



Armenian Caritas

Sociological Research

The problems of Disabled Children in Gyumri



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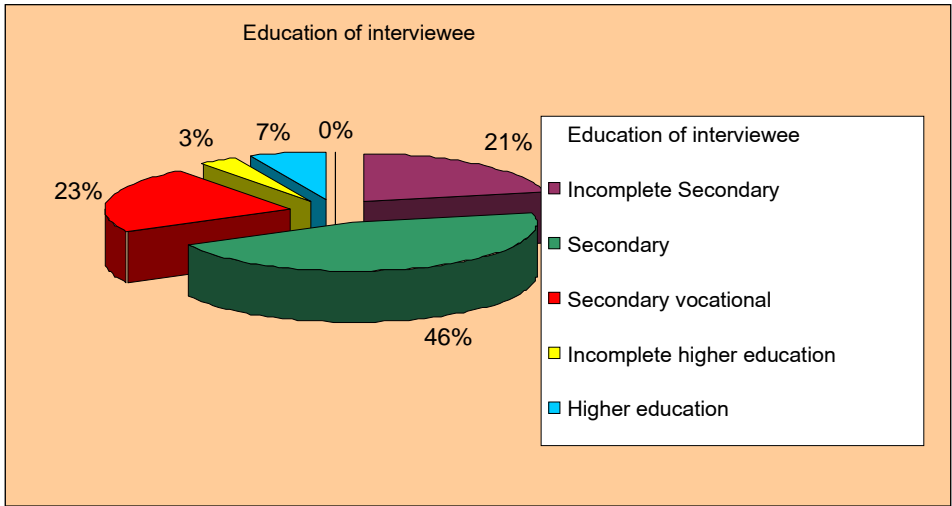
Main Conclusion

In the result of sociological research “The Problems of Disabled Children in Gyumri” important conclusions were officially registered, which concern the state of disabled children, their social-economic, family status, care, health, social environmental and educational problems.

The problem of children disability is considered all over the world as one of the problems which need urgent solution. Families, the surrounding environment of the disabled children is considered to be the major circle in their development, socialization, satisfaction of needs, in achieving perspective goals and their education.

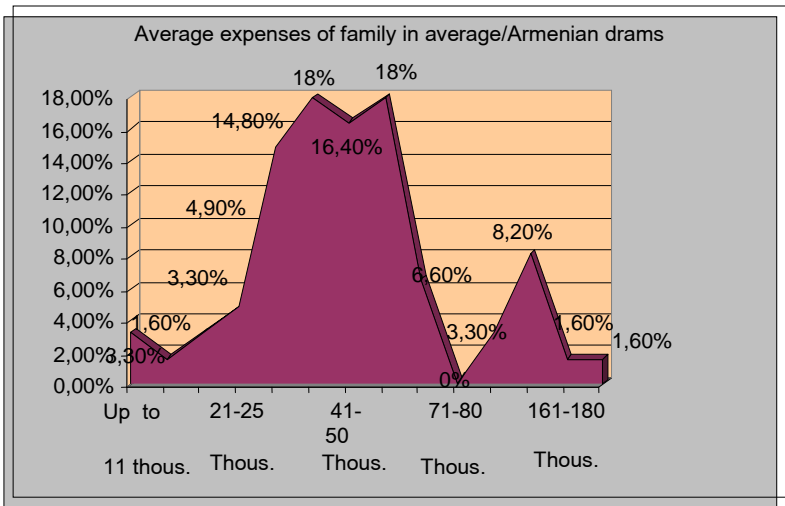
Demographical factors are rather influential in families having disabled children, which inflect on the re-establishment of the families and disabled children, their social involvement and adaptation. It includes divided families, parents’ age and educational characteristics, as well as the rehabilitation potential of disabled children.

The results of the research definitely threw light on the demographical characteristics of the families that have disabled children. There is a significant number of single mother families, 29%, and in the case of 1,6 % families child is orphaned and is in the charge of an old grandmother. It means that 1 of 3-4 disabled children doesn’t have a father. This condition gains additional importance because of the fact that in families having disabled children mothers’ have low educational level. The majority of mothers don’t have higher education. Only one mother had higher education. Only one in five mothers has incomplete secondary education. This aspect decreases their full- time employment perspectives. It in its term directly causes harsh social-economic conditions in the families, which was stated in the result of the sociological research.



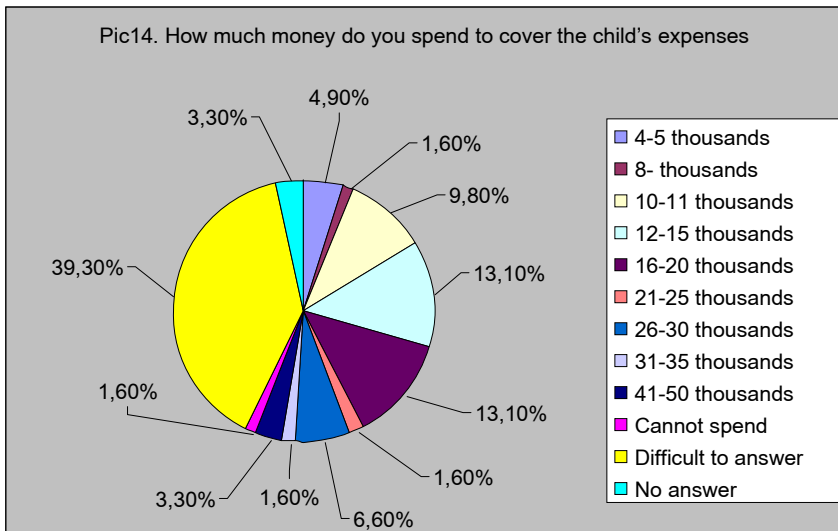
The predominant majority of families having disabled children don't have a family member who works. Only 23% of children's fathers work, and only 19,7% of children's mothers work.

The results of the research proofed that none of the problems of disabled children in Gyumri and Republic of Armenia has been solved yet. The overwhelming majority of the families having disabled children are in extreme poverty, live in bad social-economic conditions. Taking into account the results of sociological research, which says that families having disabled children have in average 4,4 members, and the average monthly income of the families makes 33.295 Armenian drams, we see that each person's average monthly income makes 7.567 Armenian drams. Each person gets 252 Armenian drams daily. The monthly income of one out of two families with a disabled child is not higher than 40.000 Armenian drams.





The case of the child disability gives rise to numerous problems which need urgent solution, such as constant treatment, re-establishment, acquiring special rehabilitation items, changing or repairing them, making use of the specialists' services, gaining hygienic items, using transport and the like for what children's parents and tutors mainly have to pay. The research proves that the expenses allocated to a disabled child make in average 10.777 Armenian drams. It is the 32.4% of average family income. The research revealed that the expenses for covering health care expenses of a disabled child makes 82% of the whole allocated amount, i.e. 8.844 Armenian drams.



The disability issue of the child increases additional problems in acquiring food, clothing, domestic utensils, even bed and hygienic items. On the whole families don't have necessary elementary items for child care: a private room, transport, and telephone. It increases the needs on better material, living conditions and shelter problems. It's a deplorable fact that today the overwhelming majority of disabled children have nutritional problems. Only one out of four children gets relatively good nutrition.

We have the same situation in health-care, educational spheres and in satisfying other important requirements. Currently none of the important requirements of disabled children are satisfied. The results of the research prove that nowadays only one out of five disabled children's vitally important needs are somehow satisfied in Gyumri.

The research found out that poor families who have a disabled child first have to deal with their social-economic condition, and then turn to solving the child's specific problems.

Today the fact is that only people affected by the situation know the real problems; those are families, children, other relatives, close friends and people to work with them. The society knows almost nothing about the problems of such children. The society is not interested in them and avoids problems. As a rule even clergymen don't visit them.



Family is considered to be the most important institution for the child's socialization. Families carry the whole burden in taking care of disabled children; that is why they need the assistance and encouragement of the society and the government. Currently the social patronage and social assistance mechanisms are imperfect.

The results of the research state that families having disabled children don't get assistance from different social institutions, such as the government, society, church, business organizations. In that sense the help of social and charitable organizations are more vivid for disabled children. In particular, the activity of "Aregak" daycare centre for disabled children is mentioned, which is the only life-giving ray for such children. The research stated that poor families survive mostly due to their relatives' assistance: 37.7%.

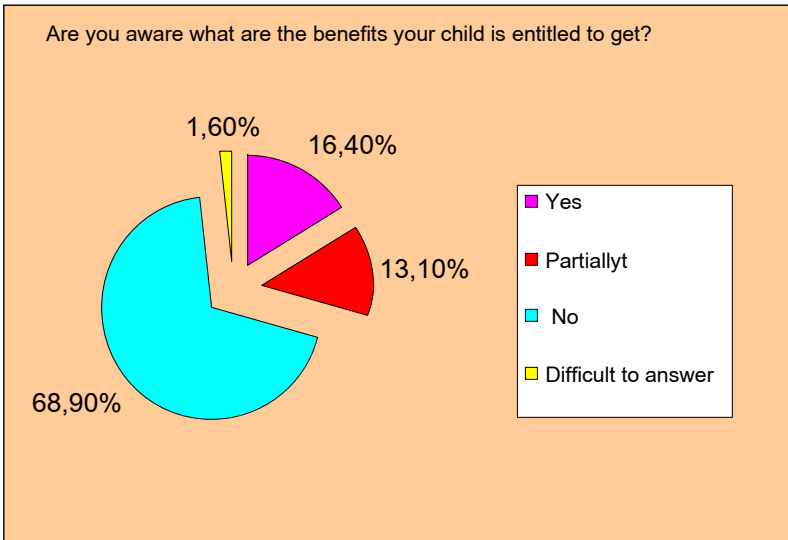
The assistance of the state institutions is very important; the current level of state assistance has been evaluated by parents as unsatisfactory. Families with disabled children first of all expect material, financial assistance, as well as provision of food commodities. They mentioned that it would be very important to have projects that create employment for parents or care takers of disabled children, which would increase the overall income in families.

A large number of children and their families live in severe social and housing conditions. This fact brings forth necessity to develop special social projects to solve the listed problems.

The results of the research suggest that the state must organize and distinctly work out health care, operation and rehabilitation system for disabled children. We found out that nowadays we don't have even an accurate database of disabled children. The interviewers met some disabled children during the research who are not registered in any list until now.

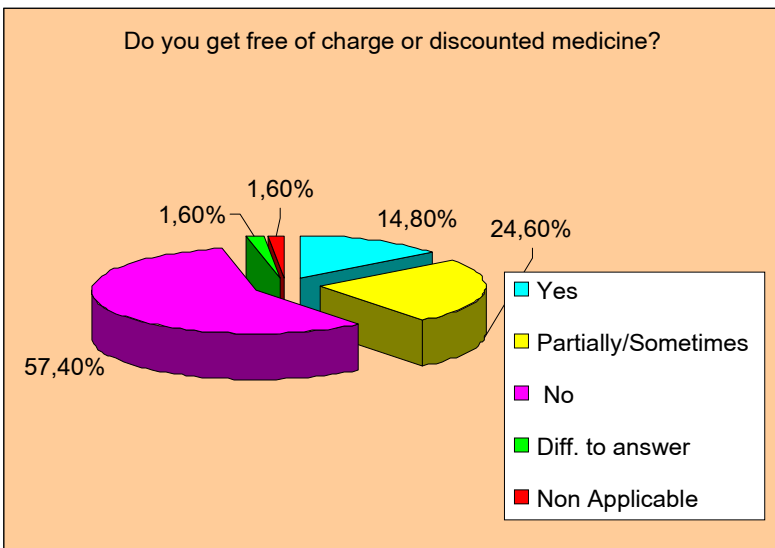
The fact is that medical-social institutions and organizations that work with disabled children and their families do not unite their activities.

The results of the research stated that awareness on their rights and benefits is very low. It stated also, that only 1 out of 3 disabled children's parent has a distinct idea of the authority officially anticipated for the child. Mass-media, charitable organizations and families having the same problem are the main sources of information.



The results of the research showed that the majority of disabled children didn't benefit from any type of assistance and was unaware of them. Compared to other services free of charge health care and medications provision services are to some extent delivered. But more than half of the disabled children are not supported by those services.

According to the results of the research, 1.4 of disabled children is deprived of getting access to the following public services/areas; apartment and public infrastructures, transportation, telephone, TV. They live in their small, isolated world. For the rest of the children such assistance is available partially – only with the help of parents and other members of society.





On the whole the needs of disabled children are carried out by mothers and sometimes by grandmothers. Taking into account the time spent on the care of disabled children, it was obvious that each family spends 9.4 hours to take care of a disabled child. The results of the research prove that the majority of mothers having disabled child/children spend considerable time on the child care during a day. It eliminates the employment chances for the caretaker.

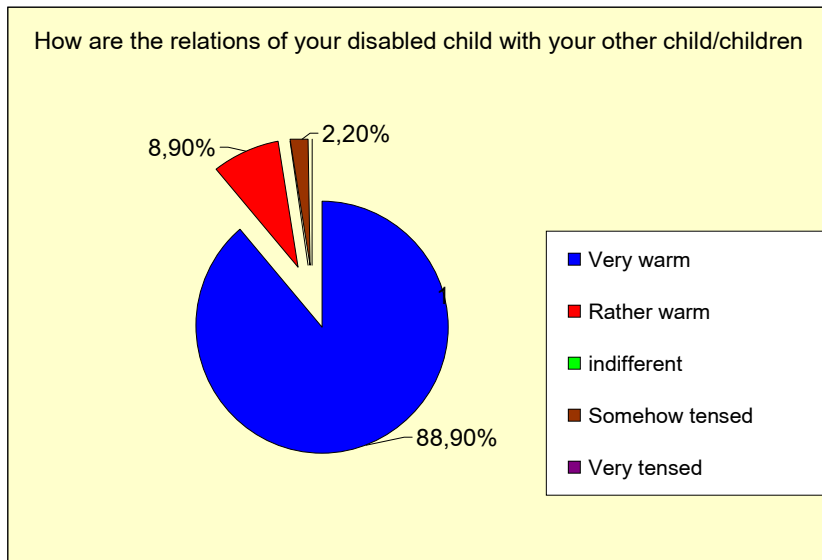
Each 3rd disabled child has full or partial incapability of functioning independently, disorder of social activity and limited capacity.

Daily care of each 2nd disabled child requires use of special knowledge and skills, for which ½ of the interviewed parents have to pay.

A family having a disabled child is a family with a special status. The peculiarities and problems are predetermined not only by the personal peculiarities of the family members and their relationships, but also by their involvement in solving a child's problem. Families with disabled children are mostly isolated from the society. This topic is normally very painful for them and they are seldom open in their opinions. It is important to mention that 1/5 of families having disabled children have observed a positive change in increasing their social network after they had a disabled child. For the majority of families the network has narrowed. In fact the results of the research prove, that the majority of families having disabled children don't notice any change in the attitude of the society, or they don't want to notice, the thing is about either sympathy or some treatment that has negative shades.

Families with disabled children who carry the heavy load of childcare and the troubles caused by the child's illness, appear in an extremely difficult social-psychological crisis. Taking into account the tendency of not discussing family problems "with strangers" the following fact can be stated: each 2nd family having a disabled child experiences negative change in moral-psychological condition of the family. Thus, national-culture distinctive features of Armenian families are observed: to consolidate in difficult situations and to unite their efforts in order to resist difficult situations. There is another extremity which is less expressed: child disability causes serious tensions within families.

The issue of child's inclusion in the problem solution plays a great role in evaluating child's rehabilitation potential. We don't speak about the family; the problem is related to other children of the same age. According to the results of the research each 6 out of 7 disabled child has no friend among children of the same age, he/she lives in the family; in most cases in an isolated room or is in bed.



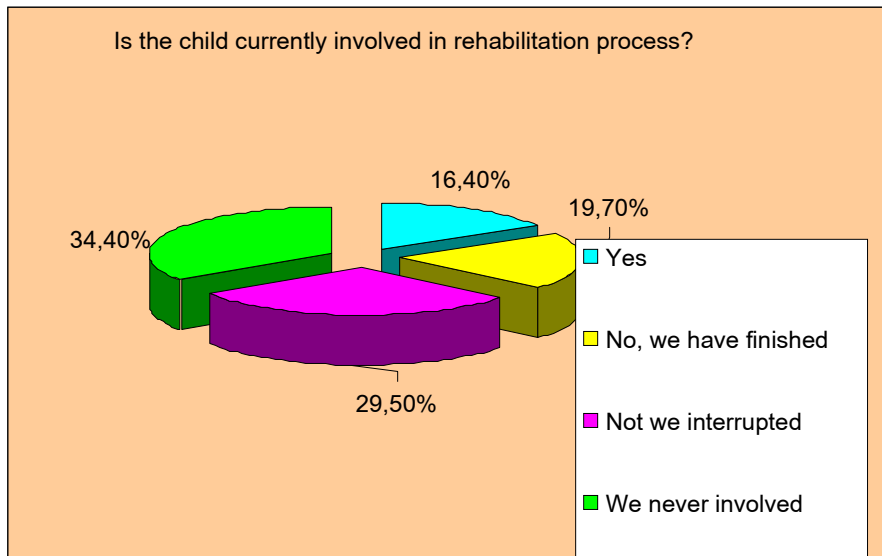
In evaluating the social conditions of families with disabled children the communication possibilities with families having the same problem is of great importance.

One of the important goals of the research is to analyze the disabled child's health care, rehabilitation, adaptation problems and perspectives. Diagnosis is a matter of great importance, as often is not carried out in due time or is done in an incorrect way, which causes inefficient treatment and rehabilitation of disabled children.

Here are the diagnoses the research team came across during the interviews: disorder of psychological development, as well as sensory organs, organ diseases, seizure syndrome, endocrine, inherited disorders. There is a great amount of disorders in motoric apparatus.

Each third disabled child's diagnosis was set during the first year of the child's life. Very often further development of the disease and its treatment perspectives depended on correct and in-time diagnosis.

Children's disability problems first of all deal with rehabilitation process. The research found out, that only each 6th disabled child is in the process of rehabilitation in Gyumri. 1/3 of disabled children have never undergone rehabilitation, and are not involved in it now. Rehabilitation of each 3-4 disabled child is now stopped because parents can't pay for it. The absence of appropriate specialists is a huge problem.

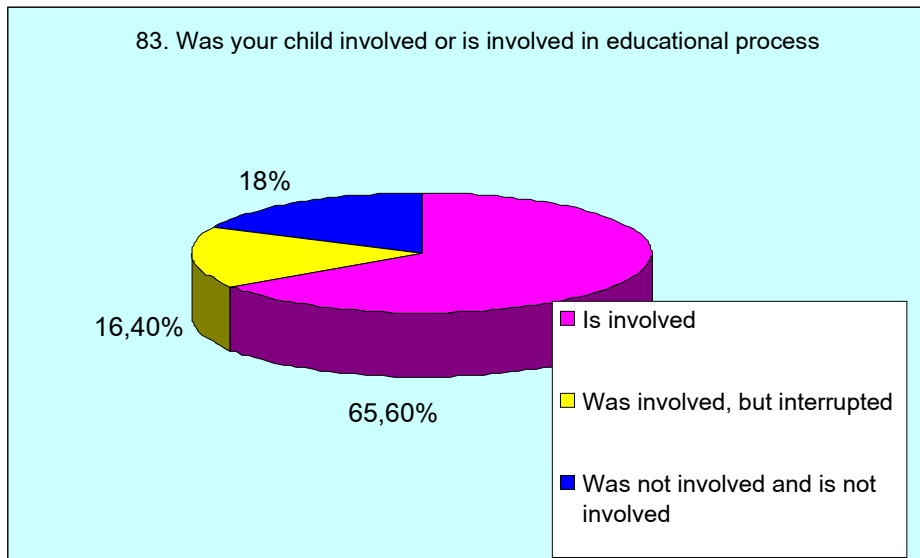


Services of disabled children are mostly not free of charge; for example rehabilitation, medicine, treatment, massage, rehabilitation tools, repairing and changing of tools, getting access to rehabilitation resorts, ensuring transportation for the child, etc. All this requires financial resources, and as a rule, the income of such families mostly depends on pension (child disability since birth pension) and social poverty allowance, and maybe on salary of only one parent.

During this research we found out that most of the time parents of disabled child have to pay for rehabilitation and for appropriate medicine. Each 2nd disabled child's parent always or from time to time has to pay the doctor responsible for the rehabilitation services.

The results of the research state that the most of the parents are satisfied with the special knowledge of the doctor who works with their child, by his/her ability to help them in practice and by the attitude shown towards the child. The work of medical-social examination staff was evaluated considerably low; low evaluation is mainly related to indifferent attitude, lack of specialist knowledge and the level of ethics.

Another main problems of the research was to discover peculiarities and problems of the educational process. Each 5/6th disabled child is not involved in educational process. The overwhelming majority of disabled children who took part or is currently involved in educational process, study or have studied in secondary educational institutions. There was little number of children who are involved in "home education".



4 out of the 5 disabled children’s parents have a definite position about the child’s educational perspective. The research found out that parents have an important role in solving the educational problems of disabled children. But it is effective only in the case when the overall health status of a disabled child allows considering education, otherwise the importance of parents’ involvement decreases. We have a few disabled children having home-education, but according to the results of the research, if the following educational process is organized and carried out appropriately, that it would be the most effective way of education for every 7th disabled child. The overwhelming majority of parents think that in order the disabled child’s socialization and rehabilitation process is effective, special conditions for education of disabled children should also be established in secondary schools.

Thus, the bringing up and educational processes should be organized not by isolating disabled children from others, but with them. If the problem is elucidated and the approach towards disabled children is developed in an appropriate way, the integration will be very effective for disabled children and they will pass the process of social rehabilitation more easily. Moreover, it will have a very positive influence on the moral health of our society and in educating the new generation to be more tolerant. It’s necessary that healthy people and children learn to communicate with children and people who are different from them, also to understand and recognize their problems. Our children need to be taught in this issue. They should learn how to get in touch with people, whose abilities are less than theirs.

As an important conclusion the following statement was elaborated; medical and social rehabilitation of disabled children should be started at early ages, which will include not only health-care, but also psychological, pedagogical, social, lifestyle, legal and other projects, the choice of which should correspond to the needs and characteristics of disabled children.



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Social advocacy and social advertisement projects are very important, which aim at raising awareness about the problems of disabled children and their families, to create new perspectives for social assistance.

In order to improve social- economic conditions of families having disabled children projects that will develop parents', especially mothers' vocational skills, will build their capacity. It's very urgent to ensure employment opportunities that will allow parents work at home, and at the same time have stable income.

Problems of disabled children first of all deal with rehabilitation process and social inclusion. It's very difficult to solve this problem. They need to be assisted by the society. That assistance must be tangible. IT is very important to realize that the assistance should be directly targeted to the disabled child, as he or she needs personalized attitude. Abstract projects that are meant to improve their condition, but are not directly addressed to them, don't bring any change.