</p> <ul style="list-style-type: none"> <li>• The perception of general rules is flexible. For example, children can be without pampers outside if it is warm weather, or girls can have a long hair and the principal will support it, while at some other institutions for CWII children's hair are cut very short because of sanitary reasons</li> </ul>	<p>once per week during the limited period of time and cannot enter if they are late</p>
--	--	--	--

**Table 5. Comparative analysis of the better practice boarding-home for children with intellectual impairments in St. Petersburg (Russia) in time (1974 - 2010)**

Criteria	1974	2010
Human resources	<p>Groups contained 20 CWMI, and one care-nurse cared about them.</p> <p>There was very limited set of services which children with severe impairments got and limited number of the personnel: one care-nurse cared about 20 children and there was no rate for educator.</p>	No more than 12-13 CWMI per group, and one care-nurse cares about them. At the BPBH there are groups where five-six-nine children live.
		Some new doctors were found and some of the staff members got additional education to be able to work at the functional diagnostics department.
		A lot of different specialists work with children and children make a positive progress in their development.
		The best teachers and educators are on the groups for children four-seven years to discover children's capabilities as early as possible.
		The majority of the additional services have appeared during last 10 years (see table2).
Other resources	<p>There were no diapers; nurses used napkins, and it was very difficult to keep cleanness of the body of children and of their beds. There was a bad smell in the rooms.</p>	<p>Now children get diapers from the government (from the Found of Social Insurance) 3-5 diapers per child per day depending on the severity of impairments.</p>

	There was a lack of special equipment for CWI.	Fund of Social Insurance <sup>11</sup> provides wheelchairs, walking-frames, and standing frames. However, it is still not enough and not all these equipment fits well for CWMI.
		There are different kinds of equipment which help to care about children (for example, special lifting tool to put children in the bath, washing machines at the MDs, etc.).
	If the child needed some kind of health examination (encephalography, ultrasonic examination, electrocardiogram, etc.) the BH should apply for that at one of the hospitals in St. Petersburg, wait at the long waiting lists and could get information only in about 6 months. It always was too late and hard for a child and for the personnel.	During last 10 years more children have severe impairments and the BH has reoriented on the work with them and has organized the system of complex rehabilitation for them. This system includes all additional services (see table 3) and the department of functional diagnostics (encephalography, ultrasonic examination, electrocardiogram, etc.). The BH with support of the government and sponsors bought special equipment and apparatus. Now children can get health examination very fast at the BH.
Policy	There were no summer health holidays which were paid by government.	There are summer health holidays and there is special income item for that.
	Children with invalidity did not have welfare payments and other social benefits.	Now all CWI who have invalidity ( <i>инвалидность</i> ) get the social welfare payments(see table 1). Other social services: Social taxi (parents pay only 50% of the cost). Social worker can come twice per week and stay with a child.

<sup>11</sup>Fund of Social Insurance controls the budget of State Social Insurance of the Ministry of Public Health and Social Development of Russian Federation and has its regional departments at the subjects of Russian Federation.

		<p>Disability benefits for CWI and their parents.</p> <p>Groups “Special child” at the correction schools of 8<sup>th</sup> type (<i>школы восьмого вида</i><sup>12</sup>).</p> <p>Free travel at the public transport for the child who has impairments and for one attendant.</p>
	<p>CWI were hidden from the society, and there was a lack of information about such children and how to work with them.</p>	<p>There are seminars and qualification courses for the staff of the BH as well as there is a wide range of European, Canadian and American partners who help personnel to learn better how to work with such children<sup>13</sup>.</p>
	<p>There were no rates for educators at the MDs.</p>	<p>There is a lot of new literature about children with special needs.</p> <p>There are rates for educators at every group including groups for children with the most severe impairments.</p>
Attitude toward CWMI	<p>CWMI are ill and needs treatment.</p>	<p>CWMI need pedagogical, psychological, emotional support apart from the medical care.</p>

<sup>12</sup> Children with slight mental impairments study at these schools.

<sup>13</sup> During that period of time Russia has come through significant political changes. For example, the Cold War which ended in 1990<sup>th</sup> blocked Russia from the contacts with foreign countries. After the end of the war the scientific relations between former USSR and other countries were established.

### **The list of the partners of BPBH:**

- Diakonie Stetten, Federal Republic of Germany
- Federation of Anthroposophical Institutions in England
- Norwegian King Karl Foundation
- American Medical Care Foundation
- Raoul Wallenberg International University, St. Petersburg - Family and Child Department
- The association of public organizations “Great Bear”
- The PROGRESS Scientific & Technical Information Centre
- Herzen State University, St. Petersburg
- Academy of Early Learning Support, St. Petersburg
- Russian State University, St. Petersburg
- Gaoordi Association, St. Petersburg District
- Special Olympics
- Russian Foundation for Children
- Canadian "Adoption" Foundation
- Tacis
- Mission of Tears
- Christian-Horizons

### **Semi-Structured Interview Questions:**

#### *Questions to the staff of the boarding-home:*

1. How long have you worked at the Boarding-Home?
2. What has been changed during this period of time?
  - What has got better?
  - What has got worse?
3. Which difficulties do you still face?
4. If you had more resources, what would you like to change in your work?

#### *Questions to the parent of the child:*

1. How long have your child been at the Boarding-Home?
2. What do you like at the BH?
3. What would you like to change?

#### *Questions to the person with impairments who lived at the BPBH when she was a child:*

1. When did you leave the BH?
2. What have you reached in your life?
3. How the staff of the BH have helped you to reach it?
4. What was good at the BH?
5. What was bad at the BH?

## References

- Disability, Inclusion and Development*. (2005) London: Source.
- 'Constitution of the Russian Federation'. (1993).
- Barnes, C. and G. Mercer (2008) *Disability: Key Concepts*.
- Center for Curative Pedagogics (Центр Лечебной Педагогике) (Last updated 2006) 'Increasing of Discrimination of Children-Invalids in Education System' ("Нарастание Дискриминации Детей-Инвалидов в Сфере Образования"). Accessed 16 September, 2010 <<http://www.osoboedetstvo.ru/fs/archives/38-...html>>.
- Dowling, M., J. Foy and G. Fajth (2005) 'Children and Disability in Transition in CEE/CIS and Baltic States'.
- Elwan, A. (1999) *Poverty and Disability: A Survey of the Literature*. Social Protection Advisory Service.
- Federal State Statistics Service (Last updated 2010) 'Invalidity' ("ИНВАЛИДНОСТЬ"). Accessed 2 November, 2010 <[http://www.gks.ru/wps/portal/OSI\\_N/ZDRAV#](http://www.gks.ru/wps/portal/OSI_N/ZDRAV#)>.
- Gasper, D. (2006) 'What is the Capability Approach?: Its Core, Rationale, Partners and Dangers', ISS - International Institute of Social Studies, The Hague.
- Helander, E. (1993) *Prejudice and Dignity*. New York, NY: UNDP. Interregional programme for disabled people.
- Hollingsworth, J. (1992) 'Service Needs of Children with Disabilities and their Families', *Journal of paediatrics and child health* 28(4): 283-285.
- Maag, M. (Last updated 2009) 'Supportive Health Services Needs of Children with Disabilities' (a webpage of The Urban Institute). Accessed 15 October 2010, 2010 <<http://aspe.hhs.gov/daltcp/reports/2000/suphsnd.htm>>.
- Medical Dictionary (Last updated 1998) 'Social Support' (a webpage of Mondofacto). Accessed 2 June, 2010 <<http://www.mondofacto.com/facts/dictionary?social+support>>.
- Mednick, M. (2002) *Supporting Children with Multiple Disabilities*. Continuum Intl Pub Group.
- Metzler, I. (2006) *Disability in Medieval Europe: Physical Impairment in the High Middle Ages*. London: Routledge.
- Ministry of Labor and Social Development of the Russian Federation (2002) 'Concerning Recommendations for the Organization of Boarding-Homes for Children with Intellectual Impairments' ("Об Утверждении Методических Рекомендаций по



Организации Деятельности Государственного (Муниципального) Учреждения "Дом-Интернат для Умственно Отсталых Детей").

Ministry of Social Protection for the Public of the Russian Federation (1993) 'Concerning the Organization of Boarding-Homes for Elderly People and Invalids' ("Об Организации Домов-Интернатов Милосердия для Престарелых и Инвалидов").

Mitra, S. (2006) 'The Capability Approach and Disability', *Journal of Disability Policy Studies* 16(4): 236.

Mkandawire, T. (2001) *Social Policy in a Development Context*. Vol. PP SPD 7. Geneva: UNRISD.

Montgomery, H. and M. Woodhead (2003) *Understanding Childhood*. Vol. bk. 1. Chichester, Open University: Wiley.

Priestley, M. (2003) *Disability: A Life Course Approach*. Polity Pr.

Rubinstein, S. (Рубинштейн С.) (1970) *Psychology of Mentally Retarded Pupil (Психология Умственно Отсталого Школьника)*. Moscow: Prosveshenie.

Sander, M., K. Stengler, O. Pospelov and A. Iljin (2007) *House for the Normal Life and Work*. St Petersburg (Дом для Нормальной Жизни и Работы).

Sendege, E. (1998) *Disability and Development: The Role of the Disability Movement in Uganda*. The Hague: ISS.

Shipitsina, L. (Шипицына Л.) (2005) *Unteachable Child in the Family and Society (Необучаемый Ребенок в Семье и Обществе)* St Petersburg: Rech.

Sloper, P., R. Webb, V. Greco and J. Beecham (2008) 'Key Workers and Schools: Meeting the Needs of Children and Young People with Disabilities', *European Journal of Special Needs Education* 23(3): 189-205.

The State Duma of the Russian Federation (1995a) 'Concerning the Social Service for the Elder Public and Invalids' ("О Социальном Обслуживании Граждан Пожилого Возраста и Инвалидов").

The State Duma of the Russian Federation (1995b) 'Concerning the Social Protection for Invalids in the Russian Federation' ("О Социальной защите Инвалидов в Российской Федерации").

The State Duma of the Russian Federation (1992) 'Concerning the Education' ("Об Образовании").

Trani, J., M. Kett and R. Lang (2009) 'Disability, Development and the Dawning of a New Convention: A Cause for Optimism?', *Journal of International Development* 21(5): 649-661.

UN General Assembly (2006) 'Convention on the Rights of Persons with Disabilities', Retrieved June 3: 2007.

UN General Assembly (1989) 'Convention on the Rights of the Child', *Adopted by General Assembly Resolution 44: 25*.

UNICEF (2007) 'Promoting the Rights of Children with Disabilities', No. no. 13. Florence, Italy. UNICEF, Innocenti Research Centre.

UNICEF (Last updated 2007) 'Situation Analysis of Children in the Russian Federation' (a webpage of UNICEF). Accessed 28 August, 2010  
<[http://www.unicef.org/sitan/files/ru\\_en\\_situation-analysis\\_170907.pdf](http://www.unicef.org/sitan/files/ru_en_situation-analysis_170907.pdf)>.

Werner, D. (1998) *Nothing about Us without Us*.

Werner, D. (1988) *Disabled Village Children*. Hesperian Foundation.