

The World Bank

Qualitative Survey on Disability and Living Standards in Georgia

Survey Report – April 2007



Institute for Policy Studies



**The House of Children's
Harmonious Development**

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FOREWORD

This report has been prepared by PA Consulting Group (PA) and The Institute for Policy Studies (IPS). The analysis was done by Dr. Nana Sumbadze and Tatyana Yamova. Field work was carried out by Dr. Nana Sumbadze, Tamar Makharadze, Ekaterine Pirtskalava, George Tcheishvili and Tiko Nozadze. Meetings with government officials, focus and work groups were organized with the assistance and advice of Manon Khachidze.

This report reflects the status of disability issues in Georgia as of September 2006. Since the completion of the report, a number of important changes have taken place:

- The procedure of qualifying for disability status has changed. According to Order N 63 (27.02.2007) of the Ministry of Labor, Health and Social Protection, medical-social committees that used to certify disability status have been abolished and replaced by “medical facilities of general or specialized character”;
- A classification of diseases, for which a disability status could be obtained, has been reduced;
- According to the Government Resolution of January, 4 2007, utility subsidies to qualified individuals, including persons with disabilities, have been increased;
- According to the Georgian Law on Social Assistance (4289-RS, 29.12.2006) reintegration subsidies are being provided to those biological parents, who have taken their disabled children back from specialized institutions;
- According to the above law, households who have taken their adult disabled family members back from an institution, are compensated for their care;
- Disabled person can be provided with in-kind subsidies;
- An order by the Minister of Labor, Health and Social Protection has been prepared on establishing Ministry’s Coordination Committee on Disability Issues. Ten representatives from NGOs will serve as members of this committee.

The project team would like to express their deep gratitude to all study participants for their cooperation and sincerity. We realize that participation in focus groups and discussions often presented an emotional and physical challenge for many respondents.

The names of all respondents and focus group participants, with the exception of the representatives of government/official entities and experts, have been changed to protect their identity.

This report provides insights into attitudes, perceptions, thoughts and hopes of respondents with disabilities, their caregivers and other key stakeholders. We hope that it will be helpful in formulating a state policy on disability issues in Georgia and will contribute to the integration of disabled persons and improvement of their lives’ quality.

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1. INTRODUCTION

1.1 BRIEF OVERVIEW OF DISABILITY STATISTICS IN GEORGIA

This report is prepared in compliance with the requirements of the contract 7137937 “Qualitative Study on Disability and Living Standards in Georgia”.

The data on disability in Georgia is very limited and fragmented. The database of registered persons with disabilities maintained by the State United Social Insurance Fund of Georgia (SUSIFG) contains only medical information. There is a database of disabled people compiled in the Autonomous Republic of Ajara in 2004. There are also several studies and research papers published on disability issues in Georgia¹.

Needs of disabled persons of Georgia and their families have never been studied and there is no comprehensive analysis of the problems associated with specific types of disability or educational problems faced by the disabled persons. Attitudes of the Georgian population towards disability and perception of disabled persons have not been surveyed.

According to the data provided by the SUSIFG, 213,184 disabled persons were officially registered in Georgia in 2004, of which 13.9% have the first category of disability (“very severe”), 65.6% have the second category (“severe”) and 15.5% have the third (“medium”) category of disability.

However, the actual number of disabled persons in Georgia is likely to be higher than 213,184. The World Health Organization (WHO) estimates that 7-10 % of the world’s population has disabilities, implying difficulties in daily activities and participation in society. Therefore, with a population of 4.4 million, Georgia could have around 400,000 persons with disabilities caused by physical, mental or chronic disorders. Underreporting of disability is a common problem and is caused by a number of reasons such as:

- *Stigma effect* - parents are reluctant to officially register disability of their children. They believe that the registration will complicate their children’s lives and negatively affect their ability to become employed.
- *Lack of information and access to registration* – residents of remote rural areas of Georgia have no or little access to the registration services. They are not aware of the disability registration benefits, and/or perceive such benefits as negligible.
- *Prohibitive cost of registration* – in order to get examined for disability and be assigned an official disability status by special examination committee (and be re-examined on an annual basis), an applicant has to pay 25-50 GEL (\$14-\$28) recurring fee at a local clinic or hospital.

According to the SUSIFG the main causes/categories of disability in Georgia are as follows:

¹ Available publications include: study conducted with the support of the Horizonti Foundation describing the situation with disability in 2002; an assessment of physical rehabilitation services in Georgia (Eklund, 2005) describing services provided for physical rehabilitation; a needs assessment for persons with mental disorders and retardation is provided in the report published in 2005 (Sharashidze, M. et al. 2005). Information about registered patients can be found in the Statistical book on Healthcare of Georgia.

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- Disability due to chronic illnesses represents the biggest share of all disability causes in Georgia (60.1%),
- Persons disabled since birth (16% or 34,118 persons of which 10,722 are under the age of 18),
- Persons with restricted abilities (13.8%),
- War veterans (6.5%), and
- Persons disabled due to work trauma or professional disease (3.6%).

It can be stated that social and economic conditions of disabled persons in Georgia have deteriorated since Georgia's independence. "The break-up of the former Soviet Union, internal military conflicts, and disruption of the social environment in the 1990's caused quite a significant increase in the number of disabled people in Georgia. Experiments, carried out in the governing of the country's political and economical life, created after-effects, such as corruption, and lack of organization. Most of all, these negative consequences have greatly affected the unprotected population of disabled people" (Interview with the male head of NGO of disabled persons)

During the Soviet times the state policy towards persons with disabilities was not directed at their integration, but rather at creating possibilities for people with disabilities to function in a separate world. As a result, their living was isolated but somewhat secure. In the past both deaf and blind people could attend special schools and universities. Persons in wheelchairs were provided with free treatment and rehabilitation at local resorts and special clinics.

There used to be a network of special enterprises all over the former Soviet Union (SU) where deaf and blind people, and people with mental disorders could be employed. After the collapse of the SU, disabled persons in Georgia could no longer have access to special university education or rehabilitation resorts/centers because most of them were located in Russia.

Almost all enterprises that employed disabled persons in Georgia ceased to exist about fifteen years ago. The tax benefits for Georgian enterprises to employ disabled persons were revoked in 2000. The current Georgian legislation has no provisions that would force or encourage local businesses and organizations (state or private) to employ persons with disabilities.

Georgia's official unemployment rate is anywhere between 12-14%². Only 30% of the population is employed by businesses, enterprises and/or state entities. The rest (approx. 58%) are self-employed. Given high unemployment rate and scarce jobs, persons with disabilities currently stand little or no chance of employment in Georgia. In addition, social assistance provided by the state is insufficient: disabled persons receive a monthly pension (38 GEL or \$22), which is less than an alternative poverty line³ determined by the state.

The deplorable condition of disabled persons in Georgia is further confirmed by PA's qualitative survey, which comprised of 38 in-depth interviews and 9 focus groups with disabled persons, caretakers, service providers, state entities and organizations of disabled people. The survey revealed that disabled persons in Georgia (especially in the regions

² This number is underreported as unemployment benefits are negligible and people do not see benefits in registering with the state.

³ The alternative poverty line is 52GEL (\$28)

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outside of Tbilisi) are deprived of meaningful social and medical assistance, employment and education opportunities, and ability to leave their dwellings and interact with people other than their family members.

Several disabled persons and their family members interviewed were starving and managing to survive only thanks to the kindness of their neighbors. Almost all respondents said that they felt stigmatized, isolated and forgotten. Their caretakers (mothers taking care of their disabled children) were haunted by thoughts of what would happen to their disabled children when parents die.

1.2 RESEARCH METHODOLOGY

The main purpose of this qualitative research on disability and living standards in Georgia is two-fold: (i) to identify the most significant issues, challenges and barriers faced by members of disabled population to order to contributing to a better understanding of the relationship between disability and poverty in a given country and globally, and (ii) to provide recommendations aimed at designing/improving policies regarding employment, education, health care, and social protection.

The study sample was broadly representative of disabled persons in Georgia in the sense that persons with all types of disability were interviewed. The age group, sex and geographic location were also taken into consideration when choosing the sample. A sufficient number of interviews with individuals and groups were conducted to ensure that we identified the most significant issues facing this population. We recognize that “people with disabilities” is a very broad category that encompasses physical, mental, and sensory disabilities. We hope that we have managed to identify the most critical problems faced by disabled persons, their caregivers and service providers. It is impossible, however, within the scope of this study, to represent the full range of challenges faced by members of this population fully and in detail. We worked closely with disabled person organizations and NGOs/advocacy groups order to identify the major constituencies that included men and women, range of age groups, people living in capital and in regions.

Four types of in-depth interviews were conducted:

1. Interview with a disabled person
2. Supplementary interview with a family member or a disabled respondent’s primary caretaker
3. Interview with a disabled person’s primary caretaker in situations when the disabled person is not capable of answering questions herself/himself
4. Interview with heads/leaders of organizations associated with disabled people, i.e. NGOs working in the area of disability, service providers and/or relevant state entities.

The total number of individual interviews conducted was 38. In addition to that, 9 focus groups discussions were held and conducted according to the focus group guide. The interviews and focus groups were conducted in the following parts of Georgia: Tbilisi, West Georgia (Kutaisi), East Georgia (Telavi) and a remote mountainous area (Dusheti).

In addition, five interviews were completed with the representatives of state entities dealing with disability issues: Ministry of Education and Science (MoES), Ministry of Labor, Health, and Social Protection (MoLHSP), Chairman of the Parliament Commission for Health and Social Issues, and Tbilisi Municipality. Available publications on disability issues in Georgia

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and applicable Georgian laws have also been reviewed, and local experts on disability and social protection consulted.

2. RESEARCH FINDINGS

This section of the report groups main findings of the qualitative survey into the following topics:

- Key Stakeholders
- State Support/Social Protection
- Health Care
- Education
- Employment
- Recreation and Leisure
- Integration Issues

2.1 KEY STAKEHOLDERS

This section summarizes concerns, feelings, and attitudes of the key stakeholders: persons with disabilities and their household members, organizations of disabled people, government entities, education and health care providers, church, and donor organizations.

2.1.1 Disabled Persons

Physical and economic dependence, poverty, inability to participate in the life of society, isolation, the feeling of being socially disvalued are the main concerns of disabled respondents.

“You have to look at others for help, you depend on them. This is the most difficult part of it. You cannot enter a store without help” (a 40 year old male respondent with mobility restriction)

Majority of disabled respondents are confined to their houses/apartments and cannot interact with people outside of their households. Loneliness is what the majority of interviewed disabled persons feared the most.

Poverty and unemployment are the main concerns of adult respondents: *“I fear tomorrow, the day after tomorrow, I fear life... future”* (a 43 year old male respondent, a war veteran).

Hopelessness is a common feeling among disabled persons. Only very few respondents said they had hopes for the improvement of their condition.

2.1.2 Caretakers

Household members of disabled respondents find themselves in a particularly difficult situation. The burden of caring for a disabled family member is very heavy and is often carried solely by a female household member. Caretakers are physically and psychologically exhausted and overstressed. In many cases they have to lift and carry their disabled family members because they lack equipment (wheelchairs, ramps, elevators, etc) and transport adapted for the needs of disabled people.

Caretakers do not have time for themselves, opportunities to work and have social interaction. They have to spend most of their time caring for their disabled household member(s). The situation is exacerbated by the feeling of not being helpful despite their hard efforts. Many respondents were the most frightened/concerned about future of their children and who would care for their offspring when they pass away. This thought is haunting many

2. Research Findings

interviewed caretakers. A mother of 18 and 15 year old daughters with cerebral palsy confessed her darkest thoughts:

“I was thinking of killing them and myself when I knew I was going to die. But now I do not think that I will be able to do this”.

Perhaps the most tragic answer to the question about her hopes and fears was given by a 41 year old mother of 21 year young man with mental retardation and epilepsy: *“I only hope for my death and the death of my son”.*

Caretakers of disabled family members, who had a chance to meet through different programs, continue interacting and providing support to each other. Parents of disabled children pointed out that they would rather seek and rely on the information shared by other parents than on the information provided by official sources. They share their concerns with each other and inform each other about new programs/possibilities. Many caretakers said that their only friends are parents of other disabled children.

Many disabled persons and caretakers who participated in focus groups exhibited a passive attitude towards their condition and somewhat excessive reliance on the state to solve their problems. When asked about reasons for their passivity, focus group participants pointed at depleted physical energy, psychological resources and lack of time needed for struggle.

2.1.3 Organizations of Disabled People and Care Providers

A considerable number of associations and unions of disabled persons and their caretakers operate in Georgia. These are organizations uniting persons with a specific disability, like the Union of the Deaf, or associations that include persons with various types of disabilities and their caretakers.

The oldest organizations of the disabled persons in Georgia are the Union of the Blind and the Union of the Deaf. They have a high number of members and considerable amount of property in Tbilisi and the regions. Both Unions have branches in regions, although many of them are not currently active.

The Union of the Blind was founded in 1926. It consists of 4,000 members, of which 250 members are employed. The majority (139) works at the Union. The Union has a big building and a lot of property in a form of enterprises, land and other facilities. They sublease their concert hall and pay the salaries for persons working at the Union out of this money. The Union has 24 branches and up to 30 legal entities, registered organizations. In fact, they are looking for investors and are concerned that the state will take away their property. They have already experienced indirect attempts on the part of the state. The Union is the member of the European Union of the Blind as well as of the World Union of the Blind, but they cannot afford paying membership fees.

The Union of the Deaf - there are 5,000 deaf persons in Georgia and the Union has 3,000 members. The Union functions as a social club, the place where deaf persons come to learn what is happening in the country and the world, and to communicate with each other. The Union has branches in the regions. It has a good, although requiring repairs, building in the city center.

The Union of God's Children was founded in 1988. The Union took part in Parliamentary elections of 1992 and the Union's president was elected Head of the Parliamentary committee on Social Affairs (1992-1995). Committee's activities resulted in drafting and adopting a Law on Social Protection of People with Disabilities.

The League of Disabled People was created in 1995 as a result of the first congress of disabled people of Georgia. In 1995-1996 the League, with the help of foreign partners, created many new jobs for disabled people. The successful programs of the League of Disabled People resulted in a Presidential decree, which ordered all State Departments to enforce each clause of the law about social protection of disabled people within its competence. It proved to be one of the most active NGO in the Caucasus region during those years.

Coalition for Independent Living was established in 2002 and currently comprises of 32 active NGOs of disabled people and veterans. The Coalition has its own website www.disability.ge (in Georgia, Russian and English). Main activities/objectives of the Coalition are to:

- Support disability organizations whose activities are directed towards protection of the legal rights of and creating opportunities for disabled people.
- Destroy stereotypes about disability and disabled people and to establish positive public opinion through public awareness campaigns.
- Support integration of disabled people and their family members into the country's political, economic, social and cultural life, and their participation in the policy decisions regarding disabled people.

As a result of the Coalition's active involvement, the state funded and implemented several disability integration programs with the direct participation of disability organizations back in 2003. Also thanks to Coalition's activities, a President's resolution announced June 14 as a day of protection of the rights of disabled people. This is perhaps the strongest and most active organization in Georgia that deals with disability issues.

Several organizations working with people with diabetes are effective and well organized in Georgia. There are 15,000 people with diabetes registered at the **Association of People with Diabetes** and they are provided with insulin. The Association runs summer camps where children with diabetes are taught how to control their illness. In 2007 the association plans to open a rehabilitation center "Rubicon" funded by the state, the center with sports facilities, where healthy and diabetic children will exercise together.

The Hemophilia Association unites 250 members. Disabled persons with hemophilia are provided with the necessary medical supplies

There are several organizations working with people with mental disorders. Parents of the children with cerebral palsy and Down syndrome have formed their own associations.

National Network of Parents was established in 2002 and it unites parents who take care of their disabled children.

Coalition of Children with Restricted Possibilities was created in 2004. It unites 12 NGOs including parents' organizations. The main objective of the coalition is to promote inclusive education. The Coalition is working closely with the Ministry of Education and Science of Georgia.

All of the above listed NGOs are located in Tbilisi. There are a number of organizations in the regions (see below), however they are not as nearly as large, well organized and funded compared to their colleagues in the capital.

Selected regional NGOs working on disability issues:

The Gori Club implements educational and integration programs for persons in wheelchairs.

Union of Disabled People in Khareli region. Main objective is disabled persons' right protection in Khareli region

Association of Disabled Persons in Kutaisi

Association of Disabled women and Mothers of Disabled Children in Zugdidi.

Please refer to Appendix F for a summary table of the NGOs working on disability issues in Georgia.

2.1.4 Government Entities

The two ministries most directly involved in disability issues are the Ministry of Education and Science (MoES) and Ministry of Health, Labor and Social Protection (MoHLSP).

Unfortunately, the MoES has not articulated a clear policy towards the disabled people. Ministry's policy regarding inclusive education is not detailed enough and leaves many issues pertaining to the education of disabled students unresolved. Support and promotion of special schools, vocational and university education for persons with disabilities do not seem to constitute priority areas of the Ministry's activity.

Data on the number of disabled children attending educational institutions in Georgia is not available. Only information available is about school graduates who take a compulsory national test to apply to universities since the test's introduction in 2005. The questionnaire for application for the national test contains a question about special needs. Special arrangements are made for persons with disabilities to take this test (e.g. Braille is used for blind students). According to the Ministry's data, nineteen disabled persons took the test since 2005.

The MoHLSP is responsible for developing a state policy on disability. It designs state programs such as a currently running state program for integration and adaptation of persons with restricted possibilities.

The State United Social Insurance Fund of Georgia (SUSIFG) reports to the MoHLSP and is responsible for determining disability status of applicants and providing special aids for persons with disabilities. SUSIFG maintains an electronic database of disabled persons in Georgia, which is updated on a regular basis. However the information about disability is strictly medical: the database contains 47 medical variables.

As discussed further in Section 2.2, the state policy towards disability is not clearly articulated, and priorities of the state are not spelled out. Researchers, activists and disabled persons pointed to non-existence of a coherent policy and unwillingness of the state to acknowledge problems faced by the disabled population of Georgia.

"In fact the main problem is that the state does not see problems of the disabled people" (an NGO representative).

Notwithstanding the goals declared by the Law on Social Protection of Persons with Restricted Abilities and 2006 state program aimed at supporting social integration and adaptation of persons with restricted abilities, disabled respondents speak of the state treating disability as a medical and not a social problem.

"Disability is seen as a medical problem, while it is much more of a social problem and is to be dealt by various ministries: economy, education, finance, health and law" (a male director of the NGO of disabled people)

While NGO representatives and disabled activists emphasize that the policy objective should be creating conditions for the disabled population to lead an independent life, there is a

feeling that the state prefers keeping the disabled people helpless and dependent on external aid.

“Policy makers are not motivated that disabled lead an independent life. The state wants to see disabled as helpless and dependent members. This state of affairs is much cheaper for the state to maintain. The overall policy is the same as the one with regard to poverty: instead of opening enterprises and creating jobs, the state supports opening of free soup kitchens”. (a 43 year-old disabled male respondent).

2.1.5 Educational and Health Care Facilities

Regular schools with disabled pupils, schools with inclusive education components, special boarding schools and institutions for the disabled students are the key stakeholders and effectiveness of their work has a major impact on the disabled students' integration. Health care facilities and qualified medical staff play a very important role from the standpoint of detection, prevention and treatment of disabilities.

There are 21 extended stay facilities (institutions) for disabled and underprivileged children in Georgia serving 2,226 children. 73.5% of these children are diagnosed as disabled and 83.1% of children have both parents. Children with mental retardation (623 children) are placed in 8 special institutions and those with severe retardation (150 children) are placed in two institutions. Children up to 3 year of age with mental and physical disorders (133) are placed in two other institutions. 125 adults with mental retardation reside in two shelter-type facilities.

Most of these institutions are under-financed and their buildings are dilapidated. There is scarcity of food, supplies and services provided to the disabled residents. There is also a problem of human rights' violation in all closed-type institutions like these. The Council under the Ombudsmen's office was created to monitor human rights' violation in closed-type psychiatric institutions in November 2005.

2.1.6 Service Providers

Rehabilitation and medical services available for the disabled population of Georgia are very limited. Swimming pools, water treatment procedures and other therapy/rehabilitation services are available only in Tbilisi and major regional cities. On top of it, most of disabled persons in need of these services either cannot afford them or cannot use the facilities due to transportation and physical access barriers.

Special aids for the disabled are partially covered or procured by the state programs and also donated by international organizations. There are several enterprises in Georgia that manufacture prostheses, orthoses, crutches, wheelchairs, and hearing devices.

There are two main physical rehabilitation centers in Georgia providing prosthetic and orthotic services. These two centers together with three smaller ones are estimated to produce around 600 prostheses and 1,000 orthoses per year. The Center for Social Rehabilitation has a staff comprising of 32 members. It was established in 1921. It was a state enterprise with five branches in different parts of the country, from which only Kutaisi branch (West Georgia) still functions and is well equipped. The Kutaisi center used to make 8,000-9,000 prostheses a year. In 1997-1998 a new technology was introduced with the help of German donors and appropriate equipment, machinery, and components were supplied for the manufacturing of 650 prostheses. Since then, 570 prostheses were made. The center is unable to purchase materials and its production has declined to 300 prostheses an year. The state covers 170 GEL (\$100) per prosthesis.

Georgian Foundation for Prosthetic Orthopedic Rehabilitation was established in December 2003 to take over the management of the Orthopedic Centre started by the International Committee of the Red Cross (ICRC) in 1994-1995. It supports those with physical disabilities by providing prostheses and orthoses, crutches and wheelchairs.

Disabled people, especially children who need prosthesis are facing problems. Prostheses have to be replaced on a regular basis: for children is it every 6 months and for adults once in 2-3 years. Wheelchairs are mostly purchased abroad, although a small number of them are made in Georgia. Wheelchairs have to be replaced every 4-8 years. The most complicated issue is a child's wheelchair. It needs to be changed/replaced more often, it should be two times heavier than an adult's wheelchair so the child gets accustomed to balance it and not to fall out.

Association "Imedi" purchased wheelchairs under a state funded program, but according to our disabled respondents these wheelchairs were of low quality and disabled persons could not use them independently.

Adaptive equipment workshop was established by **the World Vision** with funding from USAID and Eurasia Foundation to manufacture special chairs, tables and balancing boards for children with disabilities, mainly children with cerebral palsy.

German-Georgian enterprise "Kindsmena" specializes in production of hearing aids. Assisting devices are also donated by different foreign organizations.

Stockholm Institute for Rehabilitation of Hearing and Speech assisted Georgian deaf children. In 2005 several employees of the Institute spent 20 days in Georgia. They examined children in kindergartens and schools, and provided them with hearing devices. The device helps a person if he/she has 10-15% of the hearing ability. The state program covers the cost of hearing aids and partial cost of cochlear implants.

The Therapy House is the only place in Georgia, which provides homecare services for the disabled people. They have nurses trained to assist disabled patients.

Parents' Bridge, an organization of parents of children with mental retardation, founded a day center at special school No1 in Tbilisi in 2004. The center provides services to 29 children including lessons in music and art, occupational therapy, and physical exercises.

"Aisi" is a rehabilitation center for mentally retarded children in the age range from 3 to 17. It is working with 30 children.

The Association of Mental Health is making first steps towards rehabilitation of patients with mental disorders. The association operates a psychosocial rehabilitation center for 30 persons in Tbilisi and runs day centers with some elements of rehabilitation in Kutaisi and Batumi (West Georgia).

"First Step" is working with Senaki institution for disabled children. 24 orphans were taken from this institution and placed with foster families.

Resource Center for Integrated and Inclusive Education "Imedi" is working with 25 pre-school children with physical and mental impairments.

Center for Psycho-social Rehabilitation of Persons with Mental Disorders was established in 1998 and is treating 40 persons.

2.1.7 Donors

The impact of international donor organizations on the wellbeing of disabled people in Georgia is significant. It spans from assistance in developing new policies and joining

international conventions to provision of funds for implementing programs for disabled people, supply of aids and devices, to capacity building of local NGOs and implementation of training programs. Most of services provided for persons with disabilities or programs implemented became possible thanks to the support of international organizations and donors.

Unfortunately local businesses and private persons are not much involved in the affairs of the disabled population. There are no tax benefits for charitable activities in Georgia and local businesses are not motivated to assist the disabled and socially-vulnerably population.

2.1.8 Church

Many disabled respondents said that religious faith and attendance of church services were the main source of their strength and ability to cope with their impairment. For some disabled respondents attendance of a church service represents the only social activity.

Church is involved in caring for disabled people to a certain extent by providing food and shelter.

Georgian Orthodox church printed prayers in Braille and distributed them to blind persons together with icons and candles.

A special service for disabled and ill persons was performed by a Greek monk three times a week at Sameba Cathedral in Tbilisi. A disabled respondent talked about improvement of her condition after attending this service.

Catholic church organizes meetings of disabled persons and helps them with medication and employment by ordering embroidery.

2.2 STATE POLICY AND SOCIAL ASSISTANCE

2.2.1 Overview of the Georgian Legislation on Disability

The rights of disabled people are spelled out in the Constitution of Georgia. There are several laws containing relevant provisions pertaining to disability: Georgian Labor Code; Law on Sports, Health Care Law; Law on Psychiatric Assistance; Law on Medical Insurance, and Law on Education.

More specific Georgian laws dealing with the definition of disability and rights of disabled persons are briefly reviewed below:

The Georgian Law on Social Protection of Persons with Restricted Possibilities was adopted on June 14, 1995. The legal term "invalid" was changed to "person with restricted possibilities" six years later, in June 2001 after eight months of discussions. The main objective of this law is to provide for equal rights of disabled persons and create conditions for their participation in economic, political and social life of the society. However, the law has not been supported by budget provisions, necessary institutional resources and normative acts. It has not been accompanied by an action plan that would contain implementation time frame and description of responsibilities of different parties. In fact, the law has been more of a declaration rather than an enforceable and effective legal mechanism. Since its adoption, the law has not resulted in any major differences in the lives of disabled people in Georgia.

By 2000, the economic tools of the Federal Budget law, which were used to create programs for disabled people, were abolished. Through their own representatives in the Parliament the disabled persons tried to exert an impact new legislation. A representative of disabled people's organizations was the head of the subcommittee of the Georgian parliament

responsible for the affairs of disabled people. But despite of all efforts none of the proposed legislative initiatives was successfully brought to the floor from the committee meetings.

“The majority from the ruling government party has ignored the law on "protection of social rights of disabled people" and unfortunately this situation continues today. It is nothing but the discrimination of disabled people. Parliament has to discuss these matters, since it is a democratic institution and to have democracy and discrimination together is impossible. "If one country has both, discrimination and democracy at the same time - it is discriminated democracy... (From Parliament session, 2000)”⁴

In 2002, thanks to the initiative of local NGOs of disabled people, a Coordination Council under the President was established. The Council served as an advisory body to the President and encouraged the government to carry out its policy towards disabled people based on the recommendations of the activists of disabled population of Georgia. It played an important role in establishing anti-discriminatory policy on the basis of disability. In 2003, four anti-discriminatory laws and the President's five resolutions have been adopted. Unfortunately, the Council does not exist any longer and it can be stated that disabled persons of Georgia have almost no representation in the government.

Georgian Law on Medical-Social Examination (approved by a presidential decree # 558 on December 31, 2002)

The aim of the law is to provide healthcare to Georgian citizens and non-citizens, define the status of a functional limitation (disability), prevent and treat of the reasons that caused functional limitation, and promote conditions for rehabilitation and social integration of these persons. This was a very progressive piece of legislation on disability: according to this law, restrictions on the employment of persons with disabilities have to be defined not only from the medical point of view, but also from equal opportunities. The new law eradicated previously existed legal terminology: "incapable of work". Therefore many employment restrictions, where incapability for work was the reason to fire person, were abolished, at least on the paper.

There are two orders of the Minister of Labor, Health and Social Protection dated 2003 that supplemented the above law:

- Order for approving *definition of the status of Child with Functional Limitation*
- Order for approving the *list of diseases, anatomic and mental defects/disorders with which persons with functional limitation can work under special conditions.*

Georgian Law on State Pensions (effective from January 1, 2006)

The law provides for pensions for different categories disabled persons as follows:

- a. For persons with acute functional limitation, as well as children with functional limitation who need permanent assistance/care from other persons – GEL 35;
- b. For persons with severe functional limitation, as well as children with functional limitation– GEL 28;
- c. If a disabled person belongs to one of the following categories, he/she is compensated according to the corresponding laws:
 - c.1. April 9 Participants;

⁴ From G. Kokhreidze's analytical paper "Protection of Disabled People's Rights in Georgia: Highlights 1988-2004

2. Research Findings

- c.2. Chernobyl victims and their families;
- c.3. Victims of political repressions;
- c.4. War veterans

There was a presidential order No 665 on “**State program of social rehabilitation of disabled people in 1997-2000**” (adopted back in 1995) which contained provisions for registration of the disabled people, creation of services and the system of professional education for people with disabilities. This order, similar to other legislative documents, has not translated into real actions/improvements for the disabled.

Georgia also signed a number of international documents and treaties:

- International Pacts on Civil, Political, Economic, Cultural and Social Rights in 1995
- Geneva Convention N117 (1962) on the aims and norms of social policy in 1996;
- European Social Policy Charter (with amendments)
- UN “Standard rules on equalization of opportunities for persons with disability (1993, December 20)
- Salamanca Declaration and framework action (UNESCO, 1994), which is a guiding document of the Ministry of education.

Despite a number of well-intended laws and regulations on disability adopted in Georgia in the past decade, few of their provisions have been enforced. A good example is an amendment to the Administrative Code of Georgia (effective 1 November 2003). Article 1782 of the Code stipulates a fine in the amount of 500-800 GEL (\$300-\$470) to be paid by building owners if they do not adopt entrances and structures for the needs of disabled persons. This provision has been largely ignored as there are only two or three buildings adopted for the disabled people’s access in the Georgia’s capital not to mention other regional cities. Georgian NGOs of disabled people tried to amend this provision and proposed to replace a punitive approach to architectural barriers with incentives for builders and building owners, because the experience showed that the system of fines had failed in removing the barriers. However, the NGOs were not successful in their lobbying efforts.

It can be stated that the progress towards protecting rights of disabled persons of Georgia and improving their socio-economic conditions has been mixed. The period from 1998 through 2003 was very important from the standpoint of adopting new legislation on disability, increase of disabled people NGOs’ activities and the implementation of various projects and programs aimed at supporting independent life of disabled people.

For example, in summer of 2003, the Georgian Parliament adopted changes in the election code in order for blind persons to be as independent as possible while voting. Election bulletins were made accessible to them by being printed in Braille. For deaf persons a public campaign was carried out by special translation. For persons using wheelchairs, the law requires easy access at electoral districts. Disabled people could be seen in the streets, in transport, cafes, theatres and cinemas, stadiums and other public places. Disability organizations gained important experience and expanded their resources.

These changes became possible thanks to relentless efforts of several disabled activists and support of few high-rank officials within the government. However, after the peaceful overthrow of the government in November 2003, known as the “Rose Revolution,” most of the projects have stopped and the Coordination Council under the President has been abolished. As a result, there is a lack of disabled persons’ participation in defining the state policy on

2. Research Findings

disability and solving problems faced by disabled persons. The following numbers speak for themselves:

Since Georgia's independence in 1992 **only four persons with disabilities** were elected and served as members of the Parliament: one disabled person in 1992-1995, two persons in 1999-2004 and one person in 2004-2008.

Interviewed representatives of the NGOs for disabled note that they are not consulted by government officials on any decisions made by the state with regard to disability issues.

“Everyone uses us for getting money, we are, in fact, exploited. Nobody tells us what is happening and why” (a female director of NGO of disabled people, focus group participant).

2.2.2 Social Assistance

The amount of money allocated to persons with disabilities by the state budget is insignificant. It comprises of a disability pension/allowance of 35 GEL (\$20) supplemented by 28 GEL (\$16) for blind persons, disabled persons of the 1st category and disabled children. The disability pension accounts for less than one third of an official subsistence minimum determined by the state.

Disabled persons are entitled to discounts for gas, electricity, water and garbage disposal services. In 2006 disabled persons started receiving vouchers for free medication. However many of our survey respondents complained about uselessness of these vouchers because they cover only basic drugs and not the medication needed for their type of disability.

Financing of social programs out of local budgets is negligible - only 8%. When a region is poor, the allocated amount is proportionately small while social problems are more severe than those in better-off regions.

As it was mentioned in the section on Georgian legislation, in order to qualify for a disability pension, a person has to go through an official medical examination board. There are a total of 86 boards staffed with 500 employees in clinics and hospitals in each district of the capital and regions outside of Tbilisi. The cost of medical examinations required for the issuance of an official disability “certificate” can vary from 25 GEL to 70 GEL (\$14-\$40). Upon receiving a certificate, an applicant person has to submit it to the Social-Medical Examination Board, which determines and assigns an official disability category. Persons disabled since childhood are not required to receive an official disability category until the age of 18. Their status is defined as “disabled from childhood” and entitles them to the same state pension and privileges.

Disabled respondents complained about difficulties in obtaining a disability status. They have to spend a lot of money and energy for procedures to reconfirm their disability status on an annual basis. They said that the boards were reluctant to grant certifications and mentioned corruption in the field. According to several members of the Social-Medical Examination Board who participated in our focus groups, the reason for reluctance is pressure exerted by top officials on the Board to limit the number of officially recognized disabled persons in the country.

In the past caretakers/parents of disabled people were entitled to a state pension. All interviewed caretakers said that the pension should be re-introduced because they have no time for work due the full-time need to care for their disabled household members. Several government officials also agreed with this statement.

For 2007 an International Classification of Functioning, Disability and Health (ICF) translated into Georgian and published.

2.3 HEALTH CARE

2.3.1 State Healthcare Coverage

In 2006 a new healthcare assistance program for disabled persons was introduced by the state. Free medication is available, however, as already mentioned many of our survey respondents complained about uselessness of medication vouchers. The list of medication that can be received for free is predefined and covers only basic drugs, not the medication needed by the disabled persons.

The state provides partial coverage for services, cost of medication and special aids for several categories of persons with disabilities: patients with mental disorders, persons with movement restriction, deaf, blind, persons with diabetes, hemophilia, tuberculosis, cancer, and blood circulation illnesses. The state also provides hearing aids and partially covers expenses for cochlear implants. Deaf children need to change their hearing devices every 3-4 years. There is a Georgian-German enterprise “Kindsmena”, which provides this type of hearing aids. The cost of one hearing aid piece is 500 GEL (\$290).

Persons with mental disorders are in a very difficult situation. Outpatient component of the state program for the support of mental patients is negligible and consists of covering 4.5 GEL (\$2.5) a month for medication. Director of a psycho-neurological clinic in Tbilisi noted that she manages to provide her patients with a minimal doze of required medication only thanks to the help of international donors. Doctors often have to treat their patients for free because the state covers only for one appointment a month, which is insufficient for the majority of disabled patients. Besides, the program covers only the patients diagnosed with psychosis and, by admission of an interviewed medical official, is aimed at protecting the society against possible aggressive behavior of such patients.

“In fact the main focus of the program is to safeguard the society, it does not consider interests of the disabled patients.”

Persons with mental retardation or any other mental disorders are not covered by state assistance. Psychosocial rehabilitation of patients with mental disorders, a very important component of integration and recovery, is not covered by any state programs.

2.3.2 Institutions and Services for Disabled People

Inpatient institutions for disabled persons are under the supervision of the MoES and the MoHLSP. The decision about placing a child in a special institution used to be made by medical-pedagogical commissions, which do not longer exist. The criteria for diagnosing mental disorder/disability are not well defined and records about children development in these institutions are poorly kept. Due to the lack of or low funding of these institutions by the state, living conditions and treatment provided to disabled children are of poor quality.

According to the Georgian legislation, healthcare services for disabled persons should have the following components: prevention, diagnostics, and treatment/rehabilitation. Reliable health statistics is non-existent and precludes from mapping locations and causes of disability – measures necessary for formulating a correct social policy.

However, some tendencies can be observed in the absence of detailed data. According to Horizonti Foundation's study (2002) children's disability shows the tendency to increase. Inborn disability is leading and observed in 80% of disabled children. The share of mental retardation is high with an alarming tendency of increase. Incidents of mental retardation for the population sample of 100,000 increased from 8.6 in 2000 to 23.8 in 2004.

Some researchers attribute this increase to a higher rate of registration (due to increased state pensions) and not necessarily to an increase in actual retardation instances. However, a thorough study is required for determining the real reason for this increase. An urgent need for preventive measures at prenatal level is also apparent. Inadequate diet and poor knowledge of healthy lifestyle are among the factors contributing to in-born disability that can be effectively prevented.

Early identification and accurate diagnostics of disability has important health consequences and thus, can impact integration of the disabled people in the long run. Studies show that in 80% of the cases intervention happens too late. Many disabled respondents expressed their negative attitude towards doctors. In their opinion doctors often could not or would not admit the fact that medical condition of a disabled person cannot be improved. Thus a precious time is lost visiting doctors instead of acquiring life skills.

Not surprisingly, opinions about the importance of health care for wellbeing of disabled

While officials tend to focus more on medical assistance, disabled people emphasize the importance of psychological and social rehabilitation.

persons differ between the disabled persons themselves and the state and healthcare officials. Persons who are disabled due to chronic illnesses and mental problems require more medical services and treatment than persons with sensory impairment or movement restrictions. Patients with chronic illnesses need regular examinations, treatment and medication, which are very costly and often unaffordable. A cancer patient, our focus group participant, said that she needed costly medical examinations at least twice a year, which she had no money for. Several female respondents talked about the need for a hip replacement surgery, which they could not afford.

Importance of Rehabilitation. The survey showed that a relatively small number of disabled respondents needed special medication for their impairment. However, they all stressed out the need of rehabilitation and therapy, which would include not only physical but also psychological and social components. Disabled respondents with movement restrictions needed massages, water treatments and the ability to go to local therapeutic resorts such as mud resort in Akhtala or a seaside resort with magnetic sands in Ureki.

The importance of going to special resorts (rehabilitation places) was highlighted by a 58 year-old male respondent in a wheelchair. He spent long periods at Sak, a special rehabilitation resort in Crimea for several consecutive years. He said that the most important effect was psychological. He became much stronger in spirit when he saw many people like him leading normal life. The only physiological thing he appreciated there was the possibility to stand, which he has not experienced for a long time.

"The town is designed for serving people on wheelchairs, everyone is on a wheelchair, most of its inhabitants know each other because they come regularly or even live there. One can reach any place independently, meet all kind of people and share the same misfortune. Similar to a society at large, disabled people there have their own artists, swindlers and other characters. It is a microcosm on wheelchairs."

The state finances rehabilitation of children with movement restrictions. A Center of Child Neurology and Neurological Rehabilitation in Tbilisi and three similar centers in Kutaisi,

Batumi and Bolnisi are serving such children. However, these centers' capacity is limited and they have a deficiency in qualified staff. There are more than 500 children on a waiting list for these centers while Tbilisi center with the staff of 52 persons can provide serves to 73 children and Kutaisi center to only 12 children at a time, with the rehabilitation course lasting for 20 days.

New Social Integration Program funded by the state. This year the Ministry of HLSP announced a tender for the program aimed at social integration and adaptation of persons with restricted abilities. Program's budget is 3.8 million GEL and it consists of the four components:

- Social integration;
- Institutional patronage;
- Rehabilitation of disabled children; and
- Provision of disabled people with aid devices.

About one third of the budget is allocated for establishment and operation of day centers for disabled persons. The goal of these day centers is to create opportunities for interaction, acquire life skills, and provide caretakers with an opportunity to work and rest. The day centers provide their services on weekdays, transportation for the disabled people and food twice a day. The state budgeted 7.30 GEL (\$4.2) for each disabled attendee, of which 5 GEL goes to food and 2.30 GEL for transportation, staff salaries and supplies. Disabled persons will also have an educational program with focus on acquiring personal hygiene and independent life skills, as well as vocational skills.

Opening of day centers has been delayed by undue strictness of the tender terms and the fact that the tender is subject to the Georgian Procurement Law. In addition, program's scope and expectations are very high and the proposed funding is not sufficient. Several NGOs complained that despite their solid track record in implementing disability programs, they did not qualify under the tender terms. There are 18 day centers currently operating in Georgia and the majority of them are located in the capital. It can be stated that these day centers are very beneficial for the disabled persons and their caretakers, although they are not conducive to integration.

2.4 EDUCATION

Education is the key element of social integration through creating opportunities for interaction, employment and participation. Education of persons with disabilities is a complex issue requiring serious support and funding by the state, which seems to be currently lacking in Georgia.

2.4.1 Primary Education

The qualitative survey shows that educational level of disabled respondents is generally low. Many respondents do not attend school at all, and those who go to school do not learn much.

Disabled persons in Georgia have the following educational options:

- Attend a regular school;
- Home schooling;
- Attend a school with inclusive education;
- Attend or stay at special boarding schools or institutions for disabled people; and

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- Attend day centers or groups, which are run by NGOs and not officially recognized by the Ministry of ES as educational institutions.

A. *REGULAR SCHOOLS*

Children with mild disabilities usually attend regular schools. In the regions, where educational options are less diverse than those in the capital, parents have to take their children to regular schools regardless of their children’s degree of learning ability. Interviewed parents were happy about the fact that their children could spend some time outside of home and interact with other kids even if they could not learn much.

B. *HOME SCHOOLING*

In the past schools were obliged by law to send teachers to disabled children’s homes. These days home schooling is no longer a common practice.

C. *SCHOOLS WITH INCLUSIVE EDUCATION COMPONENT*

A newly declared policy of the MoES is to pursue principles of “normalization” and to promote inclusive education. According to the Ministry’s plan, each district in Tbilisi should have one school for inclusive education. At least one inclusive school should also operate in each region of Georgia. The program was initiated by the UNICEF and the World Vision in 2003. In 2003-2005 forty disabled children studied in inclusive classes. Fifty teachers and assistant teachers have been trained and involved in inclusive education. There are special textbooks for math and Georgian for beginners. School #10 in Tbilisi serves as a positive example of inclusive education. However, the experience has revealed several problems:

- **Attitude of parents of non-disabled children** - Parents oppose to their children sitting next to disabled classmates. Their arguments are as follows: their children pity the disabled class-mates and get depressed; and teachers’ accommodation to disabled children’s learning abilities results in lower academic achievements than those in a regular class.
- **Attitude of parents of disabled children** - Parents of disabled children are often against inclusive education. Their point is that it is better for their children to be among children with similar disabilities in order to avoid feeling deficient.
- **Architectural barriers, lack of supplies and trained staff** – In addition to negative attitudes, there are many barriers related to physical adjustment of school buildings to the needs of disabled persons, lack of specialized study materials, lack of adequate knowledge about teaching techniques for disabled children, and insufficient knowledge of psychology among assisting teaching staff.
- **Evaluation criteria not defined** - The criteria for evaluating disabled children’s performance and decisions for their transfer to the next grade have not been determined. Although, the idea behind inclusive education is creating conditions for interaction with peers, it is not uncommon to see disabled children sitting next to much younger classmates. Also it is not clear what kind of certificate disabled children are to get after graduation.

Georgian NGOs working in the field of inclusive education pointed out that a decisive factor for successful integration is the preparation of non-disabled children’s parents and teachers for inclusive education.

Focus group participants in different cities stressed out the need to begin inclusive education at a very young age.

“Inclusive education is important and should be introduced already in kindergartens because small children adapt better and the right attitude forms among the healthy children towards the disabled” (a male focus group participant in Kutaisi)

D. BOARDING SCHOOLS

The most traditional form of education for disabled children in Georgia has been special boarding schools. The quality of education in special schools leaves much to be desired. Several of our disabled respondents noted that independent life skills, which are critical for the disabled people’s integration, had not been taught at all. Special schools do not have sufficient supplies and equipment: they are usually the last ones on the list of schools to be covered by Ministry’s computerization programs, and lack textbooks and other teaching aids. Special schools do not achieve their main objective, which is the preparation of a child for studying in a regular school. Most of the disabled pupils end up graduating from special schools.

Deaf Children - There is one kindergarten for 80 deaf children and one boarding school with 180 pupils in Tbilisi. Another boarding school with 58 deaf pupils operates in Kutaisi. There are plans to open a school in Batumi. However, similar to the situation with other types of disability, not all deaf children attend school. Families residing in regions outside of Tbilisi either cannot afford bringing their children to the capital or do not want to leave their children in a boarding school. Therefore, educational opportunities for children living in the regions are hardly available.

According to the Head of the Union of Deaf People, our survey’s respondent, special schools are to blame for the fact that that deaf persons can barely read and write. The level of teaching is very low and most of the teachers do not know the sign language. None of the schools conduct any training to prepare their students to be integrated into society. The school has deficiency of special textbooks. Deaf children have delays in development due to the fact that they have no information. They need psychological rehabilitation and speech therapists.

Blind Children – Blind children who attended special schools seem to be better educated than deaf children. However, the overall teaching quality is low. According to a blind school graduate, he was not taught any practical life skills at school (e.g. moving around town). A special school for blind children has been functioning in Tbilisi for almost a century. Now it enlists only 53 pupils, while there are several thousand people with sight impairment in the country. Parents do not bring their children from the regions to attend this school. In 2006 the school had problems during the winter heating season, it also lacks necessary supplies.

State Funding and De-institutionalization - The amount of funding provided by the state to boarding schools in Georgia is negligible. Therefore schools are forced to focus on providing food and elementary healthcare rather than education. One focus group participant, a boarding school director from East Georgia, lamented that his school survives thanks to his personal contacts and kindness of citizens who donate food, and doctors who treat children for free.

At the same time, there is an opinion among education professionals that a new policy of de-institutionalization (i.e. abolishment of state-run institutions for orphans, disabled and underprivileged children, etc) proclaimed by the Ministry of ES is too premature and even wrong because many disabled children in boarding school are from socially degraded and/or criminal families. Even with the deficiency in funding, supplies and low teaching quality, these boarding schools present a better living arrangement for some destitute children.

E. DAY CENTERS

There is a number of day centers for disabled persons operated by NGOs in Tbilisi and the regions with support from international donor organizations. These centers are not licensed by the MoES as official educational establishments. However, activities of these days centers are appreciated both caretakers/parents and education professionals. The centers provide disabled children with interaction, learning and recreation opportunities.

A day center in Telavi, Kakheti region, has been in operation since 1996. It was established by two Georgian females, who started from scratch and now have a big building (1,000 square meters) in the town center, land and a farm in the nearby village Odlisi. The center has 40 children who receive elementary education and study crafts. They make toys, do pottery, and learn embroidery and knitting. Pupils of the center participate in regular exhibitions of their drawings and crafts, and give performances. The center also runs a kindergarten for 20 children who are disabled and/or from poor families. The center is open five days a week. It provides transportation and food to children and members of their families. The center has a doctor and a speech therapist. Center's staff has special education training.

Association of disabled women and children in Zugdidi, "DEA", runs a day center for 18 children with physical and mental disorders. It has a building and playing ground. The day center combines rehabilitation with education.

An NGO in Signagi runs a school for disabled children and children from poor families. The age of pupils should be from 6 to 17, but children do not want to leave the school after graduation. Now they have several young adults who are already 23 years old. These activities were financed by the World Bank under the program of protected territories.

A day center "Tonus" in Kutaisi for children with cerebral palsy has 35 children from the age of 2 to 18. The center provides children with food and entertainment, but does not have an educational component.

A number of integration programs where disabled and healthy children played and studied together were implemented by various NGOs in Tbilisi. There was a kindergarten program with a music studio and also groups where children danced, sang and draw together.

Needless to say that parents/caretakers of disabled children give a very high praise to such initiatives. However, the biggest concern is the lack of programs' continuity. Grants received by NGOs are usually short-term and once they end, there are no funding sources for NGOs to continue their activities. Several focus group participants/caretakers said that their disabled children, who participated in integration projects, became depressed when these programs ended.

2.4.2 Vocational and High Education

Considering low quality of primary education for disabled persons in Georgia, attaining vocational or high education presents a much bigger challenge. Before the collapse of the Soviet Union there were several vocational schools for deaf and blind persons in Georgia. The system of vocational education has ceased to exist and only now a new system is being considered and developed. Eleven professional centers for disabled persons are planned to be opened in 2007. They will work according to US programs/curricula.

Deaf and blind persons could attend at special universities in Russia in the past. Several of our disabled respondents graduated from these universities. Four of our disabled respondents received university education in Tbilisi.

2.4.3. Main Barriers to Attending Educational Facilities

In addition to problems discussed above, mobility and architectural barriers are the main obstacles to attending educational facilities by disabled students.

Transportation is a problem for many disabled people. There is no transportation adapted to the needs of disabled people available in Georgia. Schools rarely provide transportation to bring the children who live far away. For those, who have no restrictions in movement, the price of public transport is often prohibitive and creates a barrier to education.

Mariam, who has cerebral palsy and a hearing impairment, cannot attend a regular school. A specialized school is too far away and Mariam cannot be taken anywhere by public transport. Once her mother took her for a bus ride. Child's hands were moving uncontrollably and touching other passengers. Mother was requested to control her daughter, but how could she do this?

Rural Georgia has no transport to speak of. A caretaker, mother of a girl with cerebral palsy in Dusheti shared her experience with her daughter's schooling: *"Natia went to school. She graduated for the 9th grade. At school she managed only to learn how to write and read. But she had friends there and liked her school very much. I carried her on my back to school for more than a kilometer every day"*.

Many disabled children are deprived of elementary education because their parents, especially those living in regions, as already noted did not want or could not bring their children to the capital or regional centers where boarding schools are located.

Another big obstacle is physical inaccessibility of educational facilities. One of our disabled respondents said that he was advised to choose a specialty taught on the ground floor of the university. Another respondent in a wheelchair recalled that his classmates had to carry him up the stairs to enable him to attend the lectures.

2.5 EMPLOYMENT

2.5.1 Employment Opportunities

It can be stated that very few employment opportunities are available for disabled persons in Georgia. Less than 1% of officially registered disabled persons in Georgian are employed⁵.

As it was mentioned earlier, almost all enterprises that employed disabled persons in Georgia ceased to exist about fifteen years ago. Tax benefits for Georgian enterprises to employ disabled people were revoked in 2000. The current Georgian legislation has no provisions that would force or encourage local businesses and organizations (state or private) to employ persons with disabilities. It is obvious that disabled persons cannot compete in a tight labor market.

There is neither quota system, nor any kind of benefits for hiring disabled persons to ensure their employment. The sheltered (guaranteed) employment, which was common in the Soviet period, has disappeared.

⁵ Source: State United Social Insurance Fund of Georgia, 2005

2.5.2 Importance of Employment for Disabled Persons

All adult respondents with disabilities and caretakers/parents talked about the need of being employed. If they were employed they would take care of their problems and would need no assistance or care from the state.

Importance of employment for disabled persons' integration is hard to underestimate. It gives a possibility to provide for oneself and family, instills a feeling of self-worth and increases self-esteem, creates opportunities for interaction, and allows avoid the feeling of loneliness and social isolation. Interviewed caretakers see another important benefit in employment of their disabled household members: it is a hope for a disabled person's survival after his/her caretaker's death.

"Assistance is occasional: it comes in and out. The main assistance is employment, that a person is able to assist himself. Who needs rice and oil?" (a 43 year old disabled male respondent)

Disabled respondents emphasized that they did not want assistance, but rather a possibility to earn money to support themselves and their families.

Living at the expense of their family members is especially depressing and demeaning for disabled men. A disabled male respondent remarked he was lucky not to become an alcoholic, because other men in his condition did: *"My day begins and ends with nervousness and worry... Soon I will also probably begin to drink . I cannot stand this anymore. I live at the expense of my wife"*.

Disabled respondents feel hopeless about getting a job given high unemployment in the country. A young woman with cerebral palsy remarked: *"I was invited to work as operator at a bank, but when they learned that I was disabled they refused to take me. They said this would harm the image of the bank"*

"I was very active when I found my place at the association of disabled women. I was at last employed. But now I do not work and hopelessness takes over" (a female focus group participant with movement restrictions)

"Even if I have a good qualification, nobody will take me because of my blindness. I will be only laughed at. Most of all I am concerned with the fact that cannot provide for myself" (a 29 year old male respondent)

Lela, a disabled female respondent, who has a university education, is convinced that she is unemployed due to her physical disability. She has a severe form of scoliosis and she speaks about the importance of appearance:

"Physical disability is visible, inner disability is not. Person with inner disability goes into the society and the society perceives him as normal. First eyes see and then the mind"

The disabled respondents and NGO representatives listed a number of measures to improve their employment situation:

- Organize workshops/training for disabled people;
- Reintroduce sheltered/guaranteed employment for the disabled persons;
- Introduce regulations/laws that will provide financial incentives for the local enterprises to hire disabled people;

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- Introduce a quota system, obliging enterprises to hire a certain number of disabled persons;
- Redirect a part of the social tax (e.g. 3%) for employment needs of the disabled persons.

2.5.3 Georgian NGOs Providing Employment Opportunities

The Union of the Deaf and the Union of the Blind used to have enterprises where their members were employed. However since Georgia's independence most of these enterprises stopped their operations. The Union of the Deaf managed to preserve its enterprises and property. The Union of the Blind has only buildings: enterprises' equipment was destroyed. People with mental disorders used to be employed: they made sheets, pillowcases and slippers.

Currently there are only few functioning enterprises for disabled people. **The House of Social Therapy** is the organization where people with mental disorders can work. They make candles, notebooks and wooden toys. In cooperation with the psychology department of the Tbilisi State University the House opened a copy shop at the University, where ten disabled persons are employed and interact with students and faculty.

Association of Mental Health runs a carpentry shop.

The Coalition of Disabled Persons is one of the implementing entities of the "Wheelchair Diplomacy" project. It comprises of the three components: wheelchair manufacturing, advocacy and trust building between Abkhazs and Georgians. It will operate in Georgia and Abkhazia. There will be shops established for wheelchair manufacturing: one in Tbilisi and one in Sukhumi. Disabled persons and members of their families will be employed at these shops. Wheelchairs will be sold in the South Caucasus region.

Community-based Settlement in Kakheti. The problem of employment is even more severe for the graduates of special boarding schools. Many of them have no families, no place to go and no skills to be considered for a job. One solution was found by creating community-based villages. There are two community-based organizations active in Kakheti (East Georgia). These NGOs were created in 2000 and they are implementing a state program for the "integration of young adults into the community". It is a community center that houses young adults and also provides shelter for the elderly. 43 persons live and do farming work there.

2.6 RECREATION AND LEISURE

Leisure and recreation activities are severely limited for most of the disabled respondents. Unemployed, unable to move, see or hear, they are mostly left to themselves, TV and radio.

"I have no reason for going out. I do not know where to go" (a 43 year-old male respondent in a wheelchair).

Attending theatre or cinema is impossible for the deaf. Only recently the Union of the Deaf managed to translate a Georgian classic movie (produced back in the 60s) "Soldier's Father". It was the first occasion when deaf people could see a Georgian movie in their language.

Possibilities for exercising and participating in sports are restricted. NGO "Anika" runs a swimming pool and has sports groups, however getting to its facilities presents a problem for many disabled persons.

Disabled people in Georgia used to be active in sports in the 90s. With the help of the Sports Federation, several disabled activists managed to take disabled people out of their houses

and encouraged them to participate in different competitions (arm-wrestling, chess, draughts, backgammon, table tennis, marathons, water skiing, mountain climbing, etc). In addition, they developed cultural events in the communities and educational programs on TV. In 1995 five disabled persons reached the meteorological station of the mount Kazbegi. In 1998-1999 the League of Disabled had a basketball team, disabled persons also played soccer and tennis.

Disabled respondents with restrictions in movement embroider, knit, draw, read or listen to music. They seldom manage to get out of their houses or apartments. A young female respondent with movement restrictions recalled her visit to a disco a year ago. Her neighbors took her and she stayed in a mini-bus watching people dance.

Disabled respondents pointed at problems going out of town for rehabilitation to local resorts. There are several locations in Georgia with therapeutic and rehabilitation benefits, but disabled respondents or their caretakers cannot afford the cost of transportation and treatment. The state does not cover this kind of rehabilitation.

As it was mentioned previously, several programs for disabled children were implemented in Tbilisi kindergartens. However, most of these programs discontinued when program grants ended.

2.7 INTEGRATION FACTORS

2.7.1 Severity, Type and Age at the Onset of Disability

The situation differs among disabled respondents depending on the age of disability onset, its type and severity. The later disability develops, the more chances for integration a disabled person has. Therefore, the most severe problems are associated with disabilities since birth. These disabilities are less responsive to treatment and improvement. Persons who became disabled in adulthood are in a more advantageous position because they already have an established social network, formed personality and acquired some education.

Persons with severe mental problems have more difficulties in forming and maintaining relationships than those with movement restrictions. There are also specific disability related barriers such as difficulty in communication for deaf persons.

2.7.2 Attitude of Society

Disabled respondents and their caretakers consider society's attitude as the main barrier to integration. The society at large ignores disabled people and makes them invisible.

"Nobody is interested in the disabled" (a female caretaker, focus group participant)

Feeling of not being wanted prevails among the disabled respondents.

"This country does not need the disabled" (a female caretaker, focus group participant)

When exposed to disabled persons, people usually express pity in verbal or non-verbal ways, and sometimes ridicule or even behave aggressively towards disabled people.

"Many persons pity me and it irritates me terribly. I do not consider myself miserable". (a 29 year old blind respondent)

Disabled respondents value participation in the society and their acceptance much more than assistance.

"I am ready to refuse free oil and sugar for the feeling of being a worthy member of the society" (a female focus group participant with movement restriction)

“The society looks at the disabled as objects of humanitarian aid. The policy towards disabled should be oriented on achieving the maximum of independence. Society should not be divided on able and disabled.” (a 54 year old female, head of organization of disabled people)

Focus group participants stressed out that disability should become a concern of the entire society. People should be taught to treat disabled persons as ordinary members.

2.7.3 Attitude of Parents/Caretakers

Parents’ attitude, actions, resourcefulness and optimism to a large extent determine the success of their disabled children’s integration. Caretakers’ resolve and readiness to fight against the isolation of their children, and efforts to provide education can shape their children’s future.

A very critical factor for enhancing integration is the parents’ ability to recognize their children’s disability as early as possible and to make right steps to minimize its consequences. This requires a lot of education and awareness building.

Parental attitude towards child’s disability can be harmful not only in case of neglect and lack of understanding of the problem, but also in case of overprotection. As a young female participant of focus group noted: *“My parents did me harm by protecting me from everything. As a result I formed an expectation that others should serve me”*.

2.7.4 Mobility and Architectural Barriers

Physical environment is a true reflection of the state’ and society’s attitude towards the disabled people in Georgia. There are no parking places, street ramps, buildings, facilities and transportation adapted to the needs of disabled people in the country.

A notable example is an amendment to the Administrative Code of Georgia discussed in Section 2.2.1, which requires all public buildings be adapted to the needs of disabled persons. All public places such as post offices, theatres, hospitals, hotels remain inaccessible for disabled people with the only notable exception of the Tbilisi Marriott Hotel.

Wheelchair ramps built in several central streets of Tbilisi in 1999 thanks to the Initiative of the League of Disabled were destroyed during the road renovation project in 2005.

People in wheelchairs cannot get into public transport or taxi in Georgia. Even in the capital, uneven pavements and lack of crossing ramps prevent people in wheelchair to get out in the streets.

Medical facilities that serve disabled population are not adapted for people in wheelchairs to move around. One of respondents recalled his shock when he went to the Institute of Neurology for his first medical examination: *“I could not enter the elevator, because it was not wide enough for a wheelchair, could not go into the doctor’s offices, because the doors were too narrow”*.

There is no special transportation available for the disabled people in Georgia. Back in 1988, the League of Disabled brought 15 US-made buses equipped with wheelchair lifts. At the same time street ramps and special bus stops were built in six districts of Tbilisi. The buses are no longer operational and there are no street ramps. One respondent in a wheelchair recalls how he had to pay an extra \$100 to a Georgian air company to be put on a plane.

Blind people of Georgia suffer from the lack of seeing eye dogs and the service of accompanying persons, which became a thing of the past.

2.7.5 Access to Information, Communication and Social Network

Isolation is the state of many disabled respondents. Involuntary seclusion from social life, inability to leave home or communicate, lack of jobs and places to go prevents disabled people from building and maintaining viable social networks. Mother of an 8 year-old girl with cerebral palsy and a hearing impairment: *“She needs interaction, entertainment, but she is alone. She wants to do everything, but can do nothing”*.

Pikria, who has a severe spinal deformation, blames her disfigurement for the impossibility of having a family: *“I was in love with a young man who answered me with the same feeling, but then he told me that could not take the responsibility”*.

Inability to communicate creates a very serious impediment for the deaf people. Many disabled respondents, like a 32 year-old female respondent, interact mostly with people with the same disability: *“I feel absolutely unrestricted among the deaf. But with people who hear I often get irritated when I cannot make them understand me or when I cannot understand them”*. The deaf people in Georgia are in informational vacuum because majority of them cannot read. Only one public TV channel has a news program translated into the sign language.

However, not all respondents felt they were isolated: they had good relations with their neighbors, relatives, schoolmates and friends. The disabled respondents who attended regular schools or universities tend to have a wider circle of friends and regular interaction. A 29 year-old male who is blind since the age of 11, does not feel any restrictions when among his friends. He and his friends sometimes forget that he cannot see. However, several disabled respondents talked about an inferiority complex because of their physical appearance and that they did not want to bother their friends with requests for help or visits.

Several male respondents in wheelchairs said that their social life did not change much since the onset of disability. They remain very active and maintain a wide circle of friends.

2.7.6 Economic Condition of the Household and Place of Residence

Poverty is proved to be one of the main hindrances to integration and at the same time a consequence of the lack of integration. More than fifty percent of the country’s population lives below the poverty line, but poverty incidence is higher among the households with disabled persons.

We observed poverty in almost every household we visited and interviewed. Several households were on a verge of starvation. Poverty precludes people to react promptly to their health problems and in many cases, avoid disability or make it less severe. The need to struggle for basic survival precludes household members of disabled persons from providing necessary care and finding time for social activities.

The research shows that the social and economic conditions of disabled people living in the regions are much worse than those in Tbilisi. Health care, rehabilitation and educational services are under-developed and scarce in the regions. There is also more reluctance on the part of the general public to integrate disabled persons into society.

2.7.7 Personality of Disabled People and Skills for Independent Living

Successful integration of a disabled person also depends on his/her personality features. There were several disabled respondents, both children and adults, who managed to maintain an optimistic attitude about their abilities to live a full life despite the barriers they were facing. As one of the disabled respondents noted, same illness develops differently in different persons, and the progress one can achieve is very individual.

2. Research Findings

Special knowledge and skills for leading an independent life improve disabled persons' feeling of self-esteem and ability for integration. Several disabled respondents who were fortunate to attend special training and learn independent life skills compared it with a turning point in their lives.

A male respondent in wheelchair shared his experience of attending a two-week training course in the United States. The course focused family life, sexual life, mobility and self-realization: *"This course was determining for my life. I learned to be independent and with all my life now I try to show to other disabled people that this is possible."*

2.7.8 Religious Faith

Belief in God serves as a strong source of support for many disabled respondents. Attending church services is the only social activity for many of them.

"Everyone should be religious. Nothing will help a disabled person if she/he is not spiritually strong. It is difficult for men to live without God. Due too my condition, I have more time to be with God" (a 27 year-old female in wheelchair)

3. CONCLUSIONS

3.1 MAIN BARRIERS FACED BY DISABLED PEOPLE IN GEORGIA

Social integration is a complex concept, which means different things to different people. In general, it means the process of integration of underprivileged group of the society into the mainstream of the society, and thus avail of the opportunities, rights and services available to the members of the mainstream of the society.

Our survey revealed multiple barriers to the integration of disabled members into the society, which are also confirmed by existing research on disability in Georgia. Complete integration of disabled persons in Georgia will not be possible without removing the following barriers:

3.1.1 Unclear and Inconsistent State Policy towards Disability

As discussed in detail in Section 2.2, lack of clearly defined state policy and priorities for addressing problems and concerns of disabled people leaves many issues neglected and unresolved. Disability laws have not been supported by appropriate budget provisions, necessary institutional resources and normative acts. Thus they remain to be more of a declaration rather than enforceable and effective legal mechanisms. Little achievements have been attained in making necessary changes in the legislation to promote integration of the disabled population. It can be said that certain setbacks have been encountered in the past three years (e.g. dissolving of the Coordination Council under the President).

3.1.2 Isolation, Lack of Representation and Participation in Country's life

Involuntary seclusion from social life, inability to leave home or communicate, lack of jobs and places to visit prevents disabled people from building and maintaining viable social networks. Disabled persons do not participate in defining the state policy on disability. They are not members of any elected bodies, either at federal or at local levels. The biggest concern is the lack of communication with the government, no representation and impossibility to influence decisions concerning disability.

3.1.3 Society's Attitude towards Disabled Persons

Lack of awareness and reluctance to accept existence of persons with disabilities are not unique to any particular society or culture. People do not want to be reminded that they are not safeguarded from becoming disabled, that it can happen to them at any time. Disabled respondents and their caretakers consider society's attitude as the main barrier to integration. Many of our respondents talked about experiencing not only patronizing and pitying attitudes on the part of strangers, but also mockery and aggression.

3.1.4 Mobility and Architectural Barriers

Tbilisi, a city with more than million inhabitants, has only a handful of buildings with ramps for disabled access and elevators big enough to fit a wheelchair. Almost the only building where a person in a wheelchair can independently move to any floor/area is the Tbilisi Marriott Hotel. There are no ramps in the streets of the capital and no handicapped parking signs anywhere, even by the municipal and government buildings. There is a deficiency of quality wheelchairs, prostheses and aid devices. There is no special transportation adapted to disabled persons' needs. The situation is even worse in the regions outside of Tbilisi.

3.1.5 Inadequate Social Assistance

State pension is the main and often the sole source of income for disabled persons and their families. The disability pension accounts for less than one third of an official subsistence minimum determined by the state.

3.1.6 Lack of Employment Opportunities

The value of employment for disabled persons' integration is very high. However very few employment opportunities are available for persons with disabilities in Georgia. Less than 1% of officially registered disabled persons in Georgian are employed. The current Georgian legislation has no provisions that would force or encourage local businesses or organizations to employ persons with disabilities. Georgia's official unemployment rate is around 12-14%. Only 30% of the population is employed by businesses, enterprises and/or state entities. Given high unemployment rate and scarce jobs, persons with disabilities currently stand little or no chance to compete in Georgian labor market. A handful of organizations and NGOs of disabled people provides jobs for disabled persons, but these jobs are too few.

3.1.7 Poverty

Poverty is a consequence of no employment and insufficient social assistance for disabled persons and their caretakers, and is one of the main barriers to integration. More than fifty percent of the country's population lives below the poverty line, but poverty incidence is higher among the households with disabled persons. We observed poverty in almost every household we visited and interviewed. Several households were on a verge of starvation. Poverty deters people from obtaining health care, which almost entirely is based on patient's payments. It precludes from appropriate pre-natal care, which is a basic preventive measure for in-born disability, as well as from the timely detection of disability.

3.1.8 Access to and Quality of Health Care and Services

Most of disabled respondents cannot afford medication, medical treatment such a surgery and rehabilitation procedures due to their prohibitive costs. Therapy and rehabilitation services are underdeveloped and almost non-existent in the regions partly due to the population's inability to pay for them.

3.1.9 Access to and Quality of Education

Education of persons with disabilities is a complex issue requiring serious support and funding by the state, which seems to be currently lacking in Georgia. The Ministry of ES does not have a clear policy towards education of disabled persons. Ministry's policy regarding inclusive education is not detailed enough and leaves many issues pertaining to the education of disabled students unresolved.

The survey showed that educational level of disabled respondents was generally low. Many respondents did not attend school at all, and those who did, had not acquired valuable skills. Considering low quality of primary education for disabled persons in Georgia, attaining vocational or high education presents a much bigger challenge.

3.1.10 Deficiency of Human and Material Resources

Lack of qualified staff trained to deal with disability issues is noticeable in all service areas. A notion and occupation of a social worker is being introduced only now. There are several local professionals who were educated in the United States, a bit more attended trainings organized by NGO "Every Child". Bachelor and Master-level courses for social workers began at the Tbilisi State University in 2006-2007. There is a critical need for professionals in the field of physical and psychological rehabilitation, mental capabilities testing, special

3. *Conclusions*

education, sign language translation, caring for patients with mental disorders and retardation.

4. RECOMMENDATIONS TO OVERCOME BARRIERS

“Independent life means to make independent choices, take risks, make mistakes and make decisions. Independent life is the person's right to be an integral part of active social life and participate in the country's social, political and economic processes; to have the free choice and option to use residential and municipal buildings, transport, communications, insurance, employment and education.

To become really independent, a disabled person has to overcome many difficulties. These difficulties could be visible (e.g. built environment) or invisible (people's attitudes). If we eradicate these difficulties, it will be possible to make the first step, to live a life of full value, to work and have a family, to raise children, to participate in sports or politics etc⁶.

4.1 STATE POLICY AND SOCIAL PROTECTION

4.1.1 Legislation and State Policy

The state should acknowledge disability as a social problem and apply a multi-disciplinary approach towards providing solutions for the problems faced by the disabled population.

- **Define and clearly articulate the goal of state policy** - Target the overall policy at creating conditions for disabled persons to lead an independent life and become full members of the society. Increased assistance from the state is needed for the severely disabled persons, while persons with less severe disabilities need opportunities for income generation. Likewise, different goals are to be set with regard to impaired children's education and living.
- **Timeline and Action Plan** - Supplement policy by the action plan, delineating specific activities, beneficiaries, actors, timeframe, indicators of success and monitoring mechanisms. Develop a timeline for implementing priorities and policies of the state (e.g. 3, 5 and 10-year plans).
- **Minimize Institutionalization** - Minimize institutionalization by improving community based programs and by, in general, making society more accessible. The key step is to prevent children/adults from getting into institutions in the first place. The next step is to identify a section of the population that can be easily deinstitutionalized. After that there are people with disabilities who can be reintegrated into the community with more effort and, finally, there are those who will spend the rest of their lives in institutions because they need state support. In this case their living conditions need to be considerably improved. Also, well-defined and transparent criteria for admission of disabled children and keeping them in state institutions should be developed.
- **Integration policy** - In designing the policy of integration, the state should aim at making government services and the society more accessible and having programs benefiting disabled people. While there should be rehabilitation programs that target disabled people only, it is critical to avoid creating disability programs that would

⁶ George Kokhreidze, a former Parliament member, one of the most active advocate of disabled people's rights in Georgia.

4. Recommendations to overcome barriers

separate disabled people from the society. The main objective is to make society more inclusive, which is especially appropriate for people with mild and moderate disabilities.

- **Introduce Tax Benefits** – It is recommended to make changes to the Georgian Labor Code and other appropriate legislation to introduce tax benefits for charitable activities and employment of persons with disabilities by businesses and enterprises.

4.1.2 Representation of Disabled Persons in the Government and other state initiatives

- **Improve communication and coordination between the state entities and the disabled people** - Establish a high-level Coordination Council under the President to influence and coordinate disability policy development and its implementation between relevant ministries, state entities, interested organizations and NGOs.
- **Ensure Adequate Representation** - Ensure adequate representation in the Coordination Council of representatives of organizations of people with disabilities and their caretakers. Form a sub-committee for the problems of the disabled population in the Parliament.
- **Disability Ombudsman** - Create an institute of ombudsman for disability matters. A concept paper on ombudsman's functions was developed by the Association of Disabled Women and Mothers of Disabled Children.
- **Create a Referral System for Disability** - A system to enable case management and provide timely and adequate response to each instance of potential impairment should be designed. It should deal with prevention of disability and involve institutions for maternity care, trade unions, schools and health care facilities to disseminate information and training on disabilities. It should be easily accessible through a 24-hour hotline and reception points at polyclinics/family doctors. The “one stop shop” system will facilitate early detection of disability and ensure timely and targeted referral of patients. Information center, center for diagnostics and monitoring of disability, and the database development should become integral components of the system. It is recommended to introduce a free and compulsory medical examination of all children at the age of one year.

Increase safety on roads. Increase sanctions for violation of road safety rules. Implement other measures to increase road safety.

4.1.3 State Assistance and Removal of Mobility and Architectural Barriers

- **Assistance to Disabled Persons and Their Household Members** – It is important to study the current pension system to balance the competing goals of social protection and promoting/enabling work. An issue of re-introducing allowances for caretakers of those disabled persons who require permanent care should be reviewed with an eye towards balancing income security with work disincentives.
- **Pension Retention** – It is important for the disabled persons to retain their pension benefits in case of employment.
- **Disability Status Confirmation** – The existing procedures for annual confirmation of an official disability status should be streamlined and become free of charge for the disabled applicants.

4. Recommendations to overcome barriers

- **Social Workers** – The state needs to support training and preparation of social workers to collect information and provide assistance to the disabled population. It is recommended to organize short-term courses on social work for professionals working in the field of social protection and education. This measure will allow to fill the void until the first group of social workers graduates from the Tbilisi State University in 4-5 years.
- **Removal of mobility/architectural barriers** – All newly built infrastructure should be made accessible for disabled people (creation of street ramps, disabled people entrances, special elevators, etc) and provide them with possibilities of moving around the city. Reasonable adjustments/accommodations should be made in the meantime for the existing infrastructure, including public transportation. It is recommended to refer to the Americans with Disabilities Act (ADA) for the information on design standards, publications and technical assistance.
- **Provision of wheelchairs, prostheses and other aids** – The state needs to support enterprises that manufacture prostheses, orthoses, crutches, wheelchairs, and hearing devices and to provide these aids to the disabled persons for free or part of the cost.

4.1.4 Data Collection

It is not possible to make informed policy decisions without relevant data about disability in the country. There is a pressing need for collecting statistical and research data on disability. The data can be used by various agencies and state entities to design and monitor prevention programs, provide services and monitor how well disabled people fare in society. While a number of state entities can be involved into information collection, it is important that there is a single state entity that coordinates data collection efforts in the country. It is also important that the approach to data collection follows the guidelines in the WHO's International Classification of Functioning, Disability and Health, and the data instruments being developed by the UN's Washington Group on Disability Statistics. These are efforts to improve disability data collection and to develop measures that are internationally comparable. It would make sense for Georgia to become a partner in these efforts and ensure that databases are in compliance with the WHO's standards.

A National disability data strategy needs to be developed and thoughts given to what kind of methods of data collection are the most appropriate (a census, survey, or administrative records). Suggested activities as part of the national disability data strategy are as follows:

- **Review and enhance the database maintained by the state** – The database maintained by the SUSIFG contains only medical information on disability. It should be expanded to include social and economic information of each disabled person and his/her household. There is a vulnerable population database maintained by the State Employment and Social Protection Agency. It would make sense to review both databases and see if they can be merged and brought in compliance with the WHO guidelines.
- **Collect additional data about disabled persons** – The state needs to collect the information about people with disabilities who are not registered in the database maintained by SUSIFG. MoHLSP has a wide network of offices throughout the country. Social workers and staff in these offices can be engaged in finding disabled people in their respective districts and collecting appropriate information.

- **Conduct studies and research on disability** – In addition to collecting information about individuals and their disability status, it is important to study reasons and consequences of not registering with the state. Mapping of disability incidence across the regions will allow for more targeted interventions. It is necessary to study inborn anomalies and genetic diseases in Georgia. Needs of disabled people and their caretakers should be better understood. A study of the labor market and abilities of persons with different type and severity of disability can help in formulating effective employment policies.
- **Study Child Disabilities** - There should be a separate study on disabled children, their educational needs and developmental issues. A separate database subset should be developed and maintained to include information about children’s medical diagnoses; mental, physical and social development; schooling type; information on socio-economic status of the household; and household composition together with the background information. Reasons for increase in mental retardation and non-attendance of school should be researched.

4.2 EMPLOYMENT

From a long-term perspective it should be more beneficial for the state to rehabilitate disabled persons and enable them to help themselves rather than keep providing assistance. Special measures for insuring the employment of people with disabilities should be undertaken.

4.2.1 Creation of Employment Opportunities

- **Prepare ground for supportive employment environment** – Create programs aimed at supporting employment environment by providing assistance in the form of job coaching, transportation, training and individually tailored supervision.
- **Open an employment agency for disabled people** - Open an employment agency for disabled people, which in addition to finding jobs for disabled, will also serve as a source of information on employment needs and capabilities of disabled population.
- **Support existing facilities for the disabled persons**- Kutaisi center (West Georgia) has good facilities and equipment to manufacture prostheses. The state should support this center with provision of materials/supply.
- **Stores Owned by Disabled Persons** – Assist in opening stores run by disabled persons in Tbilisi and Kutaisi to sell goods produced/made by disabled persons.
- **Community based organization** – Learn from the experience of two community-based villages in East Georgia and create more places where persons with different disabilities will be able to live and work.
- **Restore/start sheltered employment** – While sheltered employment is not a true path to the integration of people with disabilities, it is recognized that for some severely disabled people it could be the only option. It might be beneficial to restore sheltered employment opportunities that existed in the past for disabled people and leverage

Small printing shop
Establishment of a small printing shop run by the disabled could be an example of a sustainable project. Once set and running, the printing shop should be able to rely on self-financing. It can also print materials of social nature ordered by the state, NGOs and other organizations.

4. Recommendations to overcome barriers

their material base as well as the experience (e.g. facilities and shops owned by the Union of the Deaf and Union of the Blind). These special enterprises should be able to hire a certain number of non-disabled persons to promote integration at the workplace.

- **Work from Home** - Create home employment opportunities for those with severe movement restrictions. It can include making crafts, sewing, embroidery, small repairs, etc.

4.3 EDUCATION

4.3.1 Formulate Education Policy

Educational policy - Overall policy for disabled persons' education needs to be formulated by the MoES in close cooperation with NGOs working on educational issues of people with disabilities. Guidelines developed by UNESCO, the World Bank and other international agencies dealing with educational policies such as Education For All (EFA) should be taken into consideration. Inclusive education provides the best solution for a schools system which can meet the needs of all learners. It should be emphasized that inclusive education cannot be developed in isolation from overall school development. Inclusive education cannot be seen as a specific issue, but must be regarded as an approach to the development of the entire school system. Inclusion is not just having children with disabilities in schools: it means a different approach towards teaching all children, those with and without disabilities. At the same time, the whole spectrum of educational opportunities should be considered in the context of Georgia. As outlined in many research papers, type of appropriate education depends on many factors, such as nature of disability, available means and resources and social context. Therefore, boarding schools and special schools should not be discounted.

4.3.2 Inclusive Education

- Inclusive education should begin at pre-school age in kindergartens. It should also include training for teachers and school administrators on what it means to have child centered learning and how to support different types of children in a classroom.
- Capacity of the MoES at all levels to implement policies and programs need to be enhanced.
- Equip schools with computers, appropriate teaching aids, books, and other needed equipment and supplies.

4.3.3 Special Schools

- Refresh/renew programs and teaching methods in special schools; develop and publish special textbooks.
- Teach life skills, ways of leading an independent life, and orientation in town to disabled students.
- Provide targeted teaching of how to read and write to all disabled students capable of acquiring these skills.
- Make special efforts for teaching deaf students how to read.

4. Recommendations to overcome barriers

- Support creation of centers focused on individual work to improve speech recognition ability and teach speech to the deaf, e.g. benefit from already existing experience in the country of using audiovisual method.

4.3.4 Vocational and University education

- Incorporate programs for people with disabilities into newly developed system of vocational education.
- Provide disabled persons with possibilities to participate in refresher courses.
- Create possibilities for acquiring university education. Establish resource centers for the disabled students in at least three or four big universities in the country. Staff them with assisting personnel and provide with special equipment such as e.g. computers with voice-activated programs.
- Support distant learning.

4.3.5 Education of Parents/Caretakers

Develop and implement targeted programs for parents of disabled children, including:

- Training in sign language for parents and other household members of deaf persons.
- Trainings about learning and cognitive difficulties of disabled children and caretakers' role in assisting to overcome these difficulties.
- Training on how to care for disabled household members, including safe and easy ways of moving disabled persons.
- Develop and distribute brochures about different types of disability and caring for disabled persons.
- Provide support in creating/maintaining parent support groups.

4.3.6 Train Teachers

Prepare teaching and assisting staff for inclusion and teaching of disabled students

- Provide training on inclusion
- Provide regular training to teaching staff on educational aspects of disabled children
- Make accessible to teaching staff the information on innovative approaches to education of disabled children

4.4 HEALTHCARE AND SERVICES

4.4.1 Increase Access to Healthcare

While some disabled persons do not need a lot of special medical assistance due to their type of disorder, accessibility and quality of health care, especially rehabilitation and therapy services, represent a major concern for the majority of disabled respondents. Improvements are needed at all stages of health care: prevention, diagnostics and treatment.

4. Recommendations to overcome barriers

A. PREVENTION

In-born impairment - a number of measures can be taken to lessen the risk of in-born impairment by including the following activities in the state program:

- Free prenatal testing for possible in-born anomalies
- Education of mothers on adequate diet during pregnancy
- Genetic consultancy for the risk group of parents
- Screening of pregnant women

Work-related impairment - measures for the prevention of the work-related trauma include:

- Provide information to employees on work-related safety measures
- Monitor safety at work environment by creating groups of employees responsible for safety monitoring
- Create mechanisms for ensuring payment of penalties in case of registering the violation of safety at the work place

B. DIAGNOSTICS

- Screening of inborn malfunctioning of metabolism
- Provide information to parents on the signs of impairment and steps to be taken after its detection
- Refer parents of disabled children to the specialists, including non-medical professionals, for taking prompt measures to minimize the adverse effect of impairment
- Create mobile groups of specialists from the multi-disciplinary board for evaluation of mental impairment in the capital, West and East Georgia and collect information about children with mental disorders in remote areas.
- Ensure systematic monitoring of impairment among children.
- Develop transparent criteria for keeping patients with mental disorders at state institutions.

C. TREATMENT

- The state should cover medical treatment of disabled patients.
- Change the existing voucher system for medication, allowing it to include any medication that a disabled person needs up to an established limit.
- Create a network of rehabilitation centers, at least one in each of the ten regions of the country, to include medical, social and psychological rehabilitation, and provide opportunities to swim, exercise and get massages/manual therapy.
- State programs should cover the cost of rehabilitation of disabled people at local therapeutic resorts.
- Rehabilitation programs and therapy should be available to members of disabled persons' households.

4. Recommendations to overcome barriers

- Create a children department in the psychiatric hospital in Tbilisi.
- Refurbish building of the psychiatric hospital in Kodjori (village in the vicinity of Tbilisi) and organize an inpatient clinic for children with mental disorders and their parents. Provide training on life skills to children and caring for mentally impaired children to parents.

4.4.2 Improve Qualification of Medical Staff

- Create and implement training courses for medical staff on disability issues.
- Provide medical staff with a possibility of cross-practice (e.g. psychologists, social workers, teachers)
- Provide refresher courses for preparing rehabilitation specialists.
- Introduce a licensing system for the professional care provided to disabled patients and for manufacturing assisting devices/aids.

4.5 AWARENESS BUILDING AND OVERCOMING ISOLATION

Inclusion of disabled persons into political, economic, cultural and everyday life of the society is the biggest awareness builder, however additional measures need be taken to change the attitude of neglect and discrimination towards persons with disabilities in Georgia.

- **Public Awareness Programs** - Mass media is the key tool for raising public awareness. TV broadcasts on disability and successful cases of integration of disabled people, coverage of best international practices on disability, participation of persons with disabilities in TV and radio talk shows will educate the general public on disability problems and at the same time increase the visibility of disabled people. Printed media can supplement public awareness activities. Public hall meetings and discussions of disability issues in communities, schools and universities will also lay a foundation for appropriate perception of disability by the society.
- **Increase Access to Information for Disabled People** - Special measures can be taken to increase the feeling of belonging to the society such as regular broadcasts in sign language for deaf persons; air broadcasts showing in detail public buildings, parks, shops, cafes, streets to provide visual information for those restricted in movement.
- **Increased visibility of People with Disabilities** - Everyday exposure to disabled persons and even casual encounters should contribute to the formation of attitude of acceptance. Include pictures of disabled persons in school textbooks, print stamps with pictures of disabled people, and include disabled people in TV serials.
- **Recreation and Leisure Activities in the community** – Leisure and recreation have tremendous potential for enhancing social integration. Examples of recreation activities may include:
 - Sports and sports competitions
 - Clubs where disabled persons could meet and interact.
 - Youth centers
 - Provide translation to entertaining programs.

4. Recommendations to overcome barriers

- Disabled youth in summer patriotic camps and hobby groups
- Exhibitions and festivals with the participation of disabled people
- **Church Involvement** - Active involvement of church can prove to be a very effective tool for fostering acceptance and understanding of disabled people's issues in the context of Georgia.
- **Support for the Organizations of Disabled People and their Caretakers** - Motivate organizations to carry out advocacy programs and lobbying activities for ensuring equal rights and opportunities for people with disabilities. Strengthen ties with international organizations of disabled people.
- **Conduct public awareness campaign on road safety.** Organize at schools lessons on safe driving and on rules of crossing the street.

**Exhibit 1 – Proposed Public Awareness Campaign
“Raising society’ awareness on disability issues”**

Project implementer: “The House of Children’s Harmonious Development” association and other specialists.

Main Activities:

- Organizing TV and radio talk shows on disability issues in Georgia
- Design and implementation of social TV commercial s
- Design and distribution of informational leaflets and flyers

TV and radio talk shows will focus on current disability issues in Georgia, disabled people’s lives and activities. Representatives from governmental structures, NGOs of disabled and other interested individuals will participate in discussions (civil society, church, political leaders, famous writers, TV persons).

A tender for the best idea about disability TV commercial will be announced and the winner is selected on a competitive basis.

Informational leaflets and flyers will be prepared based on the input and recommendations of NGO’s of disabled and distributed among the general public.

Various social actions/campaigns will be designed and held on December 3 (International day of Disabled people) and June 14 (Disabled rights defense day) and etc.

Funding and resorces required:

TV and radio shows:

TV and radio show time
Operator team

Social TV commercial:

Shooting time and operator team expenses
Show time

Informational leaflets and flyers:

Printing, publishing and distribution expenses
Expenses for social actions
Office expenses

Expected outcomes:

Successful implementation of the project will increase society’s awareness on disability issues, and help changing general public’s attitude and vision towards disabled people. It will help breaking stereotypes and education people that persons with disabilities are valuable and successful part of our society. The project will enhance cooperation and networking with other disability NGO’s, their integration and promotion of their activities.

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APPENDIX A: DETAILED SUMMARIES OF IN-DEPTH INTERVIEWS

A.1 INTERVIEW 1: CARETAKER FOR DISABLED CHILDREN, TBILISI

Date: 29.06. 2006

Interview type: Caretaker

Gender: Female

Age: 34

Name of the disabled respondent: Ana

Gender: Female

Age: 10

Disability: Cerebral palsy

Name of the disabled respondent: Temuri

Gender: Male

Age: 11

Disability: Blind

Leila is a 34 year-old mother of two disabled children: 10 year-old Ana and 11- year old Temuri. Both children are disabled since birth. Ana has cerebral palsy and Temuri is blind. Leila's mother shares responsibility for looking after the children. Leila works at the hospital as a cleaning lady and her husband is a manual worker. The family is very poor. The whole family lives in two rooms. Leila's mother takes Ana to school. Ana now can walk for a short distance: sometimes she goes out of their yard, along the walls of neighboring houses. Ana has a wheelchair, which was provided by a kindergarten, but she has not used it yet because Leila thinks that using a wheelchair will make Ana lazy. Ana's condition was much worse, but after her treatment in Akhtala (local therapeutic mud resort) where they went regularly, Ana walks much better.

Both children can dress, eat and use bathroom independently. However since the floor of the house is uneven both fall down very often. Both children go out of the yard sometimes and stay in the neighboring area.

Taking care of children is difficult. She and her mother are physically and mentally exhausted and overstressed. They do not want anything anymore. But it was much more difficult when children were small.

Education

Children go to school. Ana goes to a regular school, although she has some difficulties (delays) in development and mobility restrictions. Temuri goes to a special school for blind children. The school is quite far away from their house. Leila takes Temuri to school. They take a mini-bus, which is a problem for the family as it costs them 2 GEL a day. Temuri could stay at school because it is a boarding school, but he does not want to sleep over there.

Ana has some learning problems. She also does not play with children, but still likes to go to school. Temuri is very good at writing and reading Braille. He likes school very much but he lacks books. He wants to learn computer and is very concerned that he cannot do this. He hopes to have eyesight sometimes. At school no life skills for his kind of disability are being taught.

Social Integration

Children attended a special kindergarten organized by Ms. Taduli Kekenadze who provided them with 10 GEL for transportation. They also participated in Ms. Maia Bibileishvili's program, where the food was provided and children were entertained/could interact, but the program was closed. They also went to "Tanadgoma" NGO, which arranged a trip to the local circus. All these were programs/activities implemented by local NGOs. Ana also went to Digomi rehabilitation center (district in Tbilisi) that helped her very much. All these programs were very beneficial both for children and their parents who could interact and meet each other. Leila says that now her friends are only the parents of disabled children. It is very helpful to meet these people and share thoughts and concerns.

Assistance

They receive a pension from the state. Her work as a cleaning lady at the hospital is helpful because she can get free medical services for children. Tbilisi Health Service sent her with children to Akhtala (mud resort) several times. It is very difficult to have a job and to look after disabled persons. The state should provide financial help to such families. There should be also enterprises for disabled people as they used to be in the past.

Health care

People treat them well. Temuri does not need regular medical treatment. Ana sometimes needs medication, they have a health voucher (issued by the state) but it is useless (it does not cover the medication they need). Ana also needs massage and water procedures. She needs rehabilitation, but it is complicated to get to the Digomi rehabilitation center.

What can be done?

If Leila had money she would repair the house.

A.2 INTERVIEW 2: PERSON WITH DISABILITIES, TBILISI

Date: 22.06.2006

Address: Tbilisi

Interview type: Disabled person

Type of disability: Deaf

Name of respondent: Marika

Gender: Female

Age: 15

Marika is fifteen years old. She is deaf since birth. Her mother is also deaf. All other members of the household: a brother, nephew, aunt and cousin do not have hearing problems. The family is of medium affluence and their apartment is in a good condition. Marika has a hearing device but she does not use because device's noise irritates her. She can lead independent life and does everything at home. She does shopping for the family.

The main problem she faces at home is communication. Household members do not understand her, and she does not understand them. Her cousin often serves as an interpreter.

Education

Marika attends a special school. She also attends a course to learn how to give manicures. She is in the 10th grade. She says that it is impossible to get any kind of education at school.

Many children cannot understand their teachers. Children teach each other and help in understanding. Teachers do not know the sign language.

Integration

She feels uncomfortable in public because communication in sign language attracts people's attention. Many laugh at them. She has problems communicating with outer world. She has about 10 friends, some of them are deaf and others are with normal hearing. However she often reads pity in the eyes of persons with normal hearing.

Assistance

She gets 33GEL (USD \$19) monthly pension from the state. The Union of Deaf helps her with arranging vacations/trips: they sent her to a summer camp and to the seaside. She is attending dancing and singing groups. When she has any problems she goes to the Union.

Health care

She does not need any medical treatment for deafness.

What can be done?

She thinks that it will be useful to have sport activities at the Union. If she had money she would finance the sports groups. The main thing is to have interpreters that will help deaf to communicate with others.

Hopes and fears

She does not fear anything. Most of all she relies on God.

A.3 INTERVIEW 3: PERSON WITH DISABILITIES, TBILISI

Date: 13.07.2006

Address: Tbilisi

Interview type: Disabled person

Type of disability: Blind

Name of respondent: Gocha

Gender: Male

Age: 29

Gocha is single. He lives with his mother who is also disabled. She has impaired eyesight. Gocha could only see light from the sun. He had bad eyesight since birth but at the age of 13 he lost sight completely in one and soon in his second eye. He was assisted by his sister, who used to read for him and accompanied him everywhere. Now she is married and cannot help him as much as before. His mother cannot accompany him, especially after dark due to her bad eyesight.

They live in a two-room apartment, which is in a good condition and is centrally located. The family can be considered of medium affluence.

Gocha complains that he does nothing during the whole day because he cannot get out of the house independently. When there is a gathering of relatives or friends, someone usually comes and takes him. At home he is quite independent, he can serve himself and move about.

Education

Until he could see a little he attended a regular school. At the age of 13 he went to a special school for the blind. The problem of the special school was that he could not get the education and information he needed. They did not have any computers. He points out that the school is much behind times even worse than special schools in Russia, where children are taught how to move around the town, as well as other practical skills. He has a computer with a voice-activated program, which he now begins to learn.

Employment

He does not work now, but before he worked as a lecturer at some private university, which was closed. The main obstacle for him is impossibility of going out unassisted. Even if he had a job he would not be able to go. But "even if I have a good qualification, nobody will take me because of my blindness. I will be only laughed at." Most of all he is concerned with the fact that he cannot provide for himself.

Social Integration

He does not feel any restrictions when he is among his friends, he sometimes even forgets that he cannot see, and his friends also forget this. There were occasions when he took out a cassette to see how much tape was left, forgetting that he cannot see. He has friends: these are his class or group mates. He sees them when they have time because they are busy, unlike him. They see each other once a week or a month. It depends. *"Many persons pity me and it irritates me terribly. I do not consider myself miserable"*. Some people make fun of him.

Assistance

He does not get any assistance, besides pension, although there are many ways to help the people like him. First of all they need a good pension and an accompanying person.

Health care

He does not need any medication for his eyes.

What can be done?

The quality of education at special school should be improved. School should have computers. Life skills should be taught. Medical care should be free. Some people with eyesight problems need treatment, and due to impossibility to pay for it they become blind. The escort service for the blind should be created. One should be able to call the service and be transported. But of course one should have big enough pension or voucher for it. Activities must be carried out where the blind could participate, for other people to see that blind are capable of being useful/do something... and are not to be pitied. Also the healthy children at early age should be informed about disability to be able to interact adequately with disabled people. If he had money, he would publish books on disks.

Fears and hopes

Most of all he fears of being alone. More generally of sins and the God. Most of all he relies on God.

Supplementary questions to Gocha's 68 years old mother, who is disabled of the 1st category, with impaired eyesight. They used to have an escort and reading service for the blind in the old days. She is depressed seeing that her son is doing nothing and that she cannot help him. She wants him to get married. She fears about his future and who will look after him when she dies.

A.4 INTERVIEW 4: ORGANIZATION OF DISABLED PERSONS, TBILISI

Date: 13.07.2006

Address: Tbilisi

Interview Type: Organization of Disabled Persons

Organization: The Union of the Blind

Respondents name: Merab

The Union of the Blind was founded in 1926. It consists of 4,000 members, of which 250 members are employed. The majority (139) works at the Union. The Union has a big building and a lot of property in a form of enterprises, land and other facilities. They sublease their concert hall and pay the salaries for persons working at the Union out of this money. The Union has 24 branches and up to 30 legal entities, registered organizations. In fact, they are looking for investors and are concerned that the state will take away their property. They have already experienced indirect attempts on the part of the state. The Union is the member of the European Union of the Blind as well as of the World Union of the Blind, but they cannot afford paying membership fees.

Education

A special voice-activated computer program in Georgian was developed under the Open Society Foundation's grant. It is now sold for 180 GEL. Some people have bought and used it.

Employment

Employment is a major concern. It cannot be resolved without the state policy. The State should allocate 3% out of 20% of the social tax to disabled persons. This money could be spent for the creation of jobs. Another possibility is to reduce taxes for those enterprises that employ disabled persons. The work of disabled persons cannot be compared with the work of healthy persons. A special environment needs to be created. Blind people can work on computers with voice-activated programs. Their fingers are very sensitive so they are good at work that needs this kind of sensitivity.

Integration

The biggest obstacle is mobility. Blind people in Georgia cannot use seeing eye dogs because they cost too much, although there is a man who offers to train such dogs. The integration can be supported by using seeing eye dogs, accompanying persons, and technology. Voice interactive mobile phones also help in communication. Integration means inclusion in the society. During the communists' time there was employment for the blind, but it was like a reservation (an allusion to an Indian reservation, i.e. very isolated)

What can be done?

The coordinating body for the affairs of persons with disabilities should be created under the President of Georgia. It should comprise mostly of disabled persons. Computer courses should be run at the Union.

A.5 INTERVIEW 5: CARETAKER FOR DISABLED CHILD, TBILISI

Date: 23.06.2006

Address: Tbilisi

Interview type: Caretaker

Name of respondent: Mzia

Gender: Female

Age: 47

Name of disabled person: Ana

Type of disability: Cerebral palsy, hearing impairment

Gender: Female

Age: 8

Mzia is a mother of an 8 year-old girl with cerebral palsy. She works as an accountant, but goes to work once or twice a month. Her colleagues let her do this due to her situation. The family is of medium affluence. They live in a one-room apartment. They have a gas heater-Nikala and a mobile phone. Mzia and her husband adopted Ana when she was 1 month old. Mzia noticed the symptoms when the child was 5 months old. Ana cannot stand, she does not attend school. She spends most of her time at home or gets out with her mother for a walk in the yard or to a zoo. The child has a hearing device, but she is not able to use it. She also has a wheelchair in which she sometimes sits and moves around the house. Ana cannot take care of herself independently. Her mother does everything for her. Parents take her with them when they go to visit friends or relatives. Ana cannot be left at home alone.

Mzia is overstressed because she does not have any help to look after the child. Mzia's mother cannot help her due to her old age. When she goes to work her friend stays with Ana. Her husband tells her that he is very depressed due to the situation with the child and this is the reason why he drinks. When he returns in the evening from work he interacts with the child.

Education

Ana cannot attend a regular school. A specialized school is too far away and Mzia cannot take her daughter there. Ana cannot be taken anywhere by public transportation. Once she took her on a bus, but child's hands were moving uncontrollably and touching other people. Mzia was asked to control her daughter, but how could she do this?

She hired a sign language teacher. They both studied it and Ana was much better at it than Mzia. However one lesson costs 15 GEL (approx. \$7) and she could not afford it. Ana has some retardation (developmental delays) due to her deafness, but it is not serious. She is interested in everything, wants to do everything. Ana participated in the program ran by "Tanadgoma" (NGO) where they sang, danced and were entertained, interacted with children. The program was closed.

Social integration

Their neighbor has a daughter of Ana's age. They often visited them, but then stopped as their child began dragging her feet like Ana, probably trying to imitate her. Her mother did not bring her any more. Ana needs interaction, entertainment, stimulation but she is alone. "*She wants to do everything, but can do nothing*". Impossibility to communicate is the main problem for Ana. Ana does not have friends. Attitude of the people in the street and in the neighborhood is mostly positive.

Health care

Ana does not need special medication. She only needs water procedures for rehabilitation. Mzia is afraid that she may have some problems even some pain but is not able to communicate it to her.

Needs

Most of all she needs a nanny/baby sitter and a higher pension. Mzia is exhausted. She already has health problems herself. She is especially tired of entertaining her daughter.

What can be done?

It will be good to continue financing of "Tanadgoma" program and have higher pension to hire a nanny. She thinks children with this kind of disability should not go to a regular school. They will always be in the center of unwelcome attention. Healthy children in a class will not be able to concentrate on their studies. Ana should have possibility to exercise and have water procedures. It is necessary to have a special bus that will take them to school. There should be clubs and day centers where these disabled people are able to meet each other, interact and be entertained. If she had money she would start her own business to leave something to her child.

Hopes and fears

In fact she does not hope for anything. The only thing she wants for her child is to have someone who will look after her when Mzia is not alive.

A.6 INTERVIEW 6: PERSON WITH DISABILITIES, TBILISI

Date: 22.06.2006

Address: Tbilisi

Interview Type: Disabled person

Type of Disability: Deaf

Respondent's name: Maria

Gender: Female

Age: 32

Maria is married and has two children who do not have hearing problems. The family is of middle affluence and their apartment is in good condition. The household has a car and a mobile phone. Maria's husband and parents are deaf. She is deaf since birth. She teaches sign language at the Union. She is quite independent, serves herself and does everything at home. She had a hearing device, but was not able to use it. She first used it when she was six, but could not adapt to it.

Education

She has graduated from a boarding school for the deaf. No social skills were taught there. She also had difficulties understanding study materials at school.

Employment

Maria works at the Union as the teacher of sign language, but does not get paid, as there is no financing for the program. Before she worked at the Union's workshop as a knitter.

Social integration

Maria does not experience any obstacles or barriers when among deaf people. But with people who can hear she often gets irritated/upset when she cannot make others understand her or when she cannot understand them. The only problem is not having an interpreter.

Her friends are mostly deaf people, but she has friends among neighbors as well. They pity her.

Assistance

Besides the standard assistance for disabled people (33 GEL- pension), family assistance and discount on gas and electricity she does not receive anything from the state. The Union helps her with food items and health care.

Health care

She does not need special health care for her type of disability.

Needs

The only thing she needs is an interpreter. Most of all she is hindered by the impossibility to communicate.

What can be done?

The programs of the Union of Deaf should be financed. The interpreters should be provided. There should be an opportunity to learn the sign language. If she had money she would use it for the family needs.

Fears and hopes

Most of all she fears for the future of her children. She hopes that something will change for the deaf and they will be better adapted to the environment.

Supplementary discussion with family member, Maria's husband. He is also deaf and works at the Union as the assistant of the Head. He reiterates that the most needed are interpreters. That people treat deaf people with pity, and some make fun of them.

A.7 INTERVIEW 7: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 20.06.2006

Address: Kutaisi

Interview Type: Disabled person

Type of disability: Blind

Respondent's name: Gio

Gender: Male

Age: 69

Gio cannot see anything. He lives with his brother and his family: a wife and two sons. Their apartment is dilapidated. In winter they usually use a wooden stove. But the respondent is afraid of using it, so he insists on using an electric heater, but the household cannot afford to pay for electricity. This was the reason that he got lower back pain, which made him irritable and aggressive. He is disabled since childhood, had problems with legs, but once he went to bed at night and in the morning could not see anything. He can hardly do anything independently. He finds his way to toilet with difficulty. Nephews help him with bathing and sister-in-law looks after him and cooks for him. He relies most of all on her. He spends the whole day sitting in his room. Before he had a radio and was listening to it the whole day. But now cannot afford it. Everyone in the family is unemployed. They live on a government pension.

Assistance

Besides standard pension from the state he gets medication from a Catholic organization.

What can be done?

It would be very important for him that his caretaker received a pension as well. He cannot work or do anything.

Hopes and Fears

He is very afraid of being alone. He relies on kindness of people and on God.

A.8 INTERVIEW 8: GOVERNMENT ORGANIZATION, TBILISI

Date: 18.04.06

Address: Tbilisi

Interview type: Organization

Name of the respondent: Manon Khachidze. The United State Social Insurance Fund, Deputy Chairwoman of the Supervisory Board

According to the new Georgian legislation disability is defined according to the three categories: severe, serious and moderate according to the functions that a person is able to perform. The State has no money for the rehabilitation programs. A new program of creating day centers for disabled people is being initiated. Various local NGOs are bidding for this program. The best possibilities for integration of disabled persons exist probably only in Tbilisi (the capital of Georgia).

There are several problems:

- Medical service, in fact nothing is free. Even if medical services are funded by the state, a patient has to pay upfront and then he/she can get reimbursed.
- In order to get examined for disability and get an official disability status at the special examination committee (and be re-examined on an annual basis), a person has to pay 25 GEL recurring fee at a clinic or hospital.
- Social isolation is the biggest problem.

What can be done?

- Allowances that will be enough for survival
- Employment/job creation, specially for disabled people
- Every building needs to have a ramp for wheelchair access, toilets for disabled people, street crossings.
- Translation in sign language
- Inclusive kindergartens
- Special consultant to the President on disability problems
- This year it is decided that a disabled person can work and retain his/her state pension
- Caretakers should have pensions as well, which was a practice of the past.

A.9 INTERVIEW 9: ORGANIZATION (NGO), TBILISI

Date: 11.04.06

Address: Tbilisi.

Interview type: Organization

Name of the respondent: Shalva, Union of Deaf People

There are 5,000 deaf persons in Georgia and the Union has 3,000 members. The Union functions as a social club, the place where deaf persons come to learn what is happening in the country and the world, and to communicate with each other. The Union has branches in the regions. It has a good, although requiring repairs, building in the city center.

Education

The problem is that deaf mostly cannot read and write. Special schools should be blamed for this. The level of teaching there is very low, most of the teachers do not know the sign language, because its usage was prohibited by the Ministry of Education in the past. None of the schools conduct any training to prepare their students to be integrated into the society. There is one special kindergarten with 80 children and one boarding school with 180 pupils in Tbilisi, and one boarding school with 58 pupils in Kutaisi. It is planned to open a school in Batumi (Black Sea area).

In addition, not all deaf children go to school. Due to their socio-economic conditions parents from regions cannot afford to bring their children to Tbilisi. Others simply do not want to leave their children at boarding schools. Therefore the situation in the region is much worse than in the capital. Deaf children have developmental delays due to the fact that they have no information. They need psychological rehabilitation. Deaf people find it difficult to express their thoughts. In Soviet times there were special Universities for legal studies, dental school for deaf people in Russia.

Employment

Major problem is the lack of employment opportunities. The union had 14 enterprises: three in Tbilisi and the rest were in the regions. In 1991 all tax reductions and benefits, which organizations of disabled people enjoyed, were cancelled, and all the enterprises were destroyed/shut down.

Social integration

The main problem is an informational vacuum that deaf people are living in. Only one public television channel has short news at 12 with sign language translation. The Union was fighting for this to happen for 3 years.

Even parents cannot communicate with their own children, as they do not know the sign language. In many countries the law obliges parents to learn the language. Now the Union of Deaf teaches the sign language. Integration will be possible only when there are enough sign language interpreters. There is a scarcity of interpreters. The city of Tbilisi finances interpreter service in courts. In the region there is no service of interpreters at all. The Union developed a dictionary of Georgian sign language but has no funds for publishing.

Deaf people are not elected neither at the state or local levels. They are not members of any party. The Union managed to translate a Georgian classic movie (produced back in the 60s) "A soldier's Father". It was the first occasion when deaf people saw a Georgian film in their

language. The translation of the movie cost 600-700 GEL (approx. \$350). Deaf go to the theater with interpreter. There are no halls/public places adapted for the deaf.

Health Care

Deaf people do not require any special medical treatment for their condition. The state helps with hearing devices. Also Stockholm Institute for Rehabilitation of Hearing and Speech assisted Georgian deaf children. In 2005 several employees of the Institute spent 20 days in Georgia. They examined children in kindergartens and schools, and provided them with hearing devices. The device helps a person if he/she has 10-15% of the hearing ability. The earlier he/she begins using the device, the better the results are. It should be used when a child is 2 years old, because at a more advanced age the device becomes useless.

Attitude of the Society

The society looks at the deaf as underdeveloped people because people with normal hearing cannot understand deaf people.

What can be done?

The most important is education in schools and after graduation from school. In the past there were vocational schools for the deaf. They should be resumed again. The state must either provide incentives to local business through decreased taxes to employ disabled persons or oblige business to hire disabled people.

It is necessary to work with parents. Families spend a lot of money and time taking children to various doctors when they first discover hearing problems of their children. However it is useless in most cases and the time for the development of cognitive abilities of children is lost. It is very important to introduce computers to the deaf. The Union has one computer class running.

A.10 INTERVIEW 10: SERVICE PROVIDER, TBILISI

Date: 30.06. 2006

Address: Tbilisi

Interview type: Service Provider

Name of the respondent: Nestan Duduchava

Name of organization: Tbilisi psycho-neurological clinic

The psycho-neurological clinic serves 4 districts of Tbilisi and is a part of the in-patient state program of psychiatric assistance. The programs covers only the patients diagnosed with psychosis and people with mental retardation are not included.

“In fact the main focus of the program is to safeguard the society, it does not deal with the interests of the patients”.

The program is very small and includes a medication subsidy of 4.50 GEL (\$2.5) a month. This represents 1/6 of the amount of the medication that a patient would normally require. The emphasis of treatment should be on psychosocial rehabilitation. In this case less medication will be needed for neutralizing aggression.

First steps in rehabilitation are made by the Association of Mental Health. At day centers located in Kutaisi and Batumi (Western Georgia) some elements of rehabilitation are being introduced. The Association operates a center for psychosocial rehabilitation for 30 persons

in Tbilisi. Such centers need to be oriented towards the community. Each district should have at least one center where persons with different disabilities could be rehabilitated.

Children

The clinic has 700 registered children with mental retardation. The majority of mentally retarded children have cerebral palsy. They are referred by district polyclinics, but not all parents bring their children to the clinic.

Underreporting is very common, especially in rural areas. Many parents do not want their child to have an official record of mental problems and/ or they do not see any benefits in registering. According to the Georgian law, 7 GEL (\$ 3.8) is added to the pension of a disabled person if he/she is officially registered as having mental retardation.

Employment

The clinic had its own workshops where patients worked: they made chandeliers, sewed bed sheets and pillows, and made slippers. The enterprises that employed disabled people used to have tax privileges. In Kodjori (village in the vicinity of Tbilisi) there was a hospital of high quality, where patients had to pay partly for the treatment. The hospital has a very large territory and a two-story building. A rehabilitation center for children can be arranged there. In addition, their parents can be trained how to look after mentally ill children. The length of the stay of children should be for several weeks, and during this period in addition to treatment they should learn basic life skills.

The Association of Psychiatry has a wood workshop, where mental patients work.

Organizations

There is an association in support of the parents of mental patients. Ian Sen Silag, a pharmacological company established a parents' club. A monitoring council has been recently created which has the mandate to supervise human rights' violation in psychiatric care.

What can be done?

Mental patient is a traumatic experience for the whole family. Family members need assistance. Home care and services of social workers should be accessible. Occupational (work) therapy is effective and should be widely introduced. A network of community oriented rehabilitation centers should be created.

A.11 INTERVIEW 11: CARETAKER, WESTERN GEORGIA

Date: 26.06.2006

Address: Kutaisi

Interview type: Caretaker

Name of respondent: Mzia

Gender: Female

Age: 53

Name of disabled person: Eteri

Type of disability: Cerebral palsy

Gender: Female

Age: 18

Name of disabled person: Tata

Type of disability: Cerebral palsy

Gender: Female

Age: 15

Both daughters in the family, an 18 year-old and a 15 year-old have cerebral palsy. Parents went to the doctors only after the second child was born with cerebral palsy. They were told in Leningrad (now St. Petersburg, Russia) that they had incompatibility and could not have healthy children. In Leningrad they were offered to leave the children at a special institution, but they refused. Children's father was against it.

The family is poor. Respondent's husband has some small business and can get money for elementary needs. House is clean but dilapidated. The girls are very friendly; the elder daughter is in much better physical shape than the younger one. She can move independently and can talk, although with difficulty. She can also eat independently. The younger child cannot stand or talk. They live on the ground floor but do not have a ramp, thus they cannot use a wheelchair. When the children were smaller parents took them out to the park or yard. Now it's much more difficult to look after them. Girls cannot serve themselves. Mother has to dress them and take to the bathroom.

Both parents are overstressed and have health problems. The girls occasionally attend a rehabilitation center "Tonus" which is for the children with cerebral palsy. "Tonus" took them to Borjomi (a resort in Georgia) last year. This year their finding is more restricted and they refused to take the girls. Time spent in Borjomi seems to be the most vivid and happy recollection for the girls. The elder girl said she had a boy who she fell in love with, and most of all she wanted a mobile phone to be able to talk to him. When I offered my mobile phone to her, she exchanged some general sentences with the boy and seemed very happy. The elder girl visits her neighbors. She likes small children very much. She watches TV and children programs.

Assistance

Besides state pension they occasionally get food assistance and they received a wheelchair from the organization for disabled people in Kutaisi.

What can be done?

The state should pay more attention to disabled people, try to make their life a bit more joyful. They should be taught something and be able to earn money, to be among people.

Fears and hopes

Most of mother's fears are about the future of her daughters after her death. She said she was thinking of killing them and herself when she knew she was dying. But now she thinks that would not be able to do this.

A.12 INTERVIEW 12: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 27.06.2006

Address: Kutaisi

Interview type: Disabled person

Type of disability: Cerebral palsy

Name of respondent: Ana

Gender: Female

Age: 20

Ana is a 20 years old beautiful girl, with big blue eyes full of sadness. She looks much younger than her age. It is very difficult to get in contact with her. She seems to be very depressed. She can speak but did not want to do it. She can read, she can move, but she did not go out of the house.

Her psychological condition deteriorated after an unsuccessful surgery on her legs. She hoped so much that she would be able to walk normally, but when she saw that nothing has changed she got depressed.

The family is of middle affluence. They have a good house with five rooms and a yard. Ana lives with her grandmother, mother and brother. Ana's brother is healthy. Ana's mother seemed to accept daughter's condition without trying to do anything about it. When asked why she is not seeking help of psychologist or psychiatrist, mother said that this would not help her daughter. She is hopeless and seems not to be fighting for her daughter's wellbeing. She even remarked that she already had a son who is normal.

We met another disabled person Irma who is quite active, and talked to her about Ana. We asked Irma to contact Mary. Irma said that she tried for several time to take her to church, but did not succeed. She also remarked about the passivity of the mother.

A.13 INTERVIEW 13: CARETAKER, WESTERN GEORGIA

Date: 27.06.2006

Address: Kutaisi

Interview type: Caretaker

Name of respondent: Ketí

Gender: Female

Age: 48

Name of disabled person: Ana

Type of disability: Cerebral palsy

Gender: Female

Age: 20

Ana was treated in Tbilisi rehabilitation center. She also went through a treatment course in Evpatoria (Crimea). She can walk only with the help of another person. Her condition deteriorated after a surgery two years ago. She hoped to walk independently, but nothing has changed. This depressed her. She was schooled at home, by the teacher who came from school. She managed to complete 9 grades, as much of it as she could. She can be left at home alone, but only for a short period. She had usual relations with others, but after the operation this changed. Now she does not want to interact. She got a wheelchair from the head of the Parliament, who has membership from Kutaisi.

"Sometimes I take Ana out in a wheelchair. Sometimes neighbors visit us. But children do not contact Ana, how could they contact her, you cannot oblige anyone to do so."

Keti used to work, but had to quit because she could not combine caring for Ana with being employed. She also has health problems. She regrets that did not teach Ana knitting when she was small. Her grandmother tried to do so 3 years ago, but Ana refused, although physically she can use her hands. *"If she could knit she would somehow keep herself busy. Now she is sitting motionless for the whole day."*

A.14 INTERVIEW 14: CARETAKER, EASTERN GEORGIA

Date: 5.07.2006
Address: Telavi
Interview type: Caretaker
Name of respondent: Mariza
Gender: Female
Age: 63
Name of disabled person: Lasha
Type of disability: Cerebral Palsy
Gender: Male
Age: 7

Lasha is from the family of Internally Displaced Persons (IDP) from Abkhazia. He lives at the IDP center (former hotel) in Telavi with his parents, grandmother and brother. He cannot eat or dress independently, but can move without assistance. He runs about the hotel and sometimes plays with children, but is very aggressive: he hits children and spits at them. He cannot talk. He went to kindergarten but soon teachers refused to take them due to his aggressiveness. He cannot be left alone. Lasha receives a pension and each member of the family receives an IDP allowance (11 GEL/month). This is the only source of income for this family. They are quite poor. All live in one room.

A.15 INTERVIEW 15: CARETAKER, EASTERN GEORGIA

Date: 05.07.2006
Address: Telavi
Interview type: Caretaker
Name of respondent: Mzia
Gender: Female
Age: 38
Name of disabled person: Saba
Type of disability: Cerebral Palsy
Gender: Male
Age: 11

Saba lives with mother, brother and grandmother. His father died several years ago. They live on 4th floor and their apartment needs major repairs. Saba has cerebral palsy. They found out about his disability when he was 9 months old. He cannot move independently, but when assisted Saba can walk. Saba's mother helps him to dress, he can do this himself, but it takes much more time so mother helps him. She also helps him with toilet and bathing. He can eat without help.

Saba goes to a Telavi day center. He is good at mathematics and can play chess. He plays all kinds of games: domino, darts, and cards well. He can use a computer. He can draw well and was told that he has an unusual artistic vision. He tries to do something at home and help his mother and grandmother. He has leadership qualities and is a very optimistic person. He is convinced that he will manage to do everything. He wants to learn how to drive a car.

Saba does not go out into the yard or around the neighborhood. He cannot stand when he is stared at. But he likes to go to the day center where he has friends. He is transported to the day center by car, his mother or grandmother accompany him. He sometimes goes out of

town, to the village where his uncle lives, but he does not stay there for a long time. He prefers his home. He can be left alone at home. He comes into contact with others well, but he does not like to compromise. So his brother and he often have small quarrels.

What can be done?

Society should be reminded that nobody is ensured from becoming disabled. Contacts and interaction with disabled people should be strengthened. People with disabilities should feel themselves as regular members of the society. Meetings of healthy and disabled children should be organized. The main thing is to interact. Disabled persons should be able to work, e.g. Saba can work on a computer and he would be happy to contribute to the economy of the household.

A.16 INTERVIEW 16: CARETAKER, EASTERN GEORGIA

Date: 06.07.2006

Address: Telavi

Interview type: Caretaker

Name of respondent: Tamara

Gender: Female

Age: 58

Name of disabled person: Ivane

Type of disability: Meningitis

Gender: Male

Age: 11

Ivane lies motionless in bed. He is about 11. His caretaker is his grandmother who does not know exactly how old Ivane is. They live in a dilapidated house in a village near Telavi. They are extremely poor. They have nothing to eat and survive thanks to the kindness of their neighbors.

Ivane's mother died several years ago, leaving three small children. Ivane was a healthy child until age of three when he got ill, most likely he had meningitis. When parents took him to doctors, it was too late and they could not do anything. Since then he cannot stand or talk. The family lives in Rustavi, their apartment is also in a terrible state, the water leaks from the roof. Father of the child remarried and has another son. All responsibility for these three children is on the grandparents. Grandmother is in bad health. She has tuberculosis. She wanted to take the disabled child to the institution, but her son did not allow her. She has no resources to look after the child. He lies in bed, speechless and looks at the walls and people who occasionally come in with extremely sad eyes. With thin motionless legs he looks like a 6 year old.

A.17 INTERVIEW 17: PERSON WITH DISABILITIES, EASTERN GEORGIA

Date: 7.07.2006

Address: Telavi

Interview type: Disabled person

Type of disability: Scoliosis

Name of respondent: Pikria

Gender: Female

Age: 28

Pikria has been hunchbacked since she the age of 8. She graduated from a local university, history department. She lives in a private house with her brother who is a lecturer at Telavi University and her mother.

Pikria used to work at the information center of eparchy (church). She was writing for a religious journal. But the journal has been closed temporarily. Now she is collecting history of religious persons of Tusheti. Pikria is an intelligent person, who takes life as it is. Severe deformation of her spinal cord hindered her in many ways, both physically and emotionally. Due to her problems she cannot sit, stand or walk for a long time. She gets tired very quickly and experiences pain. One of her lungs does not function and many internal organs are displaced. She has an oxygen deficiency. She is religious, her great grandfather was a pope.

Employment

Pikria is convinced that she is unemployed due to her physical disability. She says that appearance is very important. *“Physical disability is visible, inner disability is not visible, person with inner disability goes in the society but society perceives him/her as normal. First the eyes see and then mind”*

Social integration

Deformation has adverse effect on her personal life. She loved a man, but he told her that he could not take the responsibility. She feels warmth and positive attitude from others. She has an inferiority complex and it is difficult to get rid of it.

What can be done?

The society should look at disabled people as regular members of the society. *“It should understand that if someone is not like you, this does not mean than she is less of a person”* Disability should be openly discussed in mass media and television. Disabled persons need psychological training. Church should speak about disability, should support disabled people and should give deeper explanation as why it permits disability. Faith in God should increase. Psychology and faith are very close to each other. The person who does not have faith gets depressed easily. There should be visible signs of the state’s concern for disabled persons. The arrangement of sidewalks for wheelchairs could be such sign. Fitness club should be free for disabled people.

A.18 INTERVIEW 18: CARETAKER, TBILISI

Date: 20.06.2006

Address: Tbilisi

Interview type: Caretaker

Name of respondent: Manana

Gender: Female

Age: 58

Name of disabled person: Mzia

Type of disability: Cerebral palsy

Gender: Female

Age: 25

The family is poor. The apartment needs repairs. Manana works at kindergarten as a methodology specialist. Her husband is 65 years old and he works for a gas company. Her son is 28. He has a university diploma but does not work. Manana's other daughter is a student.

Mzia is disabled since birth. She is confined to bed, cannot talk or move. Her condition recently deteriorated, earlier she was able to talk a little. She cannot do anything herself. She cannot be left alone at home. When Manana is at work, her son and daughter look after Mzia. They do not have any assistance besides 33 GEL state pension. The most difficult is to see your child in such condition and not being able to help her in any way, especially when Mzia has epileptic seizures.

The entire family is very stressed out. Manana's husband urges her to leave the girl at the institution, but Manana and her children are against it. Of course having a disabled person at home reflects on the life-style of all the family members. Children cannot bring their friends home. Manana cannot go anywhere, except her work. Mzia does not need medical care any more. She only takes sleeping pills. Other people express regret and pity seeing her. She never had any friends.

What can be done?

The society and the state should support disabled people. Disabled people should be able to be useful/productive in some ways. The living conditions should be adapted to enable disabled people to live independently. Disabled persons should study in special schools, as in the environment where they are being pitied is irritating and insulting. Rehabilitation procedures/services should be available. Special adapted transportation should be available enabling disabled people to move around the town. Special clubs for disabled persons should exist.

The disabled people should be able to engage in sports. If she had money she would open a free rehabilitation center.

Fears and hopes

Most of all she fears of her daughter's death. Manana does not have any hopes.

A.19 INTERVIEW 19: PERSON WITH DISABILITIES, TBILISI

Date: 04.06.2006

Address: Tbilisi

Interview type: Disabled person

Type of disability: Mobility Restriction

Name of respondent: Goga

Gender: Male

Age: 40

Goga is an active man. He used to be a rock climber and became disabled in 1983, when he fell off a rock cliff. Since then he managed to recover thanks to a surgery and constant exercising. However he got two new injuries, and now he is not so convinced that he will be able to restore his health. He has a wife, who is disabled as well. She had an operation recently and they both hope that she will be able to walk. Now both of them are in wheelchairs. They have an 8 year-old daughter. They live in a 2-room apartment, on the first floor with a ramp therefore, they can move in and out independently.

Goga also has a car that is adapted to his condition, so he moves around the town and is quite independent. Goga is a fighter, and is proud of this quality in him. He says that thanks to his persistence the previous government provided them with an apartment. He went to the Mayor's office every day.

Goga can lead independent life. He manages to get in and out of his wheelchair, and move from it into the car and back without assistance. He does shopping and runs all other errands for the family. At their apartment everything is arranged in a way to enable them to be independent. The family usually does not need external help, except on days when both do not feel good. Sometimes Goga has severe pain and cannot get out of bed. Then they ask their neighbors or their sisters for help. They hired a woman who takes their child to school. Their daughter gets upset when parents accompany her school in wheelchairs.

Outside environment is not adaptable to disabled people, which is a problem. Some people cannot handle a wheelchair and several times he was thrown out of the chair.

Education

He got disabled when he was finishing high school. He entered a medical university as a disabled student. His classmates had to carry wheelchair up the stairs at the University, as there was no ramp.

Employment

He has a university diploma, but he never worked. After graduation he was busy with rehabilitation and did not look for employment. He also studied law, although did not finish and does not have a law degree. Later he studied jewelry as he thought that he would be able to earn money by making jewelry.

Social integration

Goga says that life of a disabled person is very difficult. He feels restrictions in everything. *"You have to look at others for help, you depend on them. This is the most difficult part of it. You cannot enter the shop without help"*.

People usually have positive attitude, but he also experienced situations when they do not want to take into account his condition and he had to stand in a line. He has many friends, but he does not like to bother them. He meets them once in two weeks. Many of his friends are disabled. They got to know each other at rehabilitation centers/local resorts. The League for Disabled used to have a volleyball team some years ago. Disabled people were transported to the sports hall. It was very good, but then due to the lack of funding, they stopped doing his.

Assistance

Each parent receives a state pension for disability – 33 GEL. In addition they receive state family assistance – 35 GEL. This is their entire income. One surgery was paid by the Ministry of Health. They have tariff discounts for gas, electricity, water and garbage disposal. The director of school, which their daughter attends, exempted them from tuition fees. "The League of Invalids" helped them occasionally.

"They will throw to us something small from the big bite they had...Nobody cares for disabled. Everyone does everything for their own interests".

Goga took initiative to ask for assistance from different businesses. *"100-200 GEL is nothing for such organizations. Let them learn how to help others. I am not a beggar. Anyone can find*

himself in my situation. Many helped me but many were rude. But I did not pay attention to this."

Now Goga is trying to persuade a local construction company "Center Point" to repair his garage and convert it into a gym for disabled people. There are 3 or 4 disabled persons like him living in the neighborhood who can use the gym.

Health care

His wife had a surgery for free (state program/medical insurance voucher). If they had to pay, it would cost them 2,500 GEL (\$ 1,380). However, not every person could accomplish this as it took Goga a lot of energy and time to obtain the voucher from the state.

He requires a lot of medication because he is immobile and the normal functioning of his body requires medication. He also takes many painkillers. He cannot use the voucher for medication. To get required medication he has to go to the other part of town first to get a prescription and then he returns to get the medication. The same problem is with medical services. They are free only in certain policlinics. For example, to get a cardiogram he has to get to the second floor of a building with no ramp or elevators for wheelchairs. What he needs is massage and water procedures, but this is unavailable.

What to be done?

More attention should be paid to medical treatment. Akhtala (local Georgian resort) mud is very effective. It should be used more widely. The problem of the employment of disabled people should be solved. The environment should be adapted to disabled persons. Ramps for wheelchair access, elevators and special transport should exist. Disabled persons should be able to engage in sports, be able to go to the theatre, cinema. If he had money he would open his business. This would be very beneficial for him and others like him as well.

Fears and hopes

"I am not afraid of death any more. Will our government pay attention at us ever?"

"I look in the future with hope. I expect novelty every day".

A.20 INTERVIEW 20: PERSON WITH DISABILITIES, TBILISI

Date: 10.07.2006

Address: Tbilisi

Interview type: Disabled person

Type of disability: Atrophy of the right side of the body

Name of respondent: Koba

Gender: Male

Age: 43

Koba is an Abkhazia war veteran. He got wounded in 1993. He has bullets in his lungs and in his spinal cord. He lives with his mother, wife and three sons of 9, 10 and 16 years of age. Koba's mother is also disabled due to illness. The family is extremely poor and their house is dilapidated.

Koba has atrophy of the right side of his body. He often has headaches, cannot lift heavy things and cannot work at night. He can serve himself and is quite independent. He gets excited and agitated easily. His wife helps him to calm down.

Employment

Koba does not work. His wife is the only one employed in the family. She works at a hospital's laboratory. *"My day begins and ends with nervousness and worry. You can see in what conditions my family has to live. I live at my wife's expense"*.

Koba is mostly busy with looking after his children. He helps them with studies. Since the time he became disabled he had only one job. His war friend was the deputy head of local administration and offered him a job. Koba worked as a night guard. When his friend was dismissed Koba also lost his job. He can work as a driver. He has never studied any profession for which he blames himself.

Social integration

Koba has many friends, among disabled and healthy people. He meets them occasionally. He does not attract any special attention in public because his disability is not obvious.

Assistance

Koba's pension as a war veteran is 124 GEL (\$68). He is also eligible for discounts for gas, electricity and other utility services. The Union of Disabled War Veterans "Demetre Tavdadebuli" (a local NGO) helped him a lot. The Union helped them with food and clothes, it funded recovery procedure, and gave cinema and theatre tickets. Veterans went to the Union every day, and the veterans from other countries were also invited by the Union. Now their financial condition is not good, so their activities have diminished. *"Assistance is occasional: it will come in and out. The main assistance is employment. That the person should be able to assist himself."*

Health care

He does not want to do anything with doctors. They would not be able to help him anyway. In fact he does not take any medication. He cannot use the state voucher (for free medical services) because it is useless for him. He is lucky that has not become an alcoholic. Everyone else in his condition is an alcoholic. *"Soon I will also probably begin to drink. I cannot stand this anymore. I am being provided for by my wife"*.

What is to be done?

"For me the main thing is to be employed. Then I will take care of my problems myself".

He dreams of getting a driver's job with the salary of 400 GEL (\$220). In case he had money, he would invest it in something.

Fears and hopes

"I fear tomorrow, the day after tomorrow, I fear life... future". "I rely only on myself"

A.21 INTERVIEW 21: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 28.06.2006

Address: Kutaisi

Interview type: Disabled person

Type of disability: Mobility restriction

Name of respondent: Maia

Gender: Female

Age: 27

Maia is an optimistic and outgoing person. In 1990, when she was 11, she fell down and injured her spine. She spent two years in bed and had 4 surgeries done in Moscow. She cannot stand on her feet. She has no feeling in her feet, but she can get in and out of a wheelchair.

The family, which consists of her mother, brother and grandmother, lives on the 7th floor. The elevator is not operational. Mother or friends take Maia up and down the stairs. She goes out of apartment building two or more times a day. The family is of medium affluence and their apartment is well kept. Maia gets up at 10 am. She cannot go to the bathroom alone.

After breakfast she prays, reads, does embroidery or paints. She exercises every day. The main obstacle in her situation is that she cannot go unaccompanied anywhere. Maia's mother is working as a cleaning woman at school. She plays a critical role in Maia's wellbeing. She supports and encourages Maia to be active. Maia's father died several years ago, he also seemed to be of great support for her.

Education

After the injury Maia studied at a hospital school in Moscow. Then she studied drawing and modeling in Kutaisi for three years. She draws well.

Attitude of the society

She is the only one who moves in a wheelchair Kutaisi⁷. People stare at her. They do not want to accept her as a regular human being.

Employment

She is going to work a fashion salon as a designer.

Social integration

In the evening she goes out. Maia has many friends: she knows them from church and the institute. She goes to church on Saturdays and Sundays, and on major holidays. She is very religious. Maia thinks that all the strength she has is from God. She feels much better after she goes to church. She attends a special service for the ill and disabled people performed by a Greek monk in Tbilisi. She travels to Tbilisi by bus.

What can to be done?

"Everyone should be religious. Disabled people cannot be helped if they are not spiritually strong. It is difficult for the person to live without God. Due too my condition, I have more time to be with God".

A.22 INTERVIEW 22: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 28.06.2006.

Address: Kutaisi

Interview type: Disabled person

Type of disability: Mobility restriction (myopathy)

Name of respondent: Mari

Gender: Female

⁷ Kutaisi is the second largest city in Western Georgia, a three-hour drive from the capital.

Age: 28

Mari was born healthy, but at the age of 5 she got severe poisoning and had a clinical death for 7 hours according to her mother. Then the pain started. She was diagnosed with myopathy. Mari has pain in her legs and hips when the weather changes. About ten years ago she could still stand, but now she is much worse, she cannot get up or sit down without help. The household is poor. Their apartment is on a ground floor therefore, it is not difficult for Mari to get in and out of the building. She usually sits outside, in front of the apartment. But she refuses to go in town. She is ashamed and does not want to be seen in a wheelchair. She is quite heavy and her mother, who looks after her, has difficulties to move her. Mother already has health problem: hypertension and kidney disease. The household consists of Mari's parents, brother, his wife and two small children. They all live in a four-room apartment. Mari has a room of her own. Her parents worked at a local car factory, but since its closure (back in the 90s) they have been unemployed. Mari cannot serve herself and her mother does everything for her.

Education

She attended a regular school. Her schoolmates helped her. Then she studied at a vocational school, but attending it was already a serious problem for her. She has a medical nurse degree. She chose this profession as the vocational school was close to her house.

Employment

She would like to knit or do embroidery.

Social integration

Mari is a religious person. She reads prayers every morning and once a month goes to church. She mostly watches TV or does embroidery. She does good quality embroidery but has not been able to sell any of her work. She also can knit; she does it for her nieces. She likes to read and listen to the music.

She has some friends, among classmates and neighbors. They visit her sometimes. Occasionally she goes to birthday parties, when her brother can take her there. She also has a male friend who sometimes takes her out. Mari has no money to go out to town by taxi. She has not been out for a year. Last year neighbors took her to disco.

Health care

She needs massage, but cannot afford it. Her condition does not allow her to do anything, she even expressed the wish not to see but be able to move.

What can be done?

Mari dreams of a house where people with disabilities can live together, be useful/productive and sell what have they produced. Caretakers should be given some financial compensation. If she had money she would donate it to the church. Then she would go to Germany to get a surgery there, would buy a car and help other disabled persons. She wants to study computer.

Fears and hopes

She is afraid of falling down. She relies on God and her parents.

A.23 INTERVIEW 23: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 28.06.2006.
Address: Tskaltubo
Interview type: Disabled person
Type of disability: Mobility restriction, serious illnesses
Name of respondent: Tsitsino
Gender: Female
Age: 60

Tsitsino has a handful of health problems and has been confined to bed for the last ten years. She had several surgeries for different illnesses. Her feet are deformed. She is quite affluent, has a good apartment and well kept. She lives with her 28 years old daughter, who is not married and looks after her. She had to quit the institute to be able to look after her mother. She also has another daughter who is married and lives separately with her family. Tsitsino cannot be left alone. She was very much cared for by her mother, who died at the age of 96 six months ago. It was touching to see tears in 60 years old Tsitsino, pointing to the TV set and saying that her beloved mother bought it for her, just before her death. She watches TV and sometimes knits.

Employment

She worked until 1987.

Health care

She needs medical assistance. Doctor and nurse from polyclinics visit her. She also needs a urologist, but cannot afford to pay for her visits.

A.24 INTERVIEW 24: ORGANIZATION (NGO), WESTERN GEORGIA

Date: 28. 06. 2006
Address: Zugdidi
Interview type: Organization
Name of the respondent: Elsa
Name of organization: Association of Disabled Women and Mothers of Disabled Children

The association was founded in 1998. It has 43 members and the number of beneficiaries has reached 700. The Association was founded as a result Oxfam's project. Elsa is disabled. Before she became disabled, she used to teach physics at school. She developed polyarthritis and had to quit her job. She has a very positive and optimistic attitude and is a very active person. Currently the association has two programs on inclusive education and public awareness.

Attitude of the society

"The society looks at disabled people as the objects of humanitarian aid. The policy towards disabled population should be oriented towards achieving maximum independence. Society should not be divided into able and disabled members. "

Education

There is no exact statistics on disability. Many parents do not register their children's disability. Some do not want to officially establish that their child is disabled due to the concerns of child's future, some are ashamed of disability, while others do not see any benefits in such registration.

The association runs a school where they have 18 children with physical and mental disabilities. They have a building and playground. This is actually a day center where physical rehabilitation is combined with education.

The association organized a three-day training event “The way to inclusion”, which was funded by the EU. The training event was aimed at four target groups: (i) young people including disabled persons; (ii) teachers; (iii) media representatives, and (iv) parents of healthy and disabled children. The respondent sees the problem in the attitude of disabled children’s parents. They mostly focus on outside assistance instead of being proactive themselves.

Environment

The association also monitors the accessibility features of public buildings. They built wheelchair ramps for several buildings and streets.

Public Awareness

The association developed and published a concept of Ombudsman for disabled population in Georgian and English. The document reviews international experience in creating an entity in the form of ombudsman for defending rights of disabled people and monitoring policies focused on disability.

The association is actively involved in drafting a document on social-economic development of the region. They outlined measures/actions to be taken for the employment and adaptation of the physical environment to the needs of people with disabilities. The association publishes a newspaper “Natlis Sveti” (1,000 copies) once in two months. They will also have a page in the main newspaper “24 Saati”.

A.25 INTERVIEW 25: PERSON WITH DISABILITIES AND CARETAKER, EASTERN GEORGIA

Date: 07.07.2006.

Address: Telavi

Interview type: Disabled person and caretaker

Type of disability: Mobility restrictions

Name of respondent: Tina

Gender: Female

Age: 44

Out of five members of the family, three are disabled. Household is extremely poor. The family lives in a dilapidated house. The rooms have no furniture. I could see only a wardrobe without doors, a table, several chairs and two beds. Father is the only household member who has occasional jobs. His wife Tina has problems with her hips since birth. She has pain, cannot stand or walk for a long time. One of her three children (a boy) is mentally retarded, has neurosis (gets agitated very quickly) and has scoliosis. Tina’s husband is also disabled. Her two other daughters are healthy.

The boy, who is 12 years old can serve himself. He goes to school. He has problems with reading and remembering, but can write well. He often gets hysterical and hits his sisters. Tina wants to work and she has been offered a job as a cleaning woman at school, but she is afraid to lose her pension if she starts working. The household is in the state poverty assistance program.

A.26 INTERVIEW 26: PERSON WITH DISABILITIES, EASTERN GEORGIA

Date: 7.07.2006.

Address: Telavi

Interview type: Disabled person

Type of disability: Mobility restrictions

Name of respondent: Irina

Gender: Female

Age: 53

Irina uses a stick. She became disabled after childbirth, when her hip was injured. She used to work as a schoolteacher, but had to quit her job. Her husband sells produce at local market. She has two grown up children. She wants to work, but she has not tried to look for a job. She is convinced that as soon as they see that she uses a walking stick, she will be rejected an employment.

Health care

Besides the hip problem, she has kidney problems. She had a surgery and one kidney was removed. She still has pain. She needs regular medical examinations, which were free until 2005, but now she has to pay and cannot afford it. Her leg is also becoming shorter. When the pain started she went to Tbilisi to be treated by a chiropractic specialist at the Askurava's medical center. The course she went through eased her condition, but she had no money to continue.

A.27 INTERVIEW 27: PERSON WITH DISABILITIES, TBILISI

Date: 17.07.2006.

Address: Tbilisi

Interview type: Disabled person

Type of disability: Mobility restrictions

Name of respondent: Aleko

Gender: Male

Age: 58

Aleko was 38 when he became paralyzed due to an infection he got in Iran where he worked as a geologist. He is very strong, realistic and optimistic person and has been fighting for his recovery for a long time. Now he is convinced that his condition will not improve. He has a family, lives with a wife and two grown up children in a good and well-kept apartment. He tries to earn money by putting together crosswords and sending them to various local newspapers. He is very eager to be of use. Aleko is not a member of any organization for disabled people as he does not trust them.

He can get in and out of his wheelchair independently and he serves himself. Only for the last two years after he had a heart problem he cannot take shower independently and for this he uses a person from "The Therapy House" which provides home care services.

The main problem for him is inability to move in and out of the house independently. He lives on the 4-th floor and needs 2 persons to bring him down the stairs. His friends usually hire help when they want to take him out. But he also has problems with transportation when in the streets. The pavement is very uneven and there are no ramps/crossings for wheelchairs. He recalls his shock when he became disabled and went to the Institute of Neurology in a wheelchair for the first time. He could not get into a building elevator, as it was not wide enough for his wheelchair, could not get into any rooms because doors were too narrow.

Social integration

Aleko had a very wide social circle before his illness. In fact in this regard his life has not changed for worse. He still has many friends who regularly visit him. This is because he has not changed psychologically. But he feels aggression from the society at large. He wants to feel himself as an ordinary person and the society to perceive him as such.

Health care

Aleko does not need any health services. He only needs massage. He says that even with the same diagnosis the illness develops differently in different persons and what can one do is very individual. He spent long periods of time for several years in Sak resort at the Crimea (Russia). He said that the main effect was psychological. The only medical thing he appreciated there was the possibility to stand, which he has not experienced for a long time.

“The town is designed for serving people on wheel-chairs, everyone is on a wheel-chair, most of the people know each other as they regularly come or even live there. One can reach any place independently and can see all kinds of people sharing the same misfortune. As in a society at large disabled people there have own criminals, own artists, swindlers. It is a microcosm on wheel-chairs.”

Aleko became much stronger psychologically when he saw many disabled people like himself leading normal life. He learned to serve himself and the skills of independent living in Moscow, at the hospital where he received special training.

What can be done?

The attitude of the society should be changed, and disabled people should be considered regular members of the society. The environment should be adapted to the needs of disabled people. The main thing is to create employment opportunities. There are many spheres in which disabled persons could work: translation, computer service, teaching and crafts.

A.28 INTERVIEW 28: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 7.07.2006

Address: Kutaisi

Interview type: Disabled person

Type of disability: Mobility restriction

Name of respondent: Eka

Gender: Female

Age: 41

Eka underwent surgery after a car accident and she has had a hip transplant for the last 15 years. Before the accident she worked as doctor in a hospital, but had to leave her job because she could not stand on her feet for a long time. She did not register her disability

because she did not want to be labeled as a disabled person. Now she works at a social insurance fund in Kutaisi. She has a 10 year-old daughter, and does everything at home.

Attitude of the Society

Disabled people should not get a feeling from the society that they are different, that they have some deficiency. Society should be taught to treat disabled people as ordinary members.

Health care

She periodically has pain. The hip transplant needs to be changed every 15-20 years, but the operation costs 5,000 GEL (\$2,700), which she does not have. She considers herself poor.

What can be done?

Rehabilitation centers should be created and operated. The disabled persons should organize themselves and fight for their rights.

Fears and hopes

Since the accident she fears open space. She gets nervous very easily. She relies on God. She hopes that with the help of God she will change her behavior and will manage her own problems.

A.29 INTERVIEW 29: PERSON WITH DISABILITIES, TBILISI

Date: 17.05.2006.

Address: Tbilisi

Interview type: Disabled person

Type of disability: Mobility restrictions (paralyzed)

Name of respondent: Koka

Gender: Male

Age: 43

Koka is very active. He lives alone, takes care of himself, moves in a wheelchair and drives a car, which is adapted to his needs.

State policy

Policy makers are not motivated that disabled people lead an independent life. The state wants to see disabled persons as helpless and dependent members. This state of affairs is much cheaper for the state to maintain. The overall policy is the same as the one with regard to poverty: instead of opening enterprises and creating jobs, the state supports opening of free soup kitchens.

The main thing for the government is to think about the problems of disabled people. In 2003 a law on adapting new buildings for disabled persons' access was adopted but nothing has been implemented. None of the buildings have ramps for a wheelchair access. Public places such as philharmonics, opera house and hotels are inaccessible. The only exception in Tbilisi is the Tbilisi Marriott Hotel.

Education

Education opportunities for disabled people are very limited first of all due to the inaccessibility of building structures.

Transportation

Some steps were made to ease transportation problem. Ten buses adapted for disabled persons were brought from US by the League of Disabled. It gave them to the city administration. A bad example: If a disabled person (in a wheelchair) wants to fly he must pay 100 USD to "Airzena" (a local airline) to be put on board of their airplane.

Social integration

Koka participated in the program of independent living on wheelchairs. This was a two-week course where participants with different disabilities were taught how to lead an independent life. The focus was on life in the family, sexual life, mobility and self-realization. This course was determining for his personal life. He learned to be independent and with his life he tries to demonstrate to other disabled people that this is possible.

Disabled people in Georgia used to be active in sports. In 1995 five disabled mountaineers reached the meteorological station of the mount Kazbegi (the highest peak of the Caucasus mountains, over 15,000 feet). In 1998-1999 the League of Disabled had a basketball team, they also played soccer and tennis.

Health care

He and people with his kind of disability need only wheelchairs. The wheelchair for the active person should be adapted to his/her body. Wheelchairs have to be replaced every 4-8 years. The most complicated issue is a child's wheelchair. It needs to be changed/replaced more often, it should be two times heavier than an adult's wheelchair so the child gets accustomed to balance it and not to fall out. The role of doctors in this matter is very negative. They look at disability as a medical problem. In most cases the medical condition cannot be improved, but the doctors would not admit this.

What can be done?

Education of parents and children is essential. There is a fear/stigma of wheelchairs. Household needs with respect to the care for disabled family members should be studied and understood. Families should not be overstressed due to the burden of caring for disabled household members. Specific abilities of persons with different types of disability should be understood and used for their subsequent employment. Disabled people should organize better and fight for their own rights. The institute of the ombudsman for disability matters should be introduced.

A.30 INTERVIEW 30: ORGANIZATION (NGO), TBILISI

Date: May 2006

Address: Tbilisi

Interview type: Organization

Name of the respondent: Gocha

Name of organization: Coalition for Independent Living

Coalition for Independent Living unities disabled persons of different disabilities. It is an umbrella NGO, under which several organizations for disabled people are united. The Coalition has its own website www.disability.ge (in Georgia, Russian and English). The site was created under the state program of disabled persons' integration in 2000.

Gocha has hemophilia and sits in a wheelchair, although he can get in and out of it without help. He drives a car and his disability is not obvious. He views it as a problem because he has to be very careful and cannot engage in any risky activities. As a child he could not fight, play football, other sports and he had to explain reasons for extreme caution.

State policy

In the long run it will be much more advantageous for the state to rehabilitate disabled persons so they look after themselves, rather than keep providing assistance. There are two aspects of disability: mental and physical. A mental aspect has to do with society's attitude towards the disabled persons. A physical aspect has to do with the environment in which disabled persons live. The environment is unfriendly to disabled people.

Employment

The Association is one of the implementing bodies of a "wheelchair diplomacy" project. It comprises of the three components: wheelchair manufacturing, advocacy and trust building. It will operate in Georgia and Abkhazia. There will be workshops established for wheelchair manufacturing: one in Tbilisi and one in Sukhumi. Disabled persons and members of their families will be employed at these shops. Wheelchairs will be sold in the South Caucasus region.

Health care

Association "Imedi" purchased wheelchairs under a state funded program, but these wheelchairs are of low quality and it is not possible to use them without assistance.

Awareness Building

Six members of the association went through training to become trainers for conducting education on the disability problems at schools and universities. They used role-play and games to show pupils and students what disabled people feel and how they perceive life. The coalition also organized a film festival on disability issues in Batumi (Black sea, Western Georgia).

What can be done?

The health statistics should be studied. It is important to know how many disabled children do not attend schools, how many are home schooled.

A.31 INTERVIEW 31: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 26. 06. 2006

Address: Kutaisi

Interview type: Disabled person

Type of disability: Mobility restrictions

Name of respondent: Ramaz

Gender: Male

Age: 50

Ramaz occupies the ground floor of a two-storey house. His family has two rooms. He has a wife, daughter and son. His wife at the time of the interview was in a hospital, recovering from a surgery. His daughter works at a pharmacy store and his son serves in the Army.

Ramaz got injured in 1988 when he fell off a crane at a construction site. He has mobility problems, cannot lift hands to the mouth, and cannot sit. He cannot serve himself, has to be dressed and taken to the bathroom. His wife and son help him with these daily activities. He can be left at home alone only for several hours. It was 7 years ago that he got out of the apartment into a courtyard.

Employment

He repairs umbrellas and irons occasionally to generate some income.

Assistance

The only assistance he gets from the state is a pension. His brothers in law who live in the village help the family with food and firewood. Some years ago they received humanitarian assistance from the Red Cross. The Association of disabled people also provided them with canned food.

Health care

Ramaz does not visit any doctors because he has no money. When he is in pain he takes medication, which is advertised on TV. He then notices that this often adversely affects other organs of his body.

What can be done?

The employment opportunities should be created for the disabled people, this would enable them to generate money and entertain a bit.

A.32 INTERVIEW 32: PERSON WITH DISABILITIES, WESTERN GEORGIA

Date: 26. 06. 2006

Address: Kutaisi

Interview type: Disabled person

Type of disability: Mobility restrictions

Name of respondent: Nata

Gender: Female

Age: 34

Nata is an Internally Displaced person from Abkhazia. She lives with her parents, her sister, sister-in-law and nephews (her brother went to Russia) in one and a half room apartment. Family is very poor and their apartment is in bad condition. When Nata was 12 she began to experience dizziness and walking difficulties, every year her condition deteriorated. She was diagnosed with Friedrich's disease: her muscles began to weaken. Now she also experiences difficulties with speech. She needs assistance in almost everything: dressing, using toilet and eating. Her mother and 16 years old sister are her primary helpers. She used to play piano 10 years ago. She even had pupils, but now she cannot use her hands and the family sold the piano also as they needed money. Nata is very religious. She is Jehovah witness. All day she reads religious literature. The faith made her strong. In good weather she goes out of the house to pray. She feels pity from the society and she does not like this. Nata has graduated from a high school. She thinks that the houses should be adjusted for the disabled persons.

Assistance

Several years ago Nata received assistance from the Red Cross. Friends gave her a wheelchair. She is diabetic and one of the Jehovah witness gave her a device for measuring sugar. She goes to the doctor once in two months.

What can be done?

She wants to have enough money to be able to hire a caretaker to ease the burden on her mother and sister. As she cannot be left alone her sister does not have a life. She received only 9 years schooling, as the family did not have money to buy her textbooks and she quit the school. Disabled people should have possibilities to move, to be able to go to the theatre and cinema. They should have free health care. A bath should be designed for special needs of disabled people. Disabled people should be taught skills that enable them to generate income.

If she had money she would donate it to Jehovah Witness society and would build a wheelchair ramp. She would go to a dentist, buy a mobile phone and pay electricity and gas bills.

A.33 INTERVIEW 33: PERSON WITH DISABILITIES, DUSHETI

Date: 26. 06. 2006

Address: Dusheti

Interview type: Disabled person

Type of disability: Cerebral palsy

Name of respondent: Natia

Gender: Female

Age: 21

Natia has cerebral palsy and is mentally retarded. She lives with her parents, a brother and a sister. The family is very poor. Nobody is employed. The sister of the disabled young woman attends a medical university in Tbilisi. Father leaves house for the whole day looking for a job. Natia cannot stand or walk. The whole day she either sits in a chair or lies in bed. She is listening to the music or reading a book.

Natia has a wheelchair that was given by some foreigners. Natia refuses to sit in the wheelchair. She is convinced that will be able to walk and fears that if she sits in the wheelchair she then would not be able to walk.

Education

Natia went to school. She graduated from the 9th grade. At school she managed to learn to write and read. She had friends there and liked school very much. Her mother walked her to school every day.

Social integration

She has friends among her classmates. But now they seldom visit her. She sends text messages to her classmates using her brother's mobile phone. Natia wants to become a masseuse, although she also has restrictions using her hands. She sometimes becomes apathetic. People's attitude is very positive towards her. At school everyone was very friendly.

Health care

She does not visit doctors. She does not see any sense in doing so. She also does not take any medication. She went to Akhtala and Ureki (local resorts) and both places were very beneficial for her health. She now needs massage therapy.

Fears and hopes

She relies only on God

The mother of the disabled respondent is 46 years old. She says that she feels overwhelmed and depleted physically and emotionally. She cannot lift anything heavy. It is already very difficult for her to carry her daughter. She noticed that Natia has changed recently. She does not want to be in public. She wants more to be among the disabled people.

What can be done?

Financial assistance needs to be increased. Disabled people should be involved in the society and they should not be left alone. Massages, rehabilitation procedures are very important.

Fears and hopes

She fears the future of her daughter after her death and hopes for nothing.

A.34 INTERVIEW 34: PERSON WITH DISABILITIES, DUSHETI

Date: 27. 07. 2006

Address: Dusheti

Interview type: Disabled person

Type of disability: Cerebral palsy and mental retardation

Name of respondent: Marika

Gender: Female

Age: 18

Marika has cerebral palsy and mental retardation. The family is poor. The respondent lives with her father, mother, brother and grandmother. Marika's mother is a teacher. Her father is a vet doctor. Brother studied at the law department. Marika cannot take care of herself. She cannot be left alone. The whole day she either lies in bed, reads or listens to music. She cannot do anything unassisted. Her main caretakers are her mother, grandmother and father. Her father moves/lifts her, grandmother and mother do everything else for her.

Education

Marika could not attend school and teachers came to her home. She completed 11 grades. The school graduation commission came to her home and Marika passed all graduation exams. She has a dream of becoming a journalist.

Social integration

She does not have much contact with her peers. They visit her on her birthdays. People treat her well. Everyone expresses warmth and love to her.

Health care

The family wants to take her abroad for treatment. They believe that surgery can help her. They heard that a surgery that she needed was performed in Armenia. The family borrowed money and gave it money to the person, who promised them to arrange the surgery, but the person disappeared and so did the money. If Marika had money she would spend it on the treatment.

Marika's caretaker, her grandmother is 66 years old. She says that the family most of all needs financial assistance. They would use the money to get Marika massage therapy and take her to local resorts/rehabilitation centers. All family members are very tired and stressed out. *"Most of all I fear hunger. Before my hopes were connected with the president, but now I do not believe in him any more"*.

A.35 INTERVIEW 35: CARETAKER, DUSHETI

Date: 27. 07. 2006

Address: Dusheti

Interview type: Caretaker

Name of respondent: Jujuna

Gender: Female

Age: 42

Name of disabled person: Temuri

Type of disability: Dementia, epilepsy

Gender: Male

Age: 21

Jujuna lives in an apartment building in Zhinvali, a small settlement near Dusheti. The local council gave her that apartment. She lives there with her 21 years old son, who lies in bed the whole day. He does not get in contact with anyone. Temuri can serve himself. He can eat and use the bathroom unassisted. He even takes medication that his mother lives for him on a table. The family is extremely poor. Jujuna's husband left the family several years ago and her younger son is a student in Tbilisi.

Jujuna did sewing some time ago and managed to make some money, but now she cannot concentrate on work. She is so stressed out that she admits that she is also developing some mental problems.

Temuri attended school. He graduated from the 9th grade. Then since 2002 he has become very apathetic and does not want to get in contact with anyone. Every evening he has seizures. Jujuna cannot stand to see this any more because she cannot help him in any way. She even left the house yesterday, not to see her son's seizures.

Assistance

They do not get any assistance, only state pension and a one-time payment of 10 GEL (\$5.5) from a local council. They survive only thanks to the help of their neighbors, who bring them food. Jujuna's brother and sister help them with whatever they can.

Health care

She cannot take Temuri to doctors to Tbilisi. She herself changes the medication that was prescribed to him. He needs 100 GEL (\$55) worth of medication.

Fears and hopes

"I only hope for my death and the death of my son".

A.36 INTERVIEW 36: CARETAKER, DUSHETI

Date: 27. 07. 2006

Address: Dusheti
Interview type: Caretaker
Name of respondent: Manana
Gender: Female
Age: 39
Name of disabled person: Zura
Type of disability: Mental retardation
Gender: Male
Age: 14

The family is poor. Zura lives with his family: a mother, father, sister and brother. The child can dress himself, but cannot use bathroom and cannot eat independently. After school Zura plays with his sister and brother in the yard. He likes to “herd” pigs in the yard. He can move, although with some limitations. He is seldom let out of the yard because his parents fear that if he goes far, he won’t be able to find way back home. His mother Manana is stressed out and overwhelmed; she is very tired, cannot control her nerves and often fights with her husband. These fights between parents make Zura very nervous.

Education

Zura who is now 14 goes to a regular school. His mother takes him there. She waits for him at the school because she is afraid to live him alone. The teachers get irritated at him as he is restless and constantly moves his hands. He also has some problems with speech. He knows alphabet and can calculate. The family does not hope that he will acquire any education, but they want him to be among peers.

Social integration

Zura has no friends. Nobody visits him.

Assistance

Zura receives a disability pension and once got assistance of 40 GEL (\$22) from the local administration.

Health care

They took him to doctors until he was two years old. Then they lost all hope for improvement. The only thing he needs is massage. For four years they went to Ureki (a local resort with magnetic sands) and it had a good effect on the child.

What can be done?

Families with disabled members need more financial assistance. The disabled children should not be isolated, they should go to the circus, zoo, meet other children. The caretakers should be helped. The disabled persons as well as their caretakers need to be apart from each other for some time.

Fears and hopes

What she fears the most is viruses. She was told by a doctor that viral infections can deteriorate Zura’s condition and he may not be able to stand. She hopes for the improvement of her son’s condition.

A.37 INTERVIEW 37: CARETAKER, DUSHETI

Date: 27. 07. 2006
Address: Dusheti
Interview type: Caretaker
Name of respondent: Shalva
Gender: Male
Age: 68
Name of disabled person: lakob
Type of disability: Mental retardation
Gender: Male
Age: 32

lakob has a severe mental retardation. The family is very poor. They live in a dilapidated house. Besides lakob the family has a daughter who is married and lives separately. Both parents receive pensions and they trade at a local market. They have to leave lakob alone for the day and return to feed him. While they are gone, lakob sits in an old family's car, which is parked in the yard for the whole day. He cannot talk, cannot serve himself, he does not feel hunger or thirst, cannot talk. He has a tendency of hurting himself. This is the most difficult part of the looking after him, otherwise parents got used to the situation.

Health care

They used to take lakob to doctors, but now they do not do this. They know that nothing will help their son. They only give him sedatives.

What can be done?

The caretakers must be entitled to a pension. Disabled persons should not be isolated. They should be able to go somewhere and have some amusement/interaction.

Fears and hopes

"I am afraid of poverty, of tomorrow and hope for nothing"

A.38 INTERVIEW 38: CARETAKER, DUSHETI

Date: 27. 07. 2006
Address: Dusheti
Interview type: Caretaker
Name of respondent: Guliko
Gender: Female
Age: 24
Name of disabled person: Levan
Type of disability: Down syndrome
Gender: Male
Age: 20

The family is of medium affluence. They live in a good house, have a nice yard. The disabled person, a 20 year-old Levan is cared for by his mother and his sister, Guliko. Levan is not handicapped physically. He can move, although with some restrictions. He has a problem with eyesight in one eye. He can serve himself. He only cannot take a shower independently. During the day he can be left at home alone. Guliko works at kindergarten as a teacher. She and her mother look after Levan. Guliko says that looking after her brother does not restrict

her in any way, she got used to it, but is just sorry to see him in such condition. Levan goes out of the yard into vicinity and he buys bread at a local shop. Otherwise the whole day he sits in his room watching TV or scribbling. Levan can talk although with some difficulties.

Education

He attended the first four grades in Dusheti school. Then parents took him to a special school in Tbilisi. He attended that school for three years, but was not able to learn any reading or writing.

Social integration

Levan has no friends. Nobody comes to visit him.

Health care

He does not need any treatment, only sedatives.

What can be done?

Disabled persons should have bigger financial assistance. The medication should be free. Disabled persons should be taught some crafts, to be able to sustain themselves economically. If she had money she would buy her brother a musical center because this is his dream.

APPENDIX B: DETAILED SUMMARIES OF FOCUS GROUPS

B.1 FOCUS GROUP 1: PERSONS WITH DISABILITIES, TBILISI

GR.1

Disabled persons

13.06.2006

Tbilisi

Participants

Persons with various disabilities: deaf, blind, with cerebral palsy, mobility restrictions and internal illnesses (heart, diabetes, etc) attended this focus group. Participants discussed problems that disabled persons are facing and the ways to integrate them into society.

State Policy

The living environment is inaccessible/hostile for people with many types of disability. There are no indications of the state's concern about improving living environment for disabled people: there are no parking places for disabled persons, no special entrances and ramps for wheelchair access, specially equipped restrooms, or transportation facilities. The state assistance is very small.

Economic Problems and Assistance

Disabled persons are in much worse economic conditions than healthy members of the society. Their income is meager, as they rely mostly on pension provided by the state (33 GEL or \$18) to and some additional assistance of 22 GEL. They are entitled to lower tariffs for gas and electricity, and vouchers for medication, which are mostly worthless. However the needs of disabled persons are much higher because they need more services and medication.

The state initiated a program of creating the Centers of Independent Living for Disabled People. But the money allotted for this program is not enough and the conditions for tender are very restrictive. In fact, interested NGOs were not able to bid on this program.

Education

Inclusive education is important but should be introduced already in kindergartens because younger children adapt better, and healthy children can form the right attitude towards disabled children early on.

Employment

Disabled people are not accepted in the workplace therefore they are forced to sit unemployed at home. A young woman with cerebral palsy: *"I was invited to work as operator at a bank, but when they learned that I was disabled they refused to take me. They said this would harm the image of the bank"*.

A disabled employee of the Tbilisi Marriott Hotel pointed out that the hotel invited her to work there because the hotel has privileges/benefits when it employs the disabled. If such privileges existed for Georgian businesses there would be no problem with the employment of disabled persons.

A female participant with mobility restrictions: *"I was very active when I found my place in the association of disabled women. I was employed. But now I do not work and now hopelessness takes over"*

Social Integration

The rights of disabled people are violated. Disabled persons do not have a say either in the society or in the family. A deaf male participant: *"We want to be accepted as regular members of the society."* A male participant in a wheelchair: *"I have no reasons for going out. I do not know where to go"*

A person with a visible disability in the street will immediately find himself/herself in a center of unwelcome attention and people look at him/her with pity. A female participant with cerebral palsy: *"My family was overprotective because of my disability and in fact they did me wrong with much attention. The feeling that others should care for me was formed in me"* The most valuable for disabled people is the feeling of being a part of the society. A female participant with mobility restrictions: *"I am ready to forgo free cooking oil and sugar for the feeling of being a worthy member of the society"*.

Health Care

Persons who became disabled due to severe illnesses and/or mental problems need regular medical checkups and medication that is very expensive. The vouchers, which are given to disabled persons by the state, are useless as only certain type of medication is covered. Disabled persons need medication, which is not on the list (i.e. not covered by the free medication program).

A medical commission/examination for establishing an official disability status used to be free, now one has to pay. An oncology (cancer) patient noted that she needs medical examinations at least twice a year, each costing up to 150 GEL (\$83), for which she has no money.

What can be done?

The Labor Code should have an article obliging employers to hire disabled persons or giving some privileges to the organizations, which employ disabled people. A Parliament sub-committee for the problems of disabled people should be formed. The disabled children should be taught orientation in town and life skills. The entertaining programs should be translated for the deaf.

B.2 FOCUS GROUP 2: CARETAKERS, TBILISI

GR. 2

Caretakers

13.06.2006

Tbilisi

Participants

This focus group was attended by caretakers for persons with cerebral palsy, persons with mental problems and the deaf.

Attitude of the Society

All group members stressed out society's attitude towards disabled persons as the most important factor. A feeling of being unwanted and the most ignored members of the society

prevailed. A female caregiver: *"Nobody is interested in the disabled"*. A caregiver in focus group: *"This country does not want disabled people"*

Education

NGOs provide some possibilities for education and entertainment/interaction of disabled children. They mostly interact with healthy children, but due to the disruption of financing many programs stopped operating, which is very traumatic for disabled children.

The Ministry of Education and Science is not actively involved in the education problems of disabled students. Special schools do not have computers and they are the last one the list to be covered by the program of computerization.

Social Integration

NGO "Anika" operates a swimming pool and has several sports groups for disabled children. Disabled persons have problems of going out of town for vacation. All existing programs are only for children under 18. There is nothing for disabled of older age. Transportation is a big problem for persons with mobility restrictions. Taxis cannot be used because wheelchairs cannot fit inside regular cars. For blind having telephones (voice activated) is of utmost importance.

Self-Organizing

There is a "Trust and Light" village established 10 years ago in France where disabled persons live. They should have a similar village here. The disabled population in Georgia also meet with the help of the Catholic Church. Caretakers rely more on each other than some official services. When having problems or questions caretakers ask each other as such information is more reliable.

What can be done?

At least one member of the household with disabled person(s) should be employed. Parents must be more active and should initiate activities. The problem is that in many cases parents are also impaired and even if they are healthy, they have no time and strength to do more. Disabled persons and their caregivers must be involved in the formulation of the state policy towards disability issues. Caretakers need information/education on the problems of the disabled persons. Caretakers also need psychological consultations. Disabled persons should have camps (like summer camps). If the state can have patriotic camps, why cannot it organize camps for disabled persons?

B.3 FOCUS GROUP 3: NGOS DEALING WITH PROBLEMS OF DISABLED PERSONS, TBILISI

GR.3

NGOs dealing with issues of persons with disabilities

16.06.2006

Tbilisi

Participants

This focus group was attended by the representatives of organizations dealing with disabled persons or organizations of disabled people. The discussion mainly focused on relations with the state and the state policy, and effective ways of improving the situation.

State Policy

The head of the society for disabled people pointed out that the existing approach to disability is wrong. Disability is seen as a medical problem, while it is much more of a social problem and is to be dealt with by different ministries: economy, education, finance, health and law. The government does not have a consistent policy towards social issues. The priorities of the state should be formulated and become public knowledge. Certain programs/priorities should receive continuous government funding. The disabled persons should be attracted as experts in formulating the policy on disability.

The critical thing is for the state to have the will to solve the problem. The ultimate goal of the state policies towards disabled people should be achievement of their maximum independence. However, the state does not recognize problems of people with disabilities.

Communication with the Government

Focus group participants pointed to poor communication with the government, lack of a dialogue between the government and disabled people, and lack of cooperation with state entities.

As the head of the organization of disabled people pointed out, two advisory bodies/committees existed at the government before the "Rose Revolution": one was for affairs of disabled persons, and the other one for the veterans. Local NGOs could communicate with the high-ranking government officials through these committees. However these committees ceased to exist.

There is scarcity of information about people with disabilities in Georgia. Only in Adjara (The Autonomous Republic in Western Georgia) there is a database about disabled people.

Education

Education of disabled people is a problem and solving it requires state resources. Education problem is especially acute for the deaf.

Employment

Nothing is done for the employment of disabled people. Employers should be motivated economically (e.g. tax breaks) to employ disabled persons.

Social integration

Participation of disabled persons in decisions on state policy is zero.

A female leader of an NGO of the Disabled People: *"Everyone uses us for getting money and, in fact, we are exploited. Nobody tells us what is happening and why"*

Most of all, disabled people need social development and integration. The day centers, which are being created under a state program, can be viewed as reservations (*this is an allusion to Indian reservations*) that are not conducive to integration into the society. The newly established day centers for disabled people do not have any provisions for the deaf. Deaf people are in bad need of interpreters. Blind people face problems with mobility.

Health care

Veterans of the war in Abkhazia most of all need psychosocial rehabilitation. The most severe problems are associated with disabilities since birth. These are more permanent problems, less prone to improvement.

What can be done?

The entities dealing with disability problems in the government should be restored. Coordination/advisory councils should be formed at the government. Each ministry should have its own policy towards disabled people and a key person or expert on disability. The dialogue with the government should begin. An action plan for the integration of the disabled population should be worked out. Policies towards those who are capable to work and those who are not should be formulated.

The database of disabled persons in the country should be formed and become accessible. Statistics on the needs of disabled people should be developed.

Currently social programs for people with disabilities operate according to the Procurement Law: this is not right because they are being taxed. These programs should operate under grants' provisions.

Rehabilitation centers need to be opened. Integration could not be achieved without medical, social and occupational rehabilitation. Such integrated centers operate in many countries and proved to be very effective. Rehabilitation specialist should be recruited and trained.

It is difficult to deal with disability issues without social and medical insurance. Federal and municipal programs should be created towards this end. Transportation adapted for disabled persons should function. Employment market should be studied. Focus needs to be on prevention of disability through pre and postnatal care.

Information center(s) for people with disabilities need be created to provide information on the state policies and existing services. Information and knowledge on independent living for people with disabilities should be disseminated. Cultural and sports events for disabled people are to be planned.

Work from home possibilities for the disabled persons who are not mobile should be created. Distance learning need to be promoted and supported. Home care should be organized for people with disabilities.

Caretakers should also be entitled for compensation/pension. Persons with hearing impairment now get pensions only after the age of 18. This should be changed.

B.4 FOCUS GROUP 4: SERVICE PROVIDERS, TBILISI

GR.4

Service providers

17.06.2006

Tbilisi

Participants

Service providers representing both the state and private and non-government organizations attended this focus group.

Attitude of the society

Disability should become the concern of the whole society. The society should not look at disabled person with pity. Media must be involved. Now there is very little coverage of issues pertaining to disabled people in the media.

Education

Inclusion is necessary because it has a positive effect both on disabled and healthy children, who become psychologically stronger. But it is also necessary to have more special schools because some children cannot attend regular schools.

A special school for blind children has been functioning in Tbilisi for almost a century. Now it enlists only 53 pupils, while there are several thousand people with sight impairment in the country. Parents do not bring their children from the regions to attend this school. The school had problems during the winter heating season. There was no heating in the classrooms and it was very difficult for children to write on a cold iron board. There is a problem with textbooks. The books cost are very expensive and in addition, their paper quality is very poor, therefore the written text soon disappears. There is high quality polymer-based paper for these purposes but it is very expensive. The school needs 2-3 tons of paper a year and low quality paper costs \$1,000 per ton. There is a voice-activated computer program, but the school has only one computer. The price for a special computer for the blind is 15,000 Euro. There are no kindergartens for the blind children.

Employment

The House of Social Therapy is the only place in Georgia where mentally disabled people can work. The concern is for the future of children who are at special schools and boarding houses. What will they be doing after the graduation? It is even worse for disabled children who are orphans and have to home to return to.

Integration

There are problems with children's integration. Often parents of healthy children protest against disabled children studying together with their children. They say that their children get depressed.

Health care

Disabled people, especially children who need prosthesis are facing problems. Prostheses have to be changed. Children need to have them changed every 6 months and adults once in 2-3 years. There used to be a workshop in Kakhovka, which produced 8,000-9,000 prostheses an year, now they make only 300. They have modern equipment, but lack materials. The subsidy allocated by the state for prosthesis is 170 Gel (\$94)

There are 15,000 diabetics registered at the Association of People with Diabetes. The Association runs summer camps where children with diabetes are taught how to control their illness. This fall the association is opening a rehabilitation center "Rubicon". This is a unique center with sports facilities. Healthy and diabetic children will exercise together. It is financed by state.

Deaf children need to change hearing devices every 3-4 years. A Georgian-German enterprise "Kindsman" makes hearing devices and it costs 500 GEL (\$277) a piece. Children also need speech therapists to learn how to talk.

There is a neurology center that treats children who have mobility problems. The world statistics is that for every 1,000 newborns there are 2-4 children with mobility problems. Mental retardation is present in 2% of the population. These children almost never have only motor problems. Often this is a combination of mental problems or sensory impairment. Therefore there is need for a multidisciplinary approach. There are only three rehabilitation centers in Georgia (Tbilisi , Kutaisi and Batumi) and their capabilities are limited, thus many disabled patients do not get the treatment they need. Tbilisi center can treat 73 children, a treatment course lasts for 20 days. Right now there are 500 children on a waiting list.

What can be done?

The laws should be harmonized with international procedures and laws. There is a great need in educating parents of disabled children on disability issues. Also education of doctors is needed as they often prescribe medication, which is not needed at all. There is a need to create a center for the education of parents and teachers, on how to prepare children for independent living.

B.5 FOCUS GROUP 5: SERVICE PROVIDERS, TBILISI

GR.5

Service providers

17.06.2006

Tbilisi

Participants

This focus group was attended by the deputy heads of special schools, administrators of educational programs and parents.

Attitude of the Society

Parents of disabled children pointed out that they experience discrimination and being stigmatized. The society does not want to see people with mental problems. The state funding of psychiatric in-patients is negligible: it is 6 GEL (\$3.3) per patient, which includes medication, maintenance of buildings and salaries for the medical staff.

Education

Teaching of the sign language at a special school for the deaf starts only in the 5th grade. The school should offer courses on sign language for teachers and parents. Children who come to school cannot talk. The school has deficiency of special textbooks. Children learn Georgian alphabet based on Russian. Children with hearing impairment need help of speech therapists, but doctors do not inform parents about such need. Twelve graduates of this special school are studying dentistry.

The concept of inclusive education was introduced in 2003 with the help UNICEF and the World Vision. Forty children were studying in integrated schools during 2003-2005. Fifty teachers and assistant teachers are working at these integrated schools. There is a special textbook for math and the Georgian language for beginners. Now inclusive education is a prerogative of the state. It is very important to begin inclusive education at a kindergarten level, before children go to school.

The problem with different programs implemented by NGOs is lack of continuity. These programs are very effective, but when a program is shut down (e.g. due the lack of further finding) children who participated in this program become depressed. It is almost better not to initiate anything at all, than to stop activities.

Health Care

The main issue is an early detection of disability. Age is a critical factor for the start/success of intervention in the majority of cases with disability since birth. In 80% of the cases the intervention starts too late. Psychological rehabilitation should go in parallel with medical treatment. There is a parents' school established in 2002 in Tbilisi, where parents learn about how to care for their disabled children of up to 3 years of age.

The situation with mental disabilities is grave in Kvemo Kartli region, namely in Bolnisi and Marneuli. They opened a center for 30 children from 8 to 20 years of age in Bolnisi. Center's employees need a lot of training.

Social Integration

The state budget allocated 1,200,000 GEL (\$660,000) for running day centers for people with disabilities. They allocated 7.70 GEL for each disabled person attending a day center, of which amount 5 GEL goes to food. They estimate that approximately 164,383 persons with disabilities can be received at these day centers. Transportation remains to be a big problem for people with disabilities.

What can be done?

The service of professional nannies should be established. Nannies should be specially prepared/trained. There is a lack of special rehabilitation materials and toys for disabled children.

Special rehabilitation programs for different disability types need to be developed and implemented. Once these programs begin, it is important to ensure their continuity.

Day centers should work as a network and should cover the entire country. They should not be located only in the capital. The idea behind the day center is to give an opportunity to caretakers to use their time for work/other activities thus improving the quality of life of disabled persons as well as the whole household. Additional or alternative approach may be finding jobs for household members.

It is very important to identify strong/productive qualities of disabled people and to teach them corresponding skills, to enable them to lead an independent life. The workshops should be opened where disabled persons are able to work.

B.6 FOCUS GROUP 6: PERSONS WITH DISABILITIES AND CARETAKERS, WESTERN GEORGIA

GR.6

Persons with Disabilities and Caretakers

27.06.2006

Kutaisi, West Georgia

Participants

This focus group was attended by persons with various types of disabilities (cerebral palsy, deafness, paralysis, hypertension, sight impairment) and their caretakers. The discussion mostly focused on extremely poor economic condition of disabled people and the lack of support from the state.

Shared Experiences

Participants mostly shared their stories of misfortune and at the end of the meeting expressed satisfaction that for the first time they were able to speak up and discuss their concerns openly. We were struck by the degree of poverty that these people are experiencing. At the same time they were ashamed of the state/conditions they were in. The talk mostly revolved around basic survival and there was no room left for discussing integration into the society.

Especially touching were a young man and his father. The young man has cerebral palsy but he is quite developed mentally. He has graduated from a vocational school and could repair

TV sets. He had hearing problems and when his father applied for a hearing device two years ago, he got an answer that they barely had enough devices for normal people. The family has been living without electricity for the last 5 years. For the last three years young man's mother has been paralyzed and laying in bed. The young man had an acute psychiatric problem and was hospitalized. Now he is heavily medicated. He talked very little and in a very low voice when asked a question. During the whole meeting, he and his father were holding hands under the table.

Murman became disabled after a stroke. Now he manages to walk and use one hand. He lives with his 15 years old daughter. Their only income is 35 GEL pension and 22 GEL assistance. He receives no other kind of assistance.

Rusiko had 5 children, four of them died. Her daughter has cerebral palsy. Rusiko also has a 9 years old son. They live in a dilapidated house and the rain comes through the roof. Her children do not have enough food to eat.

Mzia came with her mother and a 9 year- old son Giorgi who has cerebral palsy. He cannot stand or walk therefore his mother and grandmother took turns to carry him. They do not have a wheelchair. Giorgi needs a surgery on his legs. The surgery is performed in Tbilisi and Zestaphoni, but they do not have money to pay for it. The child is in pain. The family survives on state pensions. Kutaisi has a day center for children with similar disabilities. Giorgi attended it for a while, but his family has no ways of taking him there. The children are not learning anything there.

Nana who has disability due to nervous system illness came with her husband who has impaired eyesight. They need medication but have no money. Their house is dilapidated and they eat at a soup kitchen.

Natela came with her 35 years old son, who has cerebral palsy. She treated him in Evpatoria (resort in Crimea) for several years, and the treatment was very effective, he began to walk. But now his condition worsened. Natela was concerned about who would look after her son after her death. Therefore she married her son to a girl from a poor family. They have two children, but his wife left him and the children. Now Natela has to look after her son and his children. All they have is the pension for three persons, 33 GEL each.

Neither state, nor local government provides disabled people with any assistance, besides the pension. They also have a feeling that Kutaisi (second largest city in Georgia) is not in the focus of government's interest. All information and events covered by media are about the capital.

What can be done?

- Opening a service center for disabled persons
- Providing additional assistance
- Opening day centers and providing transportation
- To be able to get the medication they need by using vouchers (state issued vouchers for certain types of medication)

B.7 FOCUS GROUP 7: SERVICE PROVIDERS AND ORGANIZATIONS OF DISABLED PEOPLE, WESTERN GEORGIA

GR.7

Service providers and organizations of disabled people

27.06.2006

Kutaisi, Western Georgia

Participants

The group was attended by representatives of the state entities working with disabled people, service providers and the Union of the Disabled People.

Position of the state

Participants pointed out the necessity of increasing a share of programs for disabled persons in the state budget. More involvement is also needed on the part of local governments. The participants remarked on a big difference between the situation in capital and in the regions (it is much worse in the regions).

There is a need to develop a uniform (unified) state program of medical and social rehabilitation for people with disabilities. There is a problem with local financing. According to participants, 8% of the local budget is allocated to social programs. When the region is poor, amount is small while problems are more acute than in more affluent regions.

Employment

The head of the Union of the Disabled People evaluated the situation with disabled people as regressive. He stressed out the necessity of a different approach towards disability: the focus should be on employment. He had a program for which 13,000-14,000 GEL (\$7,500) were needed. He could employ 15-20 disabled people as ice-cream salespersons.

Deaf people in Kutaisi used to have a union and workshops, but now only a building is left. There used to be a machine knitting shop where 6 disabled persons worked.

Another participant also talked about creating workshops for disabled people where they can work on computers, knit, and repair electric devices.

Services

There is a day center for children with cerebral palsy in Kutaisi. It has 35 children from 2 to 18 years of age. They feed these children and entertain but do not have an educational component. School age children go to a nearby school.

There is a branch of Tbilisi workshop where prostheses are being made. It is being financed by the state, but the funding has decreased considerably. There is a rehabilitation center but due to the shortage of funds, it operates only 3 months out of the year for the last two years. There is also a rehabilitation center for children with cerebral palsy in Kutaisi. However their services/abilities are limited.

Social integration

It is important to introduce integration programs/training as early as possible. Kindergartens where disabled and healthy children interact with each other are very effective. Approach to disability should vary according to the age of disabled persons. The needs of young are quite different from the needs of adults or elderly.

What can be done?

It is very important that people with disabilities had the opportunity to retain their pensions while they are employed and receive salaries.

B.8 FOCUS GROUP 8: PERSONS WITH DISABILITIES AND CARETAKERS, EASTERN GEORGIA

GR.8

Persons with Disabilities and Caretakers

4.07.2006

Telavi, East Georgia

Participants

This focus group was attended by persons with sight impairment, mobility restriction, hypertension and a caretaker of a young man with cerebral palsy. Similar to discussions in Kutaisi, West Georgia, the leading theme was economic conditions of the disabled population and the need of assistance from the state.

State policy

The state should give compensation to caretakers. Caretakers should not be stressed by other problems while looking after their disabled household members.

Employment

There are no employment opportunities for persons with disabilities. The Union of Deaf and Blind used to operate in the region. They had their workshops and many disabled persons were employed there. It does not exist anymore.

Health care

Two female participants pointed out that they had a hip surgery and needed operation on the second leg, which they could not afford. One participant said that her sons took a bank credit for her surgery and now they pay back it and almost nothing is left for daily living. They said that it is wrong that medical assistance is not free. Many said that needed regular medical exams and medication but cannot afford to see doctors and buy required medication.

A female participant with a son with cerebral palsy remarked that her son is not capable of leaving house. He wants to move independently and he needs massage therapy, but the family has no means for his rehabilitation.

What can be done?

A rehabilitation center should be opened. An entertainment channel focused on disabled persons should be created. Most of disabled people spend almost all of their time watching TV. There should be broadcasts that would calm disabled persons down and entertain. The Unions of Deaf and Blind Persons should be restored. Disabled people need vouchers that would provide all the medication they need for free. Employment opportunities for the disabled persons should be created. Mentally retarded persons need to be taught basic skills and employment opportunities need to be created for them as well.

B.9 FOCUS GROUP 9: SERVICE PROVIDERS, EASTERN GEORGIA

GR.9

Service providers

4.07.2006

Telavi, East Georgia

Participants

This focus group was attended by directors of two day centers operating in the region, boarding school administration for mentally disabled persons in Bodbe, representatives of the state entities, and community organization of disabled persons. The discussion mainly focused on education problems and problems of children with mental disabilities.

Attitude of the Society

The society has to be prepared for accepting disabled people as members of the society. The idea was expressed about the need to prepare society in a way that people are willing and ready to become foster parents for disabled children.

Education

An NGO in Signagi runs a school for disabled children and children from poor families. The age of pupils should be from 6 to 17, but children do not want to leave the school after graduation. Now they have several young adults who are already 23 years old. These activities were financed by the World Bank under the program of protected territories. The school is not officially licensed. There is a similar school in Telavi. It also does not have a license. School employees are trained to work with disabled children.

The director of a boarding school in Bodbe talked about negligible amount of funding that his school receives. He said that school's survival is only possible thanks to his personal contacts and kindness of citizens who donate foods and doctors who treat children for free. He emphasized that an overall de-institutionalization (i.e. abolishment of state run institutions for orphans), which is the proclaimed policy of the Georgian Ministry of Education and Science is wrong. Many disabled children in his boarding school are from socially degraded/unstable and criminal families. It's criminal to send these children back to such households.

One group member spoke against the integration of disabled children at regular schools. He said that mentally retarded children negatively affect other pupils. Parents should be prepared and taught how to look after disabled children.

Employment

There are two community-based organizations active in the region. These NGOs were created in 2000 and they are implementing a state program for the "integration of young adults into the community". This program is aimed at resolving problems of children who graduated for boarding schools but they have no home and family to return to. It is a community center that houses such children/young adults and also provides shelter for the elderly. 43 persons live and work there. They have land plots and cattle.

What can be done?

- Create a youth center where disabled and healthy young people can meet and interact.
- Organize sports events and festivals.
- Create a rehabilitation center for disabled people in the region.

- Create opportunities for vocational training and employment of people with disabilities.
- Create farms where disabled people could work and earn money to buy their own housing
- Give the graduate pupils of boarding schools a certain amount of money to avoid their criminalization.
- Create social services that help families with disabled children.

APPENDIX C: LIST OF OFFICIALS AND EXPERTS CONSULTED

This table provides a list of state officials and disability/social assistance experts consulted during the course of this study.

No	Name	Organization	Position	Contact information
1	David Okropiridze	Ministry of HLSP	Head of Department of Labor and Social protection	
2	Gigi Tsereteli	Parliament of Georgia	Head of commission of healthcare and social issues	
3	Devi Tabidze	State United Social Insurance Fund of Georgia	Deputy Head	
4	Moris Tsamalashvili,	Ministry of HLSP	Deputy Director, State Agency for Social Assistance and Employment	
5	Tamta Golubiani	Ministry of ES	Head of Department of National and Regional Programs	
6	Archil Morchiladze	Tbilisi Municipality	Head of the City department for healthcare and social assistance	
7	Irakli Kvaratskhelia	Tbilisi Municipality	Head of Licenses Branch, Urban and Planning Department	
8	Tamar Gagoshidze		Expert	899-932713
9	David Gzirishvili	Curatio International	Social and healthcare expert	
10	Keti Makhashvili	Chavchavadze University	Professor	899-270403
11	Nino Peradze		Expert	
12	Manana Sharashidze	Association of mental health	Head of the association	312070 899-531051
13	Iva mindadze	Center for	Head	
14	Nona Kenchoshvili	NGO "God's Children"		

APPENDIX D: LIST OF NGOS WORKING ON DISABILITY ISSUES

This table provides a summary of NGOs working on disability issues in Georgia.

No	Organization	Main Activity	Contact Person	Contact Information
1	Association "Anika"	Social integration of disabled children, inclusive education; parents' involvement	Irina Inasaridze, Chairperson	75a, Kostava str (99532) 445503 (99599)510595 geoanika@hotmail.com
2	Association "House of harmonious development of children"	Preparatory programs for integration of disabled children in kindergartens	Tiko Nizadze, Chairperson	Tbilisi. 24, Zemo Vake (99532) 903515 (99599) 785578 hchd@myoffice.ge
3	Association "Disabled child, family, society"	Individual rehabilitation programs for disabled children, special educational programs with parents participation	Maia Bibileishvili, Chairperson	Tbilisi. Vazha-Pshavela 76b (99532) 304168 (999577)715609 maiabibi50@hotmail.com
4	Association "Centre for legal assistance"	Popularization of disability law, disability legislation initiatives, legal services for disabled people	Shorena Jankhoteli, Chairperson	Tbilisi (99532) 932258 (99599) 105086 shorena@parlament.ge
5	Club of disabled persons in Gori	Integration and education of persons in wheel-chairs	Tina Bregadze, Chairperson	Gori. 18, Tarkhnishvili str. (99593)334596 (8270) 24833 Tina1@rambler.ru
6	Global Initiative for psychiatry- Tbilisi	Support of mental health in South Caucasus and Central Asia	Nino Makhashvili Director	Tbilisi. 49a, Kipshidze str. (99532)-235314Tbilisi@gip[-global.org http://gip-global.org
7	Youth Center for Independent Life	Raising of public awareness on disability. Inclusion of disabled in community life	Irakli Kharadze Chairman Koba Nadiradze Director	Tbilisi. 215, Nutsubidze str (99532)-329166 (99595) 701517
8	Association of the protection of diabetic children	Protection of diabetic children	Koba Amirkhanashvili Chairman	Tbilisi. 27, Kavtaradze str. (99532) 301015 (99577) 420062
9	Association of disabled of Imereti region	Support in integration of disabled	Vladimer Tortladze Chairman	Kutaisi (995231)733770 (995231) 50425
10	Association of Disabled Women and Mothers of Disabled Children	Protection of rights of disabled women and children, Education and health care of disabled children.	Madonna Kharebava Director	Zugdidi. 51, Rustaveli str. 8215-50139; 877-454588 Madonna_k@gol.ge http://adw.iatp.ge
11	Disabled persons' league	Supporting independent living, legislation initiatives against discrimination	Giorgi Dzneladze, Chairman	Tbilisi. 7 Kedia, str (99532) 356609 ligadzneladze@yahoo.com

No	Organization	Main Activity	Contact Person	Contact Information
12	“Demetre Tavdadabuli” Union of Invalid military persons and veterans	Support to disabled veterans	Manana Mebuke	Tbilisi. 7 Kedia, str (99532)227385 (99532)315952 (99577)440022 (99577)420914 dtveterans@yahoo.com
13	Union for people with special needs	Social therapy for people with mental disorders	Makvala Sukhishvili, coordinator	8, Dzmebi Ubilava’s str. (99532) 775485 (99532)776307 heim@heim.ge
14	Union “Parent’s Bridge”	Cultural -creative programs for disabled children and adolescents	Teona Yacheishvili Chairperson	Tbilisi. 7, Kedia str (99532) 399966 (99577) 473440 ktea@rambler.ru
15	Association for mother’s and disabled children	Day center for poor and disabled children	Nunu Gilashvili	Signagi (99595)540718
16	First Step	Assistance to disabled children	Keti Melikadze Director	Tbilisi. 74a, Chavchavadze av. Room 504 (99532)252519 (99532)230140 Keti.melikadze@tfs.ge
17	Georgian international association of disabled women	Protection of rights of disabled women, legislation initiatives, organizing PR companies for changing society mentality	Manana Galuashvili, Chairperson	34, brother Zubalashvilebi (99532) 920911 (99599) 973006 gdwia@access.sanet.ge
18	Georgian Para-Olympic committee	Development of sports activities for disabled persons, active participation in Para-Olympic movement	David Maisuradze, President	Tbilisi. 7, Kedia str (99532) 356609 (99599) 939911 datomaisuredza@disability.ge
19	Georgian association of mental health	Integration of persons with mental problems. Support of the reform of mental health	Manana Sharashidze Chairperson	Tbilisi. 30, Vaja-Pshavela (99532)312070 (99599)531051 mental@ghamh.org.ge www.ghamh.ge
20	UGCG/ADP The union of God-children of the Georgia/Association of disabled people	Social rehabilitation of disabled, their adaptation and defence of their rights	Zaza Sikharulidze, President	Tbilisi. 49a, Chavchavadze av. (99532) 250145 (99532)225417 junona@yahoo.com
21	Georgia union of blind people	Social adaptation and social integration of blind people, creative-intellectual programs	Rezo Maisuradze, President	Tbilisi. 14, Bochorma str (99532)700099 (99599) 179584
22	Georgian union of the deaf people	Involvement of deaf people in social life, employment programs, translation of TV programs into sign language	Badri Batataunashvili Chairperson	12, Debi Ishkhnelebi str. (99532)341621 (99532)718595 (99577) 456615 geodaef@mai.ru

No	Organization	Main Activity	Contact Person	Contact Information
23	Georgian association of hemophilia and donation	Supporting people with hemophilia	Roman Khomasuridze President	(99599) 504099 gahd@wanex.net www.gahd.org.ge
24	Union Temi	Organization of community life of disabled	Nato Mosiashvili	Gremi (99599)927623
25	Association for assisting children with hearing and speaking disorders	Social integration of children with hearing and speaking disorders; inclusive programs, involvement of parents in the programs	Maia Asakashvili, Chairperson	Vazha-Pshavela 73, III kvart, block 14 (99532)997324 (99532)323482 (99532) 626861 (99599) 513397
26	Foundation for Social Assistance- New Life	Protection of rights of disabled children and children from poor families, their education and health care.	Nato Rostomashvili Director Mariam Dognaridze	Telavi. 39, Cholokashvili str (995250)7 61 03. (99599) 567426 (99599)-694401 nrostomashvili@yahoo.com
27	Integrated and inclusive education centre for disabled children	Registration, medical and social rehabilitation of children with mental disabilities	Tamara Maghlakelidze, President	Tbilisi. 7, Kedia str. (99599)532732 Tearoma99@yahoo.com
28	“Balavari” Intellectual developmental foundation for blind disabled people	Intellectual developmental programs for blind persons (establishment of special audio-library)	Kakha Gloveli, Chairperson	25, Qindzmarauli str, ap.3. (99532)712362, (99532)936350, (99599)160273
29	Aktavita	Social rehabilitation and integration of disabled	Zaza Adania	Poti. 21, Tbilisi str. (995293) 28952 (99599)106480 asteroid@gol.ge
30	Disabled persons' Union of Kareli	Disabled people's rights protection programs in Kareli	Meri Gulikashvili	Kareli (995259)32292
31	Union for assisting children with hemophilia	Educational and professional programs for children with hemophilia	Mamuka Giglemiani Chairperson	Tbilisi. Al.Kazbegi av 32/34 (99532)390178 (99599)620362 m_giglemiani@yahoo.com tania_tamliani@yahoo.com