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Final Analytical Report

Educational Problems of Disabled Children

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Background

People with disabilities are the world's largest minority and eighty percent of persons with disabilities live in developing countries. About 10 percent of the world's population, or 650 million people, live with a disability.¹

Disability rates are significantly higher among groups with little *education*.²

Ninety percent of children with disabilities in developing countries do not attend school.

As of January, 2007 the number of registered disabled people in Armenia was 148 656, including around 8500 disabled children under 18 who are registered in special institutions, boarding schools or confined in their homes (*source of the information is Ministry of Labor & Social Affairs (MOLS)*). Many of them have talents and yet they are restricted either by their physical limitations, the environment is not very supportive, or the society at large is not interested in them. The special schools however are currently making a lot of efforts, through partnering with different donor organizations, to bring about change and inclusion.

On July 1, 2007 we started implementation of "Educational Problems of Disabled Children" project, funded by CRRC. The overall goal of this project was to develop strategies for improving education for home bound youth who are disabled in Armenia.

Education, integration and involvement of children and youth with disabilities is a challenge in Armenia especially in the regions: isolated in their homes, they are not heard from or seen, don't allow them to feel as full members of the society.

This research proved that disabled children do not receive sufficient education in the Hrazdan region. It is suspected that in Yerevan districts more is being done to educate disabled than in regions outside the capital. And the research by HDP for OSI proved that Yerevan is not doing enough.

1 <http://www.usaid.am/main/en/101/>: United Nations Development Program (UNDP).

2 www.independentliving.org : Organization for Economic Cooperation and Development (OECD), UNESCO

Goal and Objectives

The overarching goal of this activity was to discover and research the problem of education for home-bound youth who are disabled in Armenia and develop strategies for improving it. The project was piloted in Hrazdan region. The regional results were then compared to Yerevan results from prior research. This project is to begin a process will empower hundreds of children – who, today, are simply off any institutional map – through education, raising awareness, advocacy and skill development.

Objectives of the Research

1. Establish baseline qualitative and quantitative data through comprehensive research and monitoring of home-based education provided through schools (quality, relevance);
2. Develop complete picture of the disabled youth outside of any educational institution (number of disabled youth who are not registered or included anywhere);
3. Assess specific needs, obstacles and opportunities of disabled youth in education (Evaluation and monitoring of results of home education for youth with special needs);
4. Research and study the international experience on disabled education (alternative education);
5. Identify the gaps between the existing policy, laws and practices on disabled education and reality; determine areas needing improvement (legislative, etc.);
6. Develop comprehensive approach and policy in collaboration with the key players on creating a favourable and practical environment for disabled youth education;
7. Raise public awareness about the youth with disabilities;

Research Methodology

The research methodology included combination of qualitative and quantitative methods. A combination of these methods of data collection and analysis was employed for an in-depth understanding of the subject.

Much of the qualitative research was conducted in meetings and seminars with NGOs that have great experience working with people with disabilities. For more profound research of reasons and consequences, as well as for finding out children's abilities, opportunities and hobbies it was necessary to conduct deep and free interviews (qualitative method) with disabled, their parents, teachers and other specialists (doctors, psychologists). It helped us to reveal our problem and to study the individuality of each case.

The quantitative method gave us more information about the problem and includes wider range of population which was important for assessing the spread of the problem. The official lists of disabled children and other information was from Ministries of Education and Science and from polyclinics (Ministries of Health).

The Information we gathered through rigorous study and assessment: home visits with the students with disabilities and their families, interviews and focus group meetings with organizations, families of children, interviews with specialists such as teachers, social workers, psychologists, therapists; etc. Information was gathered also about the social status of the family, their overall needs in education, health status, concerns, etc. Finally, we created the comprehensive list with accurate addresses and contact information.

The two follow up activities were:

- a. Replicate this approach and create a data base with accurate lists for youth with disabilities countrywide, to generate a clear picture of the situation in the country;
- b. Based on strategies and recommendations of this project, design programs to actually tackle some of the educational needs of disabled youth in short and long terms.

Research Activities

Develop complete picture of the disabled youth outside of any educational institution (number of disabled youth who are not registered or included anywhere)

Inconsistency between the Existing Law and the Reality

Inclusive or home education is a complex issue and Legislation is a key component. There are some gaps and discrepancies between the current Armenian Legislature and practices. To briefly summarize, the issue is that provisions in the current Law are not executed. To illustrate, Part 4, Article 22 of the Republic of Armenia law on Education for People Needing Special Conditions for Education (819) states that “sources for financing home education should come from national and local government budget.” This by and large is constrained by scarce resources of local government.

Another illustration: Part 2, Article 5 of the same Law states that “Persons needing special conditions for education are provided with special pedagogical assistance in educational facilities by special teacher (on payroll), or through services in community rehabilitation centers or special pedagogic services.” As mentioned earlier, this is happening very sporadically, based on people’s enthusiasm and kindness, rather than incentives from school or set mechanisms.

Research on International Experience on Home or Alternative Education

Our research on international experience on activities and practices is aimed at inclusion of disabled persons in community and society, promotion of education for disabled. The purpose of this effort is to highlight some of the successful models of alternative education for disabled that will best fit the Armenian reality or adjusted to be feasible and practical tool for promoting education of disabled.

We came across different definitions and understanding of “inclusive education.” For example, the Hamburg Germany model considers inclusive education a human rights issue. The Mental Disability Advocacy Program of the Open Society Institute views education for disabled a “social inclusion”, i.e., to give all people an equal chance in life. There are many approaches that promote inclusion and integration: below are some illustrative examples of different models that have many merits and potential to be duplicated in Armenia.

The following is an outline of the most relevant programs. The philosophies and programs from the various models fit well with the present situation in Armenia. Many countries view education for youth with disabilities as a human rights issue and their legislation therefore, suggests clear provisions on inclusive or compulsory education for this group. For example, in the US, almost all children regardless of the level of disability go to public schools. Special educators, physical and occupational therapists develop programs for those children and work with them. Most of these children are interacting daily with their peers; grow together as part of the community and society. Team approach is practiced in many schools in the US and elsewhere, where a team of specialists (neurologist, psychologist, therapist, speech therapist, special educator, etc.) work together to develop an Individualized Education Plan (IEP) in coordination with the students' parents. Parents are key part of developing an IEP – something that is not practiced in Armenia yet. We will try to access outlines and information that is “parent-friendly” and very useful.

EII(Early Intervention Institute) provides their staff with a one-month educational course and afterward with continued weekly team and professional supervision in physiotherapy, early communication, child psychology, and family support. EII, an NGO, is an institute of postgraduate education in early intervention. The EII model is very solid and structured and yet possible to replicate in Armenia with minor adjustments. Polyclinics in Armenia are the first health facilities where youth (healthy and disabled) receive health services. They also have data base of disabled in their areas. However, these polyclinics are not capable of providing high level multidisciplinary services. As confirmed by many parents and family members, very often parents take their disabled children to much higher level health facilities. There are good specialists who are scattered in different facilities. Creation of such educational center or facility will greatly enhance the Polyclinics' capacity to extend the needed help to families and disabled.

Denmark Association model is a good model that can be realized in cooperation with schools (resume vocational trainings), businesses (include disabled and teach them skills) and organizations to provide internships for disabled. This model is likely to take longer time and would need cooperation of other parties. However, it could also be simplified and applied in the Armenian context: teach disabled in their homes (accounting, computer skills, languages, shoe making, leather, etc.) through volunteers and professionals.

Sources of Information

To have a full picture of the home-bound disabled, all progress report period we had meetings with organizations involved with disability issues: HDP NGO, Prkutyun NGO, World Vision, Mission East, Bridge of Hope, Kharberd Orphanage, Children Assistance Fund NGO in Hrazdan, ministries, Rehabilitation center of Armenia and Integration kindergarten, etc. The purpose of those meetings was to gather information and feedback on their perspectives, findings on home-bound disabled, their future plans. It was also to solicit partnerships in order to better address needs of disabled youth. Among organizations and entities were Polyclinics, Ministry of Labor & Social Affairs (MOLS), MOES, Mission East, “Pyunik” State Information Center, Children’s Rights Protection Department of Kotayk State, etc.

Information sharing in Armenia is still a challenge, as witnessed by us throughout the first couple of months of the project. One of the hindrances is the chain of permits needed for a single document or a list of handicap. For example, Polyclinics would not release any information on disabled unless they have permission from relevant ministries. We had to work with at least five entities (Ministry of Health, Special Committee on Disabled, MOES, MOLS, Pyunik Information Center).

During all these months we arranged a lot of meetings with organizations who are engaged in different activities with disabled children. Finally everyone cooperated and gave us the chance to get information for our project. These organizations include:

Human Dignity And Peace Foundation (HDP) (Ruzanna Ter-Ghazaryan) is a charitable NGO, which has completed three projects related to special needs of disabled children and youth. Our cooperation helped us to acquire a lot of information about disabled children in Yerevam (Malatia-Sebastia and Shengavit). HDP also gave some advice from their experience. I was involved in HDP’s research too, and took part in home visits, interviews and analysis.

Children Assistance Fund NGO in Hrazdan (Kamo Araqelyan). This is the only NGO in Hrazdan Region that works with disabled and poor children. They implement projects related to the problems of disabled children. They gave us their list of disabled children and

the information that they already have about them. After the project we will give them all the information we gathered.

Children’s Rights Protection Department of Kotayk State (Regional council/administration). The head of department Gabrielyan Gohar gave us the corrected and completed list of disabled children of Hrazdan’s Special school. It is their function to provide disabled children with home-based education, so we have conditionality for cooperation. We introduced her six disabled children for home-based education. One of them already has home-based education and others will have next year because of state budget (for 2-3 children a year).

Meeting with MoES. We met with Anahit Muradyan: the head of the department of disabled children of MoES. She gave us the list of disability: the children with that disability have rights for home-based education. Those disabilities are: Schizophrenia (F20-F29), Oligophrenia, mental problem (F70-F79), Septicemia of central nervous system (G10-G13), behaviour problems (F50-F59, moving problems (G20-G26), Cerebral Palsy (CP) (G80-G83), spinal bifida (Q05), Epilepsy (G40), etc.

Mission East, (Inna Mnatsakanyan) is an international NGO that works with disabled, poor and orphan children. Now the NGO has a project in Armenia related to inclusive education of disabled children: to create conditions in schools for children with physical disabilities and to train the specialists (psychologists, social worker, etc.) and teachers.

Mission East started implementation of many projects which are aimed at giving previously neglected children a chance to discover the world for themselves by improving education for children with learning difficulties. Mission East has continued to focus on the area of changing the rights, international conventions and national legislations (educational, health care services) of the disabled children.

World Vision (WV), (Artur Martirosyan, Marina Hovhannisyan) is a large international organization. WV has 9 Community Centers. These Centers provide health, social and legal services to children.

On July 23 we participated in WV’s seminar: it included “Discussion of inclusive education law of pre-school year children.

Rehabilitation center of Armenia and Integration kindergarten (Susanna Nersisyan). On August 16 they convened to discuss integration possibilities and inclusive education of disabled children.

Bridge of Hope (Susanna Matinyan, Armine Nersisyan) is another local organization that works with disabled children while providing them with better education, rehabilitation and other services. They too have centers countrywide.

On July 27 we took part in “Bridge of Hope’s” assembly: “Parents to parents” congress of disabled children’s parents.

Prkutyun NGO (Arpine Abrahamyan, Termine) is local a organization that is running a Day Care center for children and youth with mental problems.

Kharberd (Irina, Harutyun Balasanyan) is an Orphanage for children with mental and other disabilities, located in the outskirts of Yerevan (capital city of Armenia).

“Armenian Camp” NGO (Samvel Rostomyan, Armine) is a center, which is engaged in the issues of children and adults. Healthy and disabled children attend painting, swimming, pottery and other groups of the center.

Private Consultant (Ray Reeder) I want to thank Ray Reeder who was my consultant. He was Project Director on the “Development of Home-Based Education strategies for Youth with Disabilities” project conducted by HDP for OSI. His participation was most important during the conception of the research work and during the analysis of the completed surveys.

* * *

Introduction

Today, there is an unknown number of home-bound children with disabilities who are not registered with local schools and continue to be deprived of any semblance of education. We are struck by the number of persons who are unable to write their names in early adulthood, simply because it was deemed unnecessary to bring education to these human beings. These home-bound youth were the target for this project. The first thing was the educational arrangements for home-bound, do a reality check through study of all involved key government and other parties and stakeholders, including district polyclinics, inclusive and regular public schools, Ministry of Education and Science(MOES), Ministry of Labor and Social Affairs, Non-government organizations (NGOs), etc. The purpose of the assessment was to not only evaluate the current level of education for disabled, but also determine their immediate needs. And even more important, we want to determine possible and realistic pedagogic approaches to promote education for home-bound disabled.

We have built on research completed in two districts of Yerevan. Our approach was to compare the current situation for home-bound disabled in a region of the country-Hrazdan. Based on this assessment, and worldwide experiences in addressing home-education needs, we compiled Armenia-specific policy recommendations regarding options for and applicability of home-based education.

The disabled children living in Hrazdan have many and different interests and hobbies but there is no conditions to be occupied with their hobbies (no NGO's projects, no art lessons, etc).

HDP Results for Yerevan areas

HDP already acquired the list of children with disabilities for Shengavit and Malatia areas in 2006-2007 (after collection of information and lists of disabled from “Pyunik” Information Center). This information was considered to be a base for my research. HDP already verified those lists last year. This process was very time consuming given the inaccuracy of lists as confirmed through interviews and home visits).

We corrected and completed all information, ongoing findings and observations and analyzed it. Finally, the original list was updated, translated into English, analyzed and used for this research.

The following two tables (table1 and table 2) summarize some of the main categories of children and indicate the group of children that are outside mainstream education.

Disease codes and their accuracy - different codes represent different disabilities as diagnosed. Status of disability by and large depends on these codes. Disabled are entitled to certain privileges depending on severity of disability (wheel chair, pension, assisting devices, etc.). But only few categories of disabilities were mentioned in the lists of Shengavit and Malatia that qualify disabled to receive home education. In reality, however, there were lots of inconsistencies between the “code” and the actual diagnosis. The codes were 80% verified for Shengavit and 25% for Malatia.

Updating addresses and contact numbers for target group – many of the addresses were not right. However, through rigorous phone calls, personal visits with disabled and post offices lots of corrections were made in the list. Here too, HDP’s 12 volunteers’ (I was volunteer too) help was invaluable. The current list of 1277 disabled was roughly 70% accurate.

Updating and/or verifying the data on age groups and education status – since the list provided by Pyunik is 3-5 years old, we (and HDP did it (90%) last year) started to update it on age and education status.

Table 1: Chart of Children/Youth with disabilities in Malatia-Sebastia and Shengavit

Categories	Malatia-Sebastia	Shengavit	Total for two districts
1. Children ages: 7-16			
Total number of disabled from the districts	623	654	1277
7 - 16 years old	294	316	610
16 - 25	329	338	667
boys	437	351	788
girls	186	303	489
2. During the research we found			
Going to special or Boarding School	19	28	47

Going to public school/ inclusive school	111	176	287
Graduated school	13	18	31
Received limited or incomplete education	32	24	56
Never received education	17	22	39
Are not registered in any educational structure	9	12	21
3. Additional information			
Left Armenia	5	10	15
Deceased	2	10	12
no information	59	25	84
Number of visits & interviews	104	126	230

This table summarizes the quantitative picture of children and youth with disabilities in target areas. HDP and we were able to clarify that in both districts of Yerevan, Malatia-Sebastia and Shengavit, roughly 7-10% of children and youth with disabilities need home/alternative education. This group of children either have no or very limited and irregular education. In addition, about 6% of children were not located and that is a potential add up to the 10%. This means that approximately 10-15% of target group of children and youth do not have adequate education.

During their project HDP found that there were many mistakes in the official lists of disabled children, which were taken from polyclinics (some of the disabled children died four years before and some of them are not considered disabled anymore). This problem is more serious in a region like Hrazdan than in Yerevan, because Yerevan receives more attention.

HDP found evidence that Yerevan school districts are not doing enough for disabled children and we suspect that the situation in regions as Armenia is worse. Therefore at the conclusion of our research, we expect that other strategies or different strategies will be recommended to include disabled children in the country's education system.

Data on disabled in Hrazdan

Updating addresses and contact numbers for target group in Hrazdan– some of the addresses were not right. However, interviewer’s phone calls and our personal visits with disabled gave us a chance to check and correct the list. The nurses of the schools, Children’s Rights Protection Department of Kotayk state, and Children Assistance Fund NGO helped us to correct information too.

We have proposed research questions to develop an implementation plan reflecting key activities.

1. Which part of youth with special needs are not involved in education;
2. What opportunities have the youth with special needs;
3. Who is responsible for the education of the homebound youth with special needs;
4. Who is administrating the process and how;
5. Roles and responsibilities of public schools, teachers and parents;
6. Evaluation and monitoring of results of home education for youth with special needs.

Updating and/or verifying the data on age groups and education status – after finding the list of disabled children we started to update it on age and education status. Through questionnaire we gathered information on education, age group, health and other social issues about the disabled and their families.

The table (table 2) below summarizes the quantitative picture of disabled in Hrazdan. It also shows the magnitude of home-bound disabled needing education:

Table 2: Data on disabled in target region (Hrazdan)

	Description	city	Villages
1	Number of disabled	53	38
2	7 - 11years old	13	13
3	12 - 16	40	25
4	boys	39	26
5	girls	14	12
7	Are not registered in any educational	1	8

	structure		
8	Going to special or Boarding School or attended	11	7
9	Going to public school/ inclusive school	32	14
10	Home-based education	1	1
11	Left Armenia		1
12	No information	8	7
	Total number of disabled		91
	Number of visits & interviews		24

There is only one special school in Hrazdan region. The school is planned for children with mental problems, unfortunately there were many children with physical problem: prejudice, stigma and negative views by non-disabled people did not allow them to go to public school. As far as the special school was in the center of Hrazdan it was very difficult for children from villages to go to school. That why they are not registered in any educational structure more then children from cities.

For example, related to these problems we can note two cases__ the first is Hambarzumyan Nerses and Davtyan Araqs from Gaghsi village: Nerses is deaf and his mother wants him to attend school related to his special need (school for deaf), because in Hrazdan there is no school for the problem like this. And now Nerses doesn't attend to school.

Araqs has moving problem (Cerebral Palsy (CP)). She has no mental problem but doesn't attend to school: village's school is very far from their home. So she needs home education or inclusive education. There is no specialist in school (psychologist and specialist of defectology) to provide home education and there is no condition in Gaghsi's school for inclusive education.

There were a lot of changes during our project period: on October, after evaluating of disabilities of special school's children, majority of them were sent to public schools (children with physical problems and children without any problem): from 47 pupils (many of them aren't registered as disabled) stayed only 16 children in special school and school had to be closed. There is no separate special school in Hrazdan region now but after many

complaints, one part of school # 11 has been repaired to be used as a special school for these 16 children and it's old staff.

To provide inclusive education in Hrazdan it is planned to reconstruct a public school in the region this year. There is no condition for children with disabilities in Hrazdan's schools. So it is difficult to have an inclusive school in a short time.

There is a strong link between disability and poverty: roughly 75% of the beneficiaries come from socially vulnerable families; 30% of which are from very poor families. This factor contributes to the limited involvement of the disabled in different education and art activities or classes. This situation is even worse in semi-urban and rural areas of Hrazdan. One of the main reasons for those who do not attend school or art classes regularly is economic hardships: families do not have the means for transportation, school supplies, etc.

The main types of disabilities among the surveyed population are Cerebral Palsy, muscular disorders, congenital disorders and mental retardation.

Many organizations cooperated with this research (see Appendix3). World Vision's seminar provided some concrete information.

So the disabled children thus face few major challenges and barriers (source of information__ World Vision seminar):

1. Institutional – policies and legislation that does not provide realistic mechanisms for inclusion resulting in systematic exclusion or neglect in social, legal, educational facilities; People are disabled by society as they are deprived of rights and opportunities due to their impairment. The disabled person becomes defined only as a passive recipient of long-term aid, gifts and other help (the focus is to provide disabled people with money or gifts, such as food or clothing), as long-term recipients of welfare and support, and not as a citizen who can be a productive member of society.

2. Environmental - access to buildings for physically and otherwise challenged persons is a hindrance. Even the inclusive schools that host disabled children are not quite adjusted to the physical needs of the disabled, they are poorly equipped and do not meet the special needs of the disabled. Same applies to many other facilities such as libraries, businesses and entertainment sites.

3. Attitudinal - prejudice, stigma and negative views by non-disabled people, in some cases disrespect and negligence towards the needs of the disabled. Unfortunately, the society

perceives disabled persons as sick who are unable to perform many functions that others would do normally.

These three barriers prevent people with disabilities to effectively participate and be full members of society. Removing these barriers requires a lot of joint efforts of all major parties, i.e., the government, civil society and the society at large. The impact would be very beneficial both for the disabled people and their families and the entire society.

Internet research was conducted throughout the project (see Appendix2). Other countries are using interesting ideas that may be adapted for application in Armenia.

To discuss the education problems of disabled children like above mentioned we are going to have meeting with Anahit Muradyan: the head of the department of disabled children of MoES.

Conclusions

Successfully completed a 8-month grant (July 1, 2007 – February 20, 2008) for the “Educational Problems of Disabled Children”, piloted in Hrazdan region and the outcome we compared to two large districts in Yerevan.

Our research confirmed all the suggested research hypothesis:

1. Families of youth with disabilities are not aware of their rights;
2. In Hrazdan region many disabled children do not receive adequate education or any education.
3. Persons with disabilities are often from poor families and that creates additional hindrances to education;
4. Existing stigma and prejudice in the society: parents do not want their children ridiculed in public. The public school community, including teachers and parents are not ready to accept youth with special needs;
5. School environments are unprepared and handicap-inaccessible (relevant building facilities, classrooms, toilets, etc.);
6. Lack of special education teachers, social workers, psychologists, therapists; Absence of teachers’ experience in working with children with special needs at schools or homes;
7. Lack of funds to allow school management to create interest among teachers to provide home education to children with special needs.
8. Resistance in Special schools for releasing their students to go to public schools.

Based on the results of the survey, we can say education is a bigger problem for disabled children in regions than in Yerevan. There are different kinds of special schools in Yerevan for children with mental and physical disabilities, but the educational situation of disabled in regions of Armenia is worse. There are children with physical disabilities that want to go to school corresponding to their disability (schools for deaf, blind, etc.).

In Hrazdan Environmental (access to buildings for physically: shop, school, etc) and Attitudinal (prejudice, stigma and negative views by non-disabled people) barriers are more prominent than in, in some cases disrespect and negligence towards the needs of the disabled. Unfortunately, the society perceives disabled persons as sick who are unable to perform many functions that others would do normally.

It is necessary to point out that the mechanism of home education does not work well in Hrazdan yet: they are having the same school plan (they are having only one or two subjects (and only several times a month), maybe the monitoring (control) of home education is not adequate. A lot of children in spite of their age will have home education only after some years (because of the budget that is planned for home education for disabled children: 2-3 children can be provided with home education each year).

Policy Relevance

The findings of the research project may be used by Armenian officials in designing and implementing social policies responding to education, health and culture. Also there will be generated a database as a result of the research which may be useful for independent researchers.

This research can provide Ministry of Education and Science with information about disabled children and their needs. The Ministry can perform more effective policy and direct its resources to improve the educational problems that we have pointed already: inclusive education, home-based education.

Also the Ministry can train specialists, teachers who will have special skills for working with children with special needs at schools or homes.

Even disabled children with mental problems, who can not learn to read or write, may have other talents, hobbies and/or abilities (singing, dancing, drawing, etc.) that need to be developed, which will help them to be integrated to the society.

For the Ministry of Labor and Social Affairs and the Ministry of Health, this research will help them update the information about disabled children. The previous research showed they do have not exact information. These Ministries can then use their resources to solve necessary questions and perform such policy as free services and benefits which can improve the lives of families with disabled children. It is necessary to correct the inconsistency between the existing laws and the Reality (see Appendix1).

And the most important thing that we can do it is to inform the disabled children's parents about their children's rights about home education: "All citizens of the Republic of Armenia have a right for education".