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PERSONS WITH DISABILITIES IN ALBANIA
POVERTY ALLEVIATION AND INTEGRATION

Qualitative Assessment



Banka Botërore



→ qendra për ngritjen e zhvillimin dhe integrimin

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1.

INTRODUCTION

The aim of the study

The main aims of the study are:

- To reflect, by means of a qualitative assessment, the main indicators of the link between disability and poverty in Albania;
- To create a space for persons with disabilities and their family members to speak freely and directly about their problems;
- To promote the debate in society among policy makers, decision-makers and local and international institutions on disability problems and on the economic and social situation of the persons with disabilities, with the view to mitigating poverty, promoting their integration into society and eliminating their social exclusion;
- To contribute to the further improvement of communication between state structures and persons with disabilities and their associations;
- To promote the inclusion of disability issues into the national development agenda;

The study was deemed necessary to bring again to the attention of the society and the Albanian institutions the updated problems of the persons with disabilities, in order to help in the acceleration of the relevant measures in support of this community because "a better society for disabled persons is a better society for all"¹.

The study was initiated by the World Bank in the context of its commitment to a regional initiative and was realized during September-December 2005 in close cooperation with the Ministry of Labor, Social Affairs and Equal Opportunities and several associations of Persons with Disabilities.

¹ From the address of Mrs. Lisa Kauppinen, President of World Foundation of the Deaf, at the Copenhagen Summit

Methodology

The study was based on the analysis of the present national and sector strategies of development and the existing legal regulatory framework in support of the persons with disabilities, as well as on the direct assessments of persons with disabilities and the representatives of their associations. The opinions were taken through: (i) round tables with persons with disabilities and representatives of their associations; (ii) interviews with persons with disabilities, selected on the basis of a non-representative sample; (iii) interviews with the families of persons with disabilities; (iv) visits to some pilot projects to the advantage of persons with disabilities; (v) discussions with representatives of the central and local authorities responsible for persons with disabilities, and (vi) representatives of the local authorities on the level of the District Council, municipalities and communes.

Given the fact that there are a number of reasons accounting for disabilities and that every disability has in itself a number of reasons accounting for it, for the purposes of this study, we have used identical groups with the groups laid down in the current Albanian legislation: (i) persons with born disabilities or who are made disable up to the age of 21, or who have mental, physical, and sensor disabilities, who are blind and paraplegics and tetraplegics; (ii) and invalids of work and war².

The interviews were conducted by experts trained on the basis of a Guide for Individual Interviews (See Annex 1) which has served as a basis for designing the specific questionnaires for persons with disabilities, their family members, their associations, etc. The interviewees have also been asked special questions about the level of Albania's fulfillment of international standards on disabilities.

² "Strategy of Social Services," Tirana, 2005.

2.

INTERNATIONAL STANDARDS

Standard Rules

Standard Rules on equal possibilities for persons with disabilities have been approved by the UN General Assembly in December 1993³, based on the experience of a Decade of Persons with Disabilities, organized by the United Nations (1983-1992). Although not compulsory, the standards require a high moral and political commitment by all the countries in order to undertake concrete and fruitful actions for the creation of equal opportunities for persons with disabilities. The most important directions where these actions must be concentrated are the following:

- (i) **Creation of the conditions for equal participation:** this implies the raising of the awareness of the society, the family, the persons with disabilities, the policy makers and the decision makers, and the provision of health care, the creation of the necessary conditions for their rehabilitation and the provision of support services in support of persons with disabilities.
- (ii) **Consideration for the priority fields that assist equal participation:** this implies greater access by persons with disabilities to all the spheres of the society, and in particular, through programs that improve access to the physical environment and to information and communication; the taking of measures in the field of education, culture, employment, sport; the increase of their income, the participation of persons with disabilities in the family life and their personal integration, and the implementation of their right to religious beliefs.
- (iii) **Concrete implementation of priority measures:** this implies the collection and distribution of information on persons with disabilities, the inclusion of issues linked with disabilities in the policies and plans of development; the drafting of economic policies to their advantage; the creation of the legal basis for persons with disabilities; the

³ UN Standard Rules on the equalization of opportunities for persons with disabilities, 1993.

institutional coordination, the situation of organizations for disabled persons, the level of the monitoring and assessment of programs in support of persons with disabilities, and international cooperation in the field of disabilities.

"...Let us make no bones about it, all, grown ups and children look at us and at our disabled children as being different from them. We cannot complain about that. However the total absence of care by the state and the municipality plays a major role in this situation. If they help us, people in general would look at us differently and would not abandon us completely. The state is responsible for its citizens and the more so for those in need, because those who have money can take care of themselves and solve their problems ..." (L. L. - parent).

"...I started to work when I was still a child and have contributed for 30 years not to the communist state, as they tell me when I complain, but to the Albanian society. In the meantime, the state and the society do not give a damn about me. If the state really cannot do something for me, for lack of money, as they say, then let it promote the employment of our children, because they can help us survive..." (O. L. - invalid).

"...The problem is that the officials consider us like parasites who try to benefit as much as they can from the state and not as honorable people who have worked and sacrificed for the society. Each time a commission meets to decide on something related to us, the tendency is always to turn down our request. This is due to the fact that the laws are ambiguous and their interpretation is the prerogative of the state officials..." (B. T. - invalid).

Level of knowledge of standards

Almost all the interviewees point out that there is a very low level of knowledge about the Standard Rules of the United Nations on equal opportunities for persons with disabilities in Albania. In the central administration, these rules are recognized only by some employees in the Ministry of Labor, Social Affairs, and Equal Opportunities who deal directly with persons with disabilities. In the other ministries, these standards are not recognized and in general prevails the concept that the disability is something that is linked with the Ministry of Labor. In the local administration, there is total ignorance about the existence of standards.

Fulfillment of standards

The perceptions of disabled persons about the level of fulfillment of the Standard Rules of the United Nations in Albania are reflected in figure 1.⁴

⁴Scale 1-5, with 5 representing the highest assessment, has been used for the assessment

The level of awareness of the Albanian society about the rights, needs, potential, and contribution of persons with disabilities; the health care and services for them, which aim at enhancing their independence in the daily life, and the efforts made so far to increase the access of disabled persons to physical environment, information, communication, education, employment, culture and sport are perceived as minimal.³ The evaluation about the level of integration of persons with disabilities into the life of the family, the contribution made to increase their personal integrity, and the work done to monitor and assess national programs and services linked with the creation of equal opportunities for persons with disabilities is likewise minimal.

"...The central or local authorities do not show the least interest in us. The central authorities think that they have done their duty with the economic assistance they provide us. The municipality thinks it is showing an interest by just paying us the disability assistance that it is the counter where we get the money. They give us the money as if they are paying us alimony and not as if we deserve it. So much so that on the day when we get our money, the whole family has to be there together with the invalid. This is an "internal rule" for the municipality to make sure we are here and have not gone to Greece or elsewhere as if there are no other ways to find out about that. If you do not go to these counters in person, even if you are on the deathbed, that month you will get nothing. This is funny and sad, because there are paralyzed invalids whom their family members have to carry in their arms to climb the stairs of the municipality. Sometimes, they tell us to come back after some days because they have not yet received the money..." (Sh. Sh. - invalid).

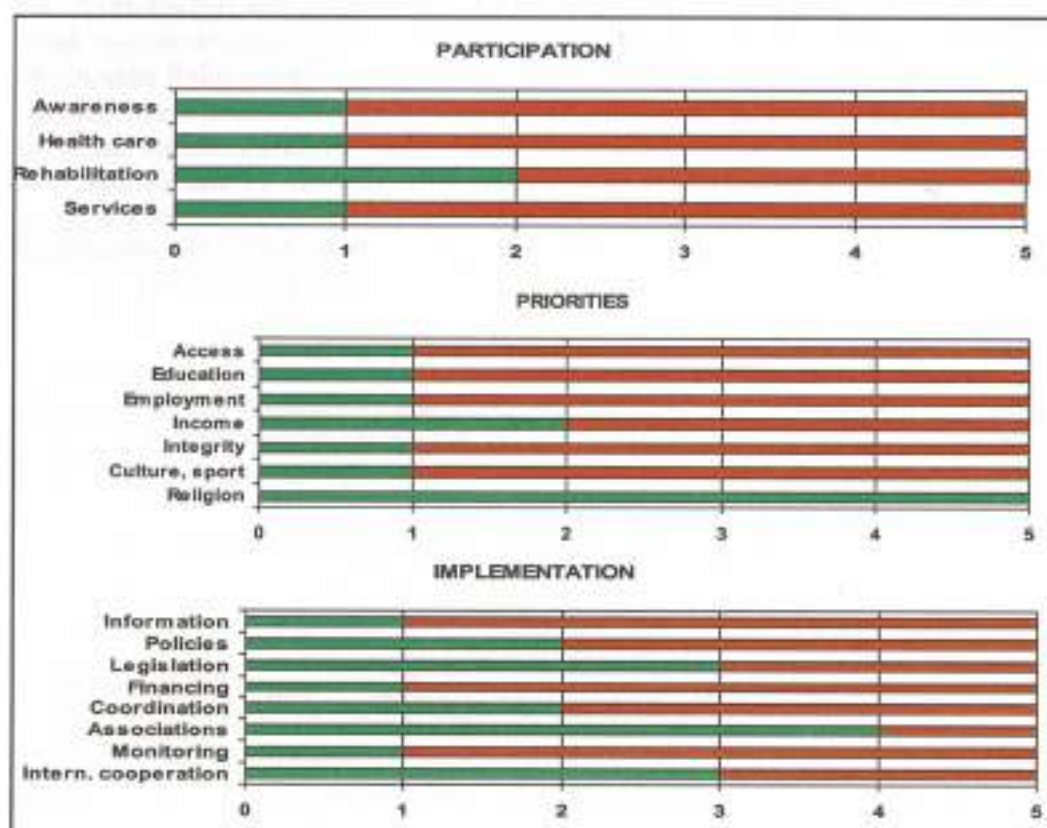
"...You ask me about the contribution of the state and the society. The state has given us some money but not a single state official wishes to see us. Whereas the society is totally indifferent to our plight because it considers it only our own. Do not ask me about standards; ask the state because I think that the public servants have no idea about the existence of standards of treating people like us. I am certain that they think that we in Albania are doing very well in terms of meeting the standards, not that they are lying but they believe that meeting the standards means giving us the pittance we are paid..." (L. K. - Mentally handicapped person, interview with his mother)

"...The prevailing mentality here is to look down and despise people like us. The others look upon us as "cripple, disabled, and invalids." They despise us. Because of the social problems created to us from our diseases, we feel under the pressure of a psychological violence. We feel isolated and this makes our diseases three times graver..." (L. S. - tetraplegic with muscular dystrophy)

"...We are discriminated against by each and everyone. Even by the embassies of the democratic countries. A businessman from our city financed the prosthesis and all the expenses for the trip and stay in Hungary of an invalid. But the embassy did not deem it appropriate to give him a visa..." (B. T. - Work invalid)

³ This coincides with level 1 of the evaluation.

Fig. 1: Perception on the level of fulfilment of international standards in Albania



The contribution made to providing rehabilitation services for disabled persons and to creating better conditions for them to attain a higher level of independence; the efforts made to establish a system of economic support for them with state funds; the inclusion of issues linked with disabilities in the national policies and the development plans, and the coordination of work among state institutions on a central and local level for issues related to disabilities are evaluated as insufficient.⁶

The legal framework, which expresses the responsibility of the state for laying down the legal basis for the necessary measures that can ensure full and equal participation of persons with disabilities into the society, is assessed as satisfactory.⁷ The same evaluation is given about the contribution of international donors to improve the living conditions of persons with disabilities and to enhance their level of integration.

⁶ This coincides with level 2 of the evaluation.

⁷ This coincides with level 3 of the evaluation.

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Recognition by the state of the right of the persons with disabilities to organize in associations on a national and local level and the taking into consideration of their opinions in the process of decision making for questions linked with disabilities is assessed as good.⁸

The maximal evaluation is given only for the favorable conditions created to the persons with disabilities for equally exercising their right of religious beliefs.

General perception

From the assessment and comments made on given components, it results that the general perception of persons with disabilities, their family members, and the associations where they adhere to, is that the level of knowledge and implementation of the rules of the United Nations for the creation of equal opportunities for disabled persons by the Albanian society and state are insufficient.

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⁸ This coincides with level 4 of the evaluation.

3.

CONCEPT OF DISABILITY

In many instances and in various countries, disability is perceived as impairment. This concept implies that the person with disability is a person with physical, mental and sensor impairments that basically restrict one or more activities in his life. One of the most important drawbacks of this concept is that disability is linked only with the person and is considered an individual quality of the person and is not linked with the social and economic environment, part of which this person is. In this case, the efforts of the society focus on the protection and medical treatment of the person with disabilities.

In the last two decades, the concept of disability has evolved from an "Individual shortcoming" into a "social phenomenon". The disability is considered a physical, mental, sensor, temporary or permanent impairment, which restricts the possibilities of the person to carry out the daily activity, which may be caused or aggravated by the economic and social environment in which the person lives. According to this concept, the disability is a social byproduct that is conditioned on the relationship of the person with disability with the social, political, economic and cultural environment in which he lives and evolves.

Three fundamental concepts stem from this definition: (i) it is admitted that disability is part of human diversity and, as such, it should not be an object of derogation, discrimination, disadvantage, and exclusion; (ii) the persons with disabilities are considered impaired and unable to carry out their daily activity due to a complexity of barriers linked partially with the person and partially with the economic, social and political environment; and (iii) the need for comprehensive development is stressed, according to which the formulation and implementation of policies, plans, programs and projects in the field of human development should facilitate and guarantee equal opportunities for civil, political, economic, social and cultural opportunities of each and everyone, irrespective of their social status, gender, physical and mental abilities, and race.

The level of the commitment of the society and the effectiveness of policies, strategies and programs in support of persons with disabilities depend greatly on its concept on disability.

Albanian legislation does not speak explicitly about disability per se, but only about persons with disabilities. As such, it implies "The individual whose abilities have been restricted as a result of physical sensor, intellectual, psychomotor impairment, born or obtained in the course of life or work, through accidents and through temporary or permanent diseases that do not stem from causes linked with employment."⁹ The work invalids are left out because they are covered by another law.¹⁰ This definition does not comprise all the elements of today's concept on disability. A unified and better definition has been included in the National Strategy for Persons with Disabilities.¹¹

Judging from the amount and the typology of support that the state budget gives to persons with disabilities, where a minimal monthly payment prevails; the restricted services provided, the little work done for the integration of these persons into the society; the low level of interest by, and information of, the society about the problems they have; as well as the few statistical data on disability, one may see that disability in Albania is seen as a problem of the individual and is still a long way from being a priority question for Albanian society. This perception dominates in the interviews taken with persons with disabilities, their families and the associations to which they adhere.

"...No one thinks that I have worked for and contributed to the society. Nobody thinks that society too is responsible for my accident, because I was working in very hard conditions in the mine ..." (Rr.I. – Work invalid)

"...The invalid is not appreciated. In fact we are physically persecuted and are the only persecuted in democracy. Because after 1991, there are no more politically persecuted. The latter continue to be favored by the state for the misfortunes they have suffered by the past regime. Their children too have a preferential treatment in terms of being admitted to universities without competition, and this year the government approved supplementary admissions for them. I think that it has done well, because these people have suffered. The society is well advised to be sensitive to this stratum. The politicians too support them. The politically persecuted suffered and made sacrifices, but now at least they are appreciated and respected and their sufferings came to an end once and for all. But not for us. We are doomed to suffer during all our life, indeed our sufferings only keep increasing.....For the invalids there is not the slightest interest shown, neither for their employment or children to be treated preferentially regarding their education. Lack of interest comes first of all from the politicians. Not because they do not feel pity for us or do not know our problems. Probably because they do not benefit much from us. We do not have any weight in the total of votes cast for them." (I.R. – Invalid)

⁹ Law no 9355, dated 10 March 2005 "On social assistance and services."

¹⁰ Law no. 7889, dated 14 December 1994 "On the status of invalids."

¹¹ This strategy was adopted by the Albanian Government in 2005.

The reasons for such a perception are various and numerous, but tradition, the cultural level, the situation and the difficulties of transition and the disinformation may be listed among the most obvious reasons. All these reasons are further accentuated by the political and intellectual mentality for the all-round engagement of the state and the society in the solution of issues linked with disability. The economic cost of the actions that should be undertaken by the state for the social integration of persons with disabilities is perceived apriori as very high (in fact there is no evidence about any calculation of this cost by the Albanian institutions), while the political benefits deriving from it less important. This explains why the sensitivity and the interest of the political parties to include in their programs concrete objectives for this stratum of people, relatively restricted in number, is low or lower than for other needy strata.

To this political disinterest is added also the intellectual disinterest. In general, the question of social integration of the persons with disabilities is put forward on the table of intellectual debates in a very sporadic manner, when there are protests, commemorative days or special features. The intellectual debates in the media on people in need are dominated by the topic on women, the politically persecuted, the trafficking in human beings, the drug users and others, while the topic of persons with disabilities is left almost out of the scope of their interest.

Irrespective of this general assessment, the interviewed persons consider some recent measures taken by the Albanian Government as encouraging, testifying to the return of public attention to the issues of disabilities. This perception is linked with: (i) the drafting by the Ministry of Labor, Social Affairs, and Equal Opportunities of the National Strategy for Persons with Disabilities and its approval by the Council of Ministers; (ii) the decision of the Council of Ministers on the establishment of an Inter-ministerial Committee on Persons with Disabilities, which is chaired by the deputy prime minister and which has in its composition representatives from all the ministries dealing with the disability and the associations of persons with disabilities; and with (iii) some clear political commitments by parliament and the current government to improving the existing legal framework in support of the persons with disabilities.

4.

INSTITUTIONS AND POLICIES

Responsible institutions

Prior to the political transformations of 1991 and the beginning of the transition period, all the issues linked with disability were dealt with by the Ministry of Health. Even the licenses for the creation of association for persons with disabilities were granted by the same Ministry. The concentration of such prerogatives in the Ministry of Health was due to the perception that disability is a question related only to the health of the individuals with disabilities and that the obligation of the state was linked only with their health treatment. With the evolution of this concept, these prerogatives were transferred to the ministry dealing with social affairs.

In Albania at present, the main institution responsible for the issues linked with disability is the Ministry of Labor, Social Affairs and Equal Opportunities. The functions related to the disability are concentrated in the Directorate of Social Services of this Ministry, which also coordinates its actions with all the other institutions under the dependence of the ministry and with other ministries. The State Social Service, responsible for the implementation of policies on disabled persons, and the National Employment Service, whose duty is to follow up their employment, is likewise under the jurisdiction of this ministry.

The Ministry of Health, the Ministry of Education and Science, the Ministry of Culture, Youth and Sports, which are respectively responsible for the issues of health care, education, culture and sports also tackle the question of disability. The other ministries address specific issues that have to do with the sectors covered by these ministries.

Based on the need to improve coordination of the activities of these institutions, it was decided to establish an Inter-ministerial Committee on Persons with Disabilities, the beginning of the operation of which is considered by the government and the associations of disabled persons as a major step forward for the rapid solution of the existing problems.

Statistics

Based on official statistics in Albania, there are 75,044 persons with disabilities, divided according to categories shown in table 1. They account for some 2.5 percent of the population of the country. The largest share in this number is that of persons with born disabilities or with disabilities acquired up to 21 years and the work invalids. A total of 8,788 guardians have been employed with state funds to support such persons.

Table 1: Number of disabled persons

Categories of the disabled persons	Total	Of which	
		In urban areas	In rural areas
Persons with disabilities born as such or become disable up to 21 yrs old	44794	19669	25125
Mental, Physical, Sensors	35547	15166	20381
Blind	8621	4197	4424
Para and tetra plegics	626	306	320
Invalids	30250	26247	3976
Work invalids	29676	25904	3772
War invalids	574	370	204
Total	75044	45943	29101

Source: Ministry of Labour, Social Affairs and Equal Opportunities

The interviewed persons think that the current statistical data have two main shortcomings:

- (i) They do not reflect the real number of persons with disabilities. The official figure with respect to the disabled population of a country is about 2.5 times lower than the average figure published by the United Nations and lower than the figures presented by their associations. This is due to the disinterest of the institutions to accurately identify this number and update it constantly. The topic of disability was not included in the Population Census of 2001, something that might have helped get a clearer idea of the situation. This is also due to the incomplete definitions on disability, which leave out a considerable number of persons who are really disabled. A case in point is the age restriction for the persons of the first group, considering paraplegics

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only those persons who have suffered damages in their spinal cord, and not considering the deaf as handicapped persons.

- (ii) The existing statistical system is limited only to collection of data on the health aspect of the persons with disabilities and the number of those who benefit financial support from the state. This system does not include complete and unified data on their social status, their access to services, their employment, rehabilitation, and others. The relevant institutions did not show any real interest to process, analyze and take into consideration the data gathered by the Living Standards Measurement Survey,¹³ which included several indicators of disability.

"...According to estimates, Albania has some 45,000-50,000 with mental impairments. About 65 percent of them live in the rural areas. The bulk of them, some 70 percent were born as such....". (N. D. President of the Association "To help the mentally handicapped").

"...Although there is no accurate figure, it is believed that in Albania there are about 2000 paraplegics and tetraplegics. But their status, approved by parliament, considers as such only 800, who have their spinal column damaged....". (N. I., paraplegic, president of the Association of para- and tetraplegics).

"...Our association has some 10,000 members but it is believed that in Albania there are some 21,000 blind. This is a matter of statistics and criteria. About 55 percent of them are in the third age generation. About 60 percent of them live in the rural areas...." (S. T., blind, president of the Albanian Association of Blind people).

"...At present, our association has 140 members who pay membership fees. But, although we do not have accurate statistics, in Albania this community numbers some 3000. It is very difficult to determine the accurate number of this community because there is no other institution in Albania that can deal with it" (E. A. president of the Albanian National Organization of Deaf persons).

Strategies

Up to the beginning of 2005, the question of disability has been treated as an integral part of sector strategies drafted by various ministries. Hence, even the fundamental programmatic document of national development, which is the National Strategy for Socio-Economic Development, prepared for the first time in 2001 and updated three times by the Albanian Government, does not foresee explicit measures to support persons with disabilities. A major step was undertaken with the drafting of the Strategy on Persons with

¹³ LSMS-2002

Disabilities, which is currently the fundamental document that orientates an integrated reform in the field of disability. This strategy foresees seven main objectives, aiming at considerably improving the economic and social status of the persons with disabilities in conformity with the standards of the United Nations: (i) the raising of the awareness of the society to encourage and ensure the participation of persons with disabilities; (ii) the implementation of their fundamental rights; (iii) the creation of the optimal conditions for their education; (iv) the enhancement of opportunities for their employment; (v) the promotion of a responsible and transparent public service; (vi) support for a more qualitative life in the community; and (vii) the gathering and use of information on disabled persons. The strategy is accompanied by an action plan for the realization of these objectives.

The timely and successful implementation of the measures envisioned in this strategy is linked with several factors which, if taken into consideration, will help enhance the effectiveness of these measures.

- (i) The existing statistical system on a national level provides only general data, which do not reflect properly the essence of the problems linked with temporary disability. The lack of this information on the one hand, is a symptom of exclusion or marginalization and, on the other, a major limitation to properly address the needs of disabled persons. In fact, the factors accounting for the poverty of this population stratum are not the same for each group of disabled persons and, as a consequence, the measures for the mitigation of poverty cannot be the same either. The persons with disabilities who live in rural areas are subjects to different scenarios of exclusion compared to those living in urban areas. The woman and girls with disabilities cope with a much more complex discrimination compared to men. The lack of information reduces the effectiveness of strategies and the envisioned concrete measures;
- (ii) Today's poverty profile, which serves as the basis for the measures taken to mitigate poverty, envisioned in the National Strategy for Socio Economic Development, must be complemented with the "hidden" part of poverty, linked with the economic and social situation of the disabled persons;
- (iii) Despite the integral strategy on the measures in support of the disabled persons, still there is not any complete estimate of the cost of these measures. Without this, it is hard to foresee the needs for funds by the state budgets and the deadlines for the implementation of the strategy;
- (iv) The priorities of the National Strategy for Persons with Disabilities must also be included in the National Strategy for Socio-Economic Development, which gave rise to the Medium Term Budgetary Program, the basis for the preparation of the annual budget. Without this organic link, the funding of the priority measures to assist the persons with disabilities will remain spontaneous and dictated by the policies of the day.

5.

LEGAL FRAMEWORK

The Constitution of Albania explicitly stipulated that the state should take care of and assist in the rehabilitation, education and integration of the persons with disabilities. Pursuant to it, the Albanian Parliament has endorsed a number of special laws.

The law on social insurance¹³ lays down the amount of the invalidity pension for the partially or fully disabled persons, reduced to this state due to a work accident or to professional or general diseases, differentiating among the invalids living in urban and rural zones. A special law has been adopted for work invalids,¹⁴ which envisions the reimbursement of the expenses for medical treatment for the full and partial invalids to the tune of 100 percent and 50 percent respectively; their exemption from direct taxes and customs duties for mobile and rehabilitation equipment; their free of charge public transportation; compensations for electricity bills, etc. There are special laws also on the blind¹⁵ and on the paraplegics and tetraplegics.¹⁶

Other laws provide for the right of disabled persons to employment, education and vocational training, facilities for road transportation, etc. Under the law on employment,¹⁷ the entities that have 25 employees should also hire one disabled person, who is capable of working. The employer who does not meet this criterion of the law, is obligated to pay to the National Employment Fund an amount equal to the minimal wage for every disabled person that he should employ. The law on the pre-university education system envisions the opening of special schools and classes, as well as the training of their personnel to work with persons with disabilities. The law on road transport lays down the measures for removing urban barriers for disabled persons. In

¹³ Law no. 7703, dated 11 May 1993, "On social insurance in the Republic of Albania"

¹⁴ Law no. 7889, dated 14 December 1994, "On the status of the work invalids," amended several times later.

¹⁵ Law no. 8098, dated 28 March 1996 "On the status of the blind."

¹⁶ Law no. 8626, dated 22 June 2000 "The status of the paraplegics and tetraplegics."

¹⁷ Law no. 7995 dated 20 September 1995 "On promotion of employment."

implementation of these laws, the Council of Ministers, the Ministry of Finance and other responsible ministries have approved Decisions, Instructions and Rules defining the concrete measures needed.

"...In general, with the help of the association, we have begun to be more aware of the laws on our rights. But we are still unclear about the instructions issued in implementation of the laws which specify what should be done. When draft laws are prepared, they ask for the opinion of our association and we are content, but when bylaws and decrees are issued, no one takes our opinion and only when they are implemented, we see that they are different from what we believed the law was. The bylaws and decrees are issued very frequently and we are not clear about them at all..." (Sh. Sh. - Invalid, Chairwoman of the Association of Invalids) ..

*"...We are very disillusioned with the state. Everything we have managed to have as paraplegics and tetraplegics, has been through strikes, protests and hunger strikes. It is paradoxical to think that a sick person can go on a hunger strike but we have been forced to resort to this means seeing the indifferentism and negligence of the state...." (V. K. - resident in a remote village)...
"The work invalids are obligated to appear before a medical commission made up of doctors and social insurance inspectors who determine whether they are or not invalids. Before appearing before this commission, the patient should carry out a number of tests and follow many procedures. The rule needs revision for the persons who suffer from incurable disease or irreparable defects...In those cases when the children of disabled persons demand scholarships to continue their studies, the calculation of their income is made including their invalidity pensions, which they think is not fair..." (B. L. - 42 yrs, resident in a suburban area of Tirana).*

In general, there is a good level of knowledge of the laws by the disabled persons and, in particular, by the representatives of their associations. The laws approved are considered by disabled persons as very important for the solution of their problems. Most of them are in conformity with their demands and the process of the preparation of the legal framework is in general a comprehensive process. Representatives of the associations of disabled persons have taken an active part in the preparation of these laws and have contributed directly to their presence in the meetings of the relevant parliamentary groups. Nevertheless, the interviewed persons make the following critical assessments:

- (i) The legal framework is focused more on the health aspect of the disability. Other important issues, linked with their integration into the society, are treated as secondary and spread out in the sector laws;
- (ii) The regulatory framework changes often, the opinion of the representatives of the associations of disabled persons are not taken into consideration, which often makes the implementation of the laws difficult;

- (iii) The preparation and approval of the legal statuses for special groups of disabled persons in general has been done based on the demands of the interest groups. As a result, these statuses do not include all the groups of persons with disabilities and are not based on unified criteria for each group. According to the National Strategy for Persons with Disabilities, about 30 percent of such persons do not have a legal status. According to the Living Standards Measurement Survey,¹⁸ about 61.2 percent of the persons with disabilities do not have a legal status;
- (iv) The approval of some essential legal amendments is considered indispensable by disabled persons and the representatives of their associations: (i) The deaf persons at present are not included in the group of persons with disabilities, therefore it is considered essential to recognize their legal status; (ii) The legal status of the paraplegics and tetraplegics is benefited only by the persons with a damaged spinal cord, leaving out the largest number of them, therefore it is considered essential to change this definition; (iii) The first group (See table 1) recognizes as persons with disabilities only those persons who are born such, or who have become such up to the age of 21. It is deemed necessary to remove from it the age restriction, because it does not guarantee an equal treatment for all disabled persons; (iv) The measures that promote employment are considered to be very insufficient and should be revised; (v) Some other measures, such as linking the disability payment with the minimal wage of the public sector employees, the increase of the payment, the expansion of the paid tutorship service, the revision of the reimbursement package, and others are likewise seen as very important.

Based on these assessments, it is believed that the drafting of an integral legal package on disability, including also a law against social discrimination, is indispensable for the approximation of Albanian laws with international standards on disability.

".....At the age of 20 I began to suffer from muscular dystrophy.... I was hospitalized on 20 December, 1989 and stayed in hospital for 12 years..... My brother is in the same condition. His disease appeared at the age of 35 and now he is 44..... The situation of sick people like me is hopeless. Imagine an old mother who has two disabled children who cannot perform even the most elementary functions. Think of her pain. I cannot do anything on my own. If someone does not give me a glass of water to drink I will remain thirsty or hungry all day. I cannot hold anything with my hands. The greatest paradox is that the state does not give me the status of the invalid because under the law, this status may be benefited only by those who suffer traumas in their spines. This is quite absurd and ridiculous, painful at the same time....". (L. S. - tetraplegic with muscular dystrophy).

¹⁸ INSTAT, LSMS 2002

6.

DISABILITY AND POVERTY

In Albania, there is clear evidence to the reciprocal link between poverty and disability. From the interviews taken, it results that malnutrition, the hard living conditions, the restricted access to health service, the insufficient care for mother and child, and the poor working conditions are in many instances causes for disability, particularly in the rural zones. From the interviews, it also results that, disability causes and deepens the poverty of the persons with disabilities and their families, because it prevents the persons from working, increases their costs of living and exposes them more to diseases.

"...The most common causes of the disease¹⁹ may be grouped into four categories: (i) inherent in the family; (ii) malformations during pregnancy; (iii) problems during birth; and (iv) infant diseases, particularly up to the age of 0-3 years. Among the children with mental disabilities, the malformation during pregnancy prevails. The main reasons are the very poor economic situation that does not allow pregnant mothers to have a balanced diet during pregnancy, the low cultural level of children and mothers, who do not know that they should avoid the use of medicaments during the months of pregnancy, and the lack of medical advice during this period. The problems during birth and the diseases from 0-3 age are likewise frequent causes, especially in rural zones. To the abovementioned causes, should be added also the lack of assistance at birth and medical consultations for raising the child." (Nasi Duka - President of the Association "In help of mentally handicapped").

However, in the studies on poverty hitherto, there are no data and analyses on this group of persons in need and, as a result; it is very hard to draft a poverty profile of the persons with disabilities.

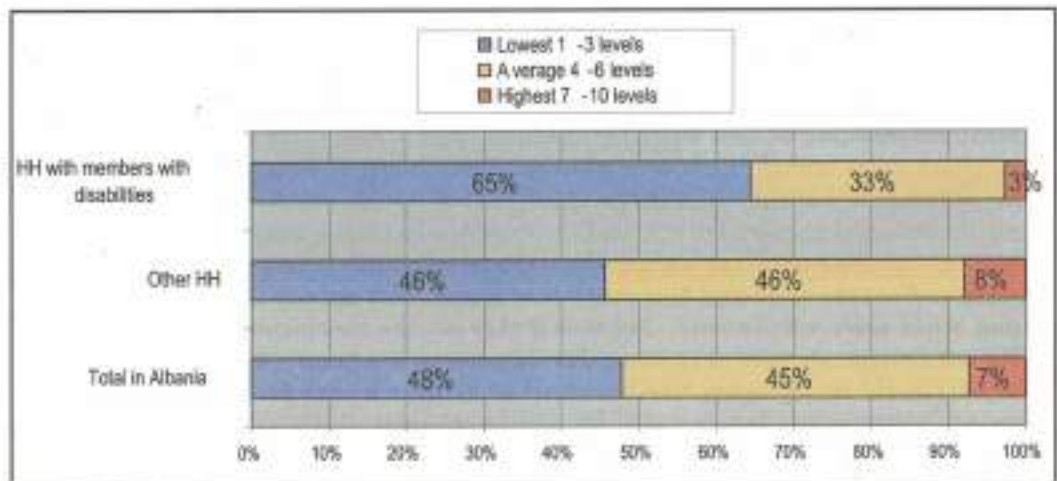
Economic situation

The largest part of the interviewees in the context of this study describe their economic situation as extremely poor, a small number of them as poor, and

¹⁹ It is spoken for the mentally handicapped

almost none says it is normal or rich or that they have savings deposited in banks. This self-assessment is in line with the results stemming from the processing of the data of the LSMS 2002²⁰. Based on these results, about 65 percent of the families with disabled persons declare that their economic situation is very poor, as against some 46 percent of other families (see figure 2).

Fig. 2 Current Economic status



This can be seen also from the analysis of monthly expenses declared by the families with disabled members, which for all categories of expenses result to be lower than those of other families (See figure 3). It can be clearly seen that the families of persons with disabilities spend about 11 percent less on food, about 29 percent less on education and 32 percent, 34 percent and 35 percent less on clothing, electrical appliances and telephone respectively.

²⁰ World Bank, Findings based on Living Standards Measurement Survey 2002, prepared by S. Sirunyan, 2005.

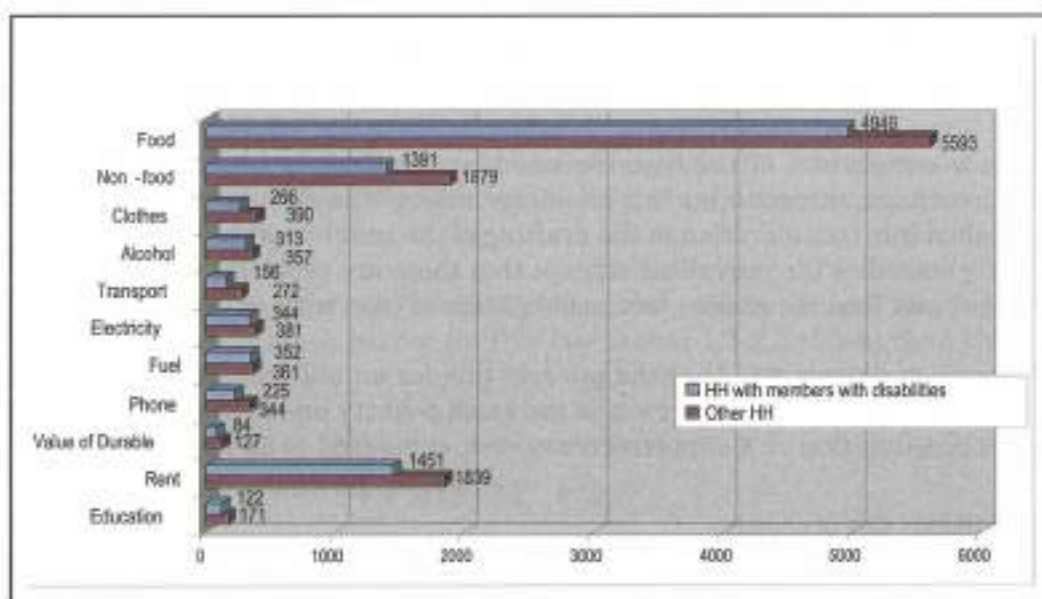
"...We are five members in our family. We have three children in school. I get 12600 leks a month as invalid, plus 5800 leks as pension for working in the mine, plus 1200 leks as chairman of the association of invalids of the district. Thus the total income of my family is 19600 leks a month. We pay for utilities 3000 leks a month. Every month, I spend 2200 leks on medicaments that are not reimbursable for the diseases I have, some the result of the invalidity and some of my old age. So practically we live on 2880 leks a month per person, or 96 leks a day per person, or by World Bank standards, on 0.94 USD a day. You consider those living on 1 USD a day as extremely poor. So you better do not ask us about our economic aspect....." (Rr.L. - Work invalid).....

"I am not talking about the variety of diseases I have today at my age, when it is hard to divide the accident and the work related diseases. The fact is that I pay back to the society all the money it gives me, because I spend all of it on medicaments and return trips for medical checks up in Tirana, and medical analyses every month. I am very pleased that the money I receive are sufficient for me to do all of this. But the problem is that besides medical check ups and medicaments, I also need to eat, and the state has not taken that into account. We have often taken with our deputy the issue of calculating how much an invalid receives from the state and how much they spend. But nobody wishes to sit down and make such calculations. Because if they do, the conclusion is very obvious. We have no money even to survive. For us poverty is a luxury, because according to you (World Bank) a poor receives about 5000 leks a month per person. Whereas we get 3400 leks per family... (Gj. Rr. - work invalid)

Cost, a taboo?

The core of the close link between the disability and poverty cannot be understood without a real perception of the cost of living for the disable person. The perception of the interviewed person is that nobody is interested to know, to reflect and to take into consideration this cost as well as differentiating it from the cost of living of the fully able persons. This is mirrored in the fact that payments and reimbursement packages for the disable persons are set based on fully able persons.

Fig. 3. Monthly Consumption (Expenditures) Per Capita (Lek)



Based on this perception, we have tried to figure out an analysis of the cost of a disabled person, not with the view to make an absolute assessment of the cost, but simply to assist or modify the perception of the society and its institutions about the economic situation of these persons and their urgent needs. Of course, the types, the combination, the intensity of disability and the age, the gender and the economic and social status of the family have various impacts on the cost of disability. Nevertheless, for the purposes of this qualitative assessment, the elements of the supplementary cost of a person with disability, which differentiate him or her from an able person, may be approximated as follows:

- (i) The direct cost of the treatment of the basic disability disease, which is reimbursable in conformity with Albanian legislation;
- (ii) The "hidden" cost of the treatment of the basic disease of disability, which includes the expenses for the most effective medicaments, which are not included in the list of reimbursable medicaments, for tests and specialized medical check ups, for transport to and from specialized clinics, which are not reimbursed;
- (iii) The supplementary costs for the treatment of other diseases due to higher morbidity compared to the able persons, which are not reimbursable;
- (iv) The supplementary costs for specific expenses linked with disability, such as prostheses, tutorship, which *in principle* are reimbursable;

- (v) The supplementary costs for special expenses linked with disability, like consumption materials, and transport, which are not reimbursed;
- (vi) The absent income, due to disability, which in this analysis is not taken into consideration.

From a comparison of the costs declared by the persons interviewed in this study with the current laws, it is clear that most of the elements of the cost are not taken into consideration in the drafting of the reimbursable packages. This clearly embodies the prevailing concept that these are problems of the disabled persons and that the society has no obligation to cope with or facilitate them.

It has been determined that the poverty line for an able person is 4,891 leks per month.²¹ The disabled person in the same poverty line needs absolutely an extra consumption or a supplementary cost, compared to an able person.

Fig. 4 Hidden side of poverty

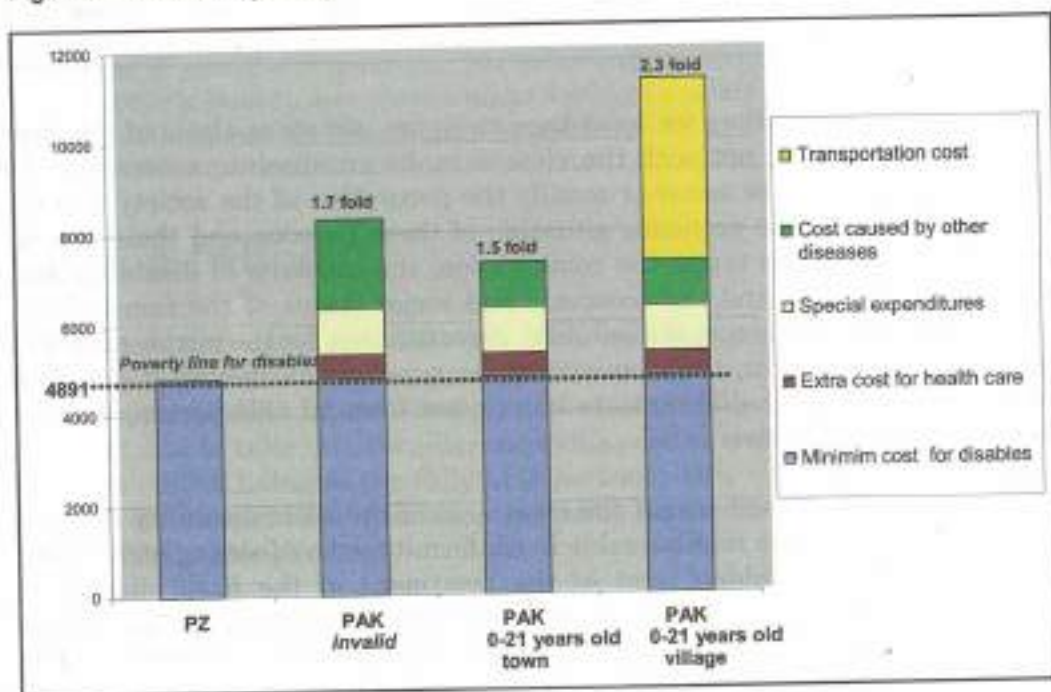


Figure 4 reflect in graphical way this comparison, bearing in mind the extra orientating costs declared by the two main groups of persons with disabilities during the interview (see table 1): persons with disabilities from 0-21 years, residing in the city and in the countryside, and the work invalids. For the three cases, the extra cost for medical treatment of the basic disability disease

²¹ LSMS 2002.

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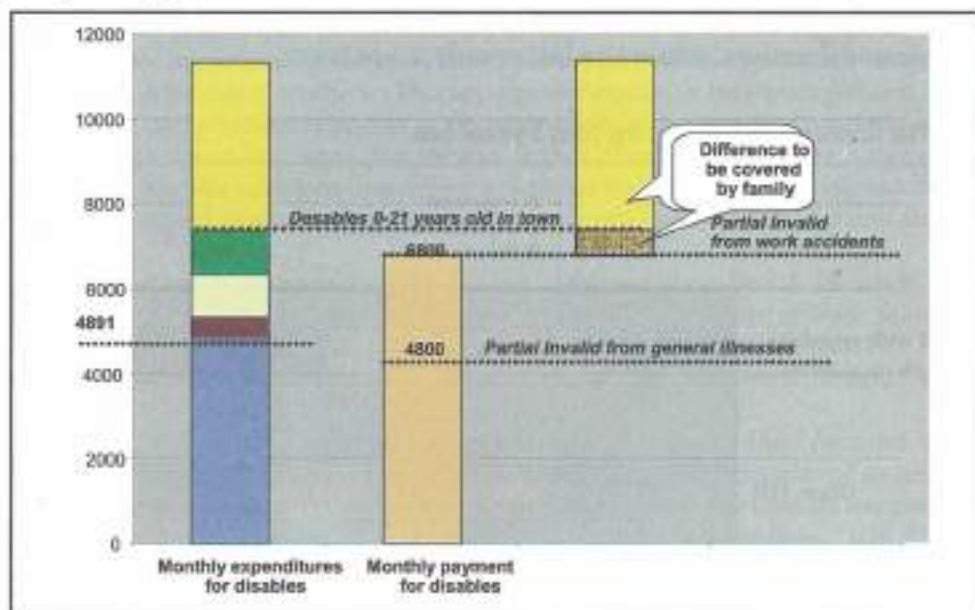
and the extra cost for special expenses linked with the disability, such as consumption materials, transport and others, have been taken the same, with minimal declared values (respectively 1000 and 500 leks a month). The supplementary cost for the treatment of other diseases, due to a higher morbidity, has been taken to be about 1000 leks a month for the first group and twice as much for the work invalids. A transportation cost has also been taken into consideration in order to make possible the attendance of daily centers only for the persons with disabilities living in the countryside (about 4000 leks a month),

From these approximations, it results that the poverty line of the persons with disabilities is much higher (in this case about 1.5-2.3 times) than that of fully able persons.

The hidden part of poverty

In order to give a general idea, Figure 5 compares the living cost of a disable person with the monthly salary he gets. It can be seen that the amount of payment of a partial invalid suffering from a general disease is under the poverty line of a full able person, while the payment of a partial invalid, whose invalidity is caused at work, exceeds the poverty line. In both cases, this implies that being able to work in suitable places for him; the partial invalid may make some supplementary income. Such a thing is not possible for most of the partial invalids (See chapter 8).

Fig. 5 Dependency level from families



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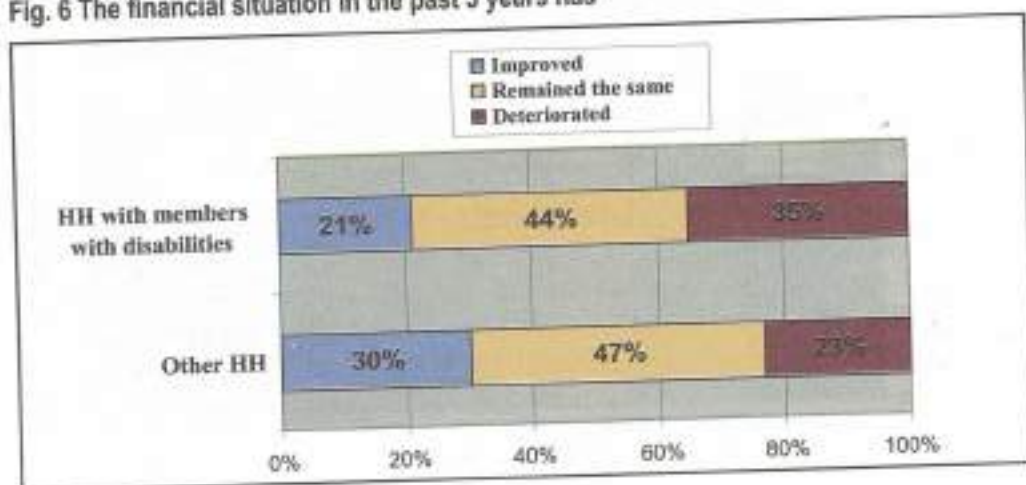
The monthly expenses for the same persons up to the extent of poverty line calculated for them, exceed the amount of payment. Thus an obvious difference is created among them, which is not covered with income. This shows the existence of a "hidden" part of poverty among persons with disabilities. Hence, the poverty of a person with disabilities is more profound than that of a fully able person.

From the psychological shock to an economic one

The part of expenditures up to poverty line, which is not covered by the revenues, is usually covered by the family of the person with disability. So, such a person remains greatly dependent economically on his family, which is obliged to make up for the lack of his income. For the poor families, this is a very serious problem, which further deepens poverty. This is especially marked in the families of the rural area, where people live far from services and have much more restricted economic opportunities compared to the urban area.

Following the psychological shock of the first years after the identification of disability, the families have to cope with an economic shock, being constantly plunged into deeper poverty. In many instances, a member of the family is obliged to stop work or to work with reduced time in order to serve or to accompany the person with disability. In general, this task is taken over by one of the parents, but when they are not alive, or when they are unable to do that, this burden falls on the other children, although meanwhile, they may have created their own families. This constant impoverishment caused by disability is pointed out also by the data of the LSMS-2002, according to which the number of families that have persons with disabilities and who declared that their financial situation has become worse is greater than that of other families (see figure 6). The former represent some 35 percent of the interviewed families, while the latter only 23 percent.

Fig. 6 The financial situation in the past 3 years has



".....I have an 18-year old brother whom we have been bringing to this daily center for six years now. Initially, it was my retired father who accompanied him here, but now he is too old and cannot leave the house. So since we have no one else in the family that can accompany him, I should bring him here. I am married and have my own family now; I have a jobless wife and two small children. I am paid some 14,000 leks a month. We also receive 6,800 leks a month for my brother and 7,000 leks from my father's pension. So we make a total of 27800 leks a month for meeting the needs of six persons. On an average, I have to start work an hour late and leave an hour earlier in order to escort my brother. This has created major difficulties for me at work not only in terms of getting less than my friends, but also because nobody likes you to work in these conditions. It is beyond imagination for us to hire someone to accompany my brother to the center because what we get are not enough to make our ends meet, let alone pay for the medicaments..." (N. N.).....

"We are seven members in our family, husband and wife and five children. We have two daughters who come to the center regularly for 10 years now. We have come here from the Diber district and live in a destroyed home in the suburbs, which in winter time is most of the time flooded with water. My husband works as a manual laborer but does not find work most of the time, while I have no work. I am 50 years old, have worked for 34 years in a state job and am waiting to become of a pension age to get a pension. We live in a dire situation. Two months ago my mother in law died and we had to borrow 200,000 leks for the funeral expenses. Then my husband was taken ill and we own the grocery store some 45,000 leks. A month ago, they installed an electricity meter and now we have to pay the electricity bill which is 4800 leks. We pay also for the water consumption although we live submerged in water. We do not get any economic assistance because my husband is considered employed. I have gone to the town hall to look for a job but they tell me there is none. We are both at breaking point and willing to commit suicide but we have our two sick children and there is nobody that can take care of them. We can at least bring them to this daily care center where they can keep themselves busy. I do not have a problem with you citing my by name. I told you the truth and feel no shame at being so extremely poor because I have worked most of my life..." (N. O.).....

"...The lack of possibilities to work makes us depend on others during all our life. Even when we are grown up, when we create our own families, we continue to rely on our parents, sisters and brothers. This is a shame because in reality we feel in a very good mental and physical state and if we are provided some minimal conditions, we can cope with life on our own. But the fact is that often we are discriminated even by our own families which cannot afford to help us financially during all our lives. We have identified several instances of deaf people leaving their families and living on their own..." (E.A.)..

"...From someone to be respected, for having sacrificed their health for work and family, the invalids have become people who live at the expense of their families adding to their problems and worries. That is why in 16 cases, the families have divorced with either the husband or the wife abandoning the other spouse..." (Sh. Sh.)..

"Our children are also discriminated because after they create their families, they should think not only of their own families, as everyone does, but also of us and of how to maintain us. And the fact is that we are living a long life because one cannot die from problems. So we will be a burden to our children all our lives.." (G. Rr).

The impossibility to contribute to the family economy and the obligation of the family to make up for the lack of income for the person with disabilities, have a negative impact on the social status of this person, in particular when he is male and head of family. This impact is smaller among the females because the mentality prevails according to which the husband is the main person responsible for providing for the family. From the interviews with persons with disabilities, and the members of their families, it results that this negative impact is manifested much more in the self-penalization of the person with disabilities than in his penalization by the other members of the family.

7

7 HEALTH SERVICE

"...I continue to suffer from kidney disease, high blood pressure and allergy. Recently I am suffering also from diabetes. Because of the frequent sicknesses and the impossibility to cope with our daily living, I have become chronically depressive and have to be under the doctor's constant supervision. The state reimburses me for the medicaments linked with the kidney disease, which cost about 4000 leks a month. This medicine is called diovan, it facilitates the filtering process in the kidney and I am alive thanks to it. The doctor tells me that this is an old medicament and that now they use a newer and more effective one. I tried to use the other "better" one for a couple of days by paying for the difference in price from my own pocket and the result were obvious. But that medicament is more expensive, is not reimbursed by the state and I cannot afford to buy it. I use regularly medicaments for my high blood pressure, for arthritis, allergy for which I spend an average of 2500 leks a month. I need to go to the doctor for periodical check ups and for various tests. Officially they are free of charge but often I have to pay even for them. The doctors advise me to follow a strict food diet, especially for diabetes, but I cannot follow it with the money we get we can hardly make both ends meet eating the most common food..." (Y. Sh. - Invalid).

"...All the medicaments for my liver are reimbursed by the state every month and cost about 5400 leks. But for some years now, other chronic diseases are ailing me which may not be linked with my invalidity. I suffer from high blood pressure, diabetes and asthma, which are all chronic diseases and need constant treatment. I must spend a total of 7800 a month for all these three diseases but I cannot afford it. Then I am forced to strike a compromise with the pharmacist, with the money from the reimbursements sometimes I buy medicaments for my liver, sometimes for diabetes, sometimes for the asthma. I alternate their treatment by weeks. The doctors tell me that I am destroying my health like this, but I do not listen to them because I have no other solution. Now that we are talking together, I suffer from diabetes because I have not treated it for three weeks..." (Sh. Sh. - Invalid).

"...I have sold all my precious possessions like rings, earrings, bracelets, only to pay for my son's medicaments. I owned the neighborhood pharmacist 15000 leks for unpaid medicaments and for some days I have not dared pass by his pharmacy because it seems to me he will think I want him to forgive my debt this year too. What can he do? There are many like us and he has his own family to provide for..." (D. Dh.)

"...We see this at best when we go to Tirana to have our prosthesis repaired or replaced. They tell us there that there are no materials, at a time that the state tells us we can to it from of charge. If you pay you can have it done. But do you know how much prosthesis cost? The cheapest costs 30,000 leks, when it is under the knee, and twice as much when it is above the knee, while the arm prosthesis costs 4800 leks. That is why I have not had mine replaced even the doctor has recommended me to have it replaced since eight years ago, because it risks infecting the sound part of my leg, but I cannot afford a new prosthesis. I wait in vain for some foreign foundation to help me but it is several years now that they have not come here.... There are two persons in our city whose legs were infected because of their failure to have their prosthesis replaced and they became from partial invalids into full invalids. And when they appeared before the medical legal commission, they did not want to give them the new status because they told them "it is your fault that you did not follow the doctor's advice." We have a saying in our part of the world, "Ok, I am guilty of not guarding well my cow, but what about the thief, is he not to blame too?"..." (B. T. - Work invalid).

Expenses for health service are considered to make up a high cost for both main groups of the persons with disabilities. The problems of health care result to be very complex:

- (i) According to Albanian legislation, the person with disability is reimbursed for medicaments for the basic disability disease according to a list of medicaments approved by the Ministry of Health. In many instances, they state that after a very long use, these medicaments are no longer effective and the doctors recommend their replacement with newer medicaments. In this case, the person with disability is obliged to pay from his own pocket for the difference in price, or to disregard the doctor's advice.
- (ii) The persons with disabilities are not reimbursed for medicaments for other diseases. Being more exposed to sicknesses than other able persons, the persons with disabilities need to spend every month considerable sums for other chronically diseases which in some cases exceeded the monthly disability payment. Many cases are reported when they purchase medicaments with borrowed money, or when they do not buy them at all, remaining without treatment for a long time;

Fig. 7. Difficulties for paying for family health care

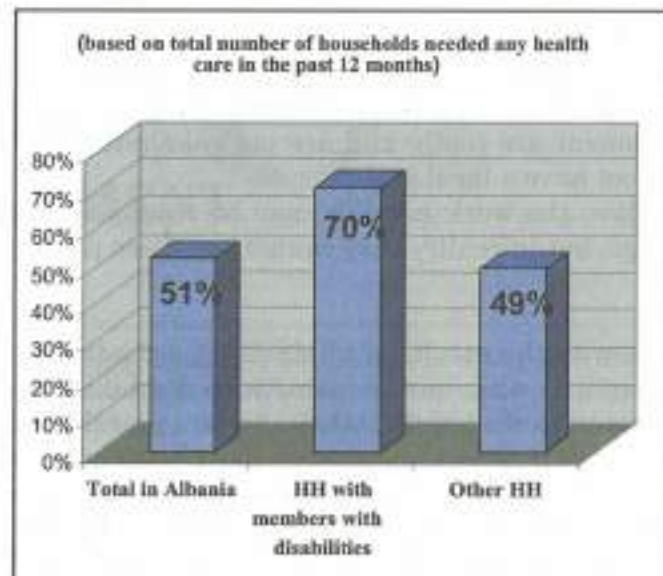
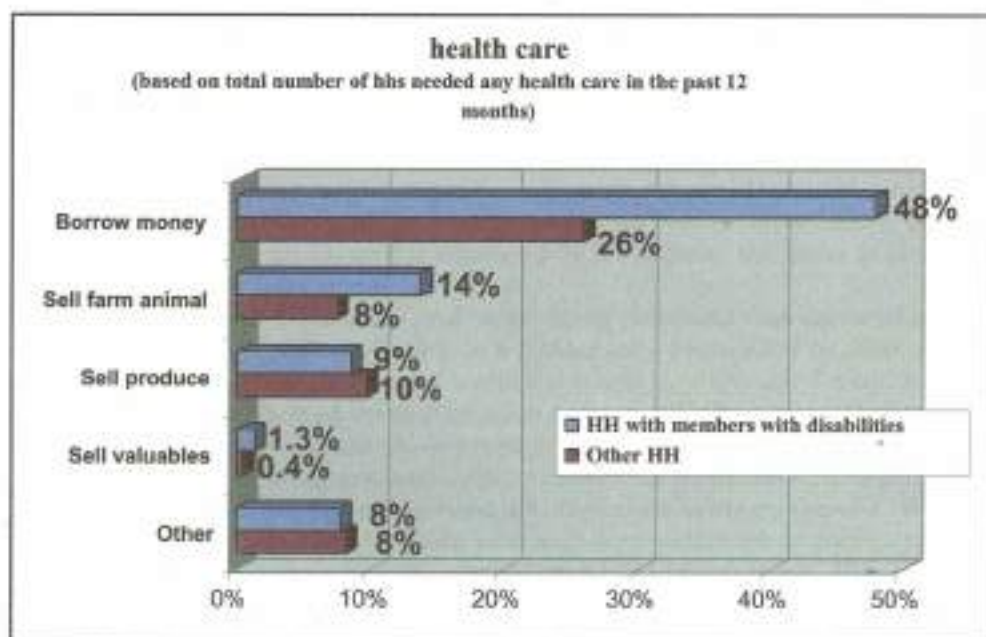


Fig. 8. Methods to raise money to pay for family members' health care



- (iii) In both abovementioned cases, the person with disability is obligated to make considerable expenses for medical analyses and for transportation from the place of residence to specialized clinics and to pay the specialist doctors. All these expenses are non-reimbursable;
- (iv) Many deaf persons need to be supplied with hearing aids in order to be able to attend school or be more easily integrated into the society. These equipment are costly and are not reimbursable, because deaf persons do not have a legal status;
- (v) Under the law, the work invalids may be equipped with prostheses free of charge, but in reality they cannot get these prostheses without payment.

These data coincide with the results of LSMS-2002, according to which about 70 percent of the families who have persons with disabilities and who have required health services in the last 12 months declare that they have difficulty in paying for their health services compared to 51 percent of other families (See figure 7). Unable to pay for the medicaments, many families are forced to borrow, to sell their livestock or household appliances (See figure 8). Their number is much greater than that of families without persons with disabilities in the same situation.

8.

EMPLOYMENT

"....My main problem is work. I am capable of doing several kinds of work with my left arm because I have finished two high schools and physically I am strong. I do not ask for alimony, I ask for work. The state should find the way to employ invalids in ticket offices, both state and privately run ones. I may also work as a guard...". (L. Q. - Invalid)....

"There are various jobs I could do for the state from a doorman, a guard, or an archivist. I may do these things very well but nobody gives me a chance. If they found me a job, I do not ask for a higher pension. All the invalids of the fourth group may do such kind of work because among them, there are many who are educated but there are no job opportunities for them. We understand that the private sector is not interested in employing us, but the state can at least give its example...". (B. T. - Invalid).

".....The employment of paraplegics should be given priority by the state and the government. In the situation we are and with the formation some of us have, we may do various jobs like secretary, receptionist, computer operator, and others. The mentality in Albania is such that it looks down upon the paraplegics. People look upon us as invalids and not as self-demanding people, s people with wishes and possibilities to contribute to the society. Not a single conscience raising campaign is organized, or propaganda campaign for people to understand our condition and possibilities. Even businesses should become more aware, because in those cases when an invalid is employed by a business, the latter is exempted to a certain degree from taxation..." (G. N).

"... I have worked in the mine, I had an accident there and was declared invalid of the second group, who may work in a lighter job. From 1991 to 2000, when I turned the pension age, I have not worked a single day because I could not find work. Nobody has helped me to find a job because all, the society, the state, my friends, my relatives consider this my own problem. They have seen me off saying, "We live in a market economy, and we are no longer in socialism." . The state itself does not respect the law on employment, let alone the private companies. We have a large number of educated invalids, who may very well work as guards to check the passes of the employees in the central and local institutions. It is true that this place of work cannot accommodate all the demands of the disabled persons for work, by in this way the state sets its own example and conveys a message to the benefit of persons with disabilities....". (Rr.I. - Work invalid).

A considerable number of problems for many of the persons with disabilities might be resolved if they could be offered work. Albanian legislation envisions as a measure for promoting employment that the employers who have 25 workers must also employ a handicapped person who is capable of working. The employer who does not abide by this legal requirement should pay to the National Employment Fund an amount equal to the minimal wage of every disabled person that he ought to employ under the law. In reality, the employment of persons with disabilities is an unsolved problem and from the interviews conducted in the context of this qualitative assessment, it results that:

- (i) In general, the question of employment of disabled persons is completely outside the attention of the society, the employers, and the central and local state institutions;
- (ii) In the responsible state institutions, there are no evidences of the number of persons with disabilities hired pursuant to this law;
- (iii) Not a single case of any employer who has not met the legal obligations of paying an amount equal to the minimal wage has been reported to the responsible state institutions;
- (iv) In the private sector on a national scale, prevail the small and medium-enterprises with an average number of workers less than 25. Those few existing enterprises with 25 workers are concentrated in two or three largest cities. Hence, the real possibilities for the persons with disabilities to benefit from this law are very few and for those living in the small cities and in villages, they are non existent.

Promotion of employment for disabled persons would require first of all that the public administration, on a central and local level, to set its own example by finding places of work for such persons in its ranks. The expansion of the range of the operation of the existing law, the provision of special measures in favor of persons with disabilities in the Strategy of Small and Medium Enterprises and the creation of the conditions for their vocational training through short-term trainings would be a major contribution to the solution of this problem.

Employment promotion for the educated disable persons and those with a professional experience requires establishment of their relations with the employers and at the same time the awareness of the latters to employ them. In order that this system functions it should not be spontaneous but an organized one.

9.

REHABILITATION, CHALLENGE OF DE-INSTITUTIONALIZATION

The UN Standards say that the state must provide for the rehabilitation services for persons with disabilities so that they can have and maintain an optimal level of independence and must develop national programs of rehabilitation for all the groups of persons with disabilities.

In Albania, at present there are 11 public centers in the 10 largest districts of the country, from a total of 36 districts, frequented by some 450 persons or about 1 percent of the persons with disabilities of the first group (See table 1). From these centers, six are residential centers, while the others are daily centers. There are also 13 non-public centers distributed in eight districts, which have been set up by international donors. The number, the geographical distribution and the capacity of these centers are insignificant compared to the demand for them. The families of the persons with disabilities, although they totally lack information, are constantly in demand of such centers. Many families, despite the difficult economic situation, sacrifice to send their children regularly to such centers, because they consider it the only possibility for the progress of their child. Other families report that they have migrated from distant villages of the northwestern zone of the country in order to come close to the existing centers.

The conditions in the public centers in terms of infrastructure, equipment, didactic means and the motivation of the staff have been in decline because of the restricted financial possibilities of the state budget. Although they have received humanitarian support now and again and although the international donors have organized training programs, yet improvements are very slight. In the case of residential centers, the situation has deteriorated also as a result of the hesitation of the international donors to support them and to ensure their continuous operation.

"...The demands for frequenting this center are great. At present we have received 50 applications, but our estimate is that they may reach 200 from 600 children with disabilities we have in the Lezhë district. The migration of the population has had a major impact on this considerable number. In the neighborhoods where the migrants have settled there are a great number of such children. For example, in the Koder Marlekaj neighborhood, there are about 30 children who require a center of their own..." (I. A.).

"...Not to bring the child to such a center is the greatest mistake we may make, it is tantamount to counting him or her with the dead. Because this is the only possibility for such children to make progress. The little ability he has to communicate is thanks to his coming here. There is nothing we can do at home for him, because we are ignorant, in general we have no education at all and in particular we have no knowledge about dealing with such children..." (N. G.).

"...We do not want to get a higher pension or financial assistance for our disabled child. This is not the solution. This can take care only of the food for the child and nothing more. The question is to treat them as human beings. This is why they should be taken to such centers because only there they can be stimulated and progress..." (N. G.).

"...We have heard that if you take our daughter in rehabilitation centers, there are specialists there who can deal with her on a daily basis and she may progress. But we have only heard it from hearsay but have no idea where such centers are located and how to go there..." (R. Sh.).

The tendency today is towards a system of rehabilitation that aims at facilitating the social inclusion of the persons with disabilities through offering a broad range of services on a community level. This is clearly determined also in the Standard Rules of the United Nations, which stress that all the rehabilitation services should be available in the local communities and in some instances, special limited courses may be organized in residential forms.

In the conditions of Albania, such a reform in the system of services for the persons with disabilities has coincided with the economic reform for the establishment of the bases of the market economy. Therefore the difficulties for the implementation of reforms are double. On the other hand, so far, this reform has been a spontaneous process and not based on clear institutional policies. As a result, the progress in this field is very small. Therefore, even though in principle the need for de-institutionalization is accepted, in real terms it is still unclear how this will be implemented in reality, what financial cost it has and when the state budget will be able to cope with it. Considering this process as a very difficult challenge, the prevalent opinion among the persons with disabilities and their families is that for the moment the residential centers are more necessary.

"...For people like us without a home and income, the best settlement would be for the state to set up residential centers. Let it keep the money it gives us because it does us no good. Let the state at least do this for us, when we see that it does not find us jobs or a home. The economic assistance is likewise no good, only the residential centers will do...". (N. O.)

"...We do not ask for privileges by the state although we are extremely poor. We will suffer our fate like the others. But we can find no way out for our disabled children. We cannot do more than that for them. We are not working, we are depriving our other children of food to pay for transportation and buy medicaments for our sick children. But this is simply to help them survive. Their integration is another matter. It requires the intervention of the state. We do not want the money the states give us for our sick children; let it resolve the question of residential centers. We understand that money is needed to set up such centers, but let it start opening one, because 15 years have elapsed and nothing has been done in this respect. The state might try to persuade foreigners to come and help us...." (E. L.)

10.

10 REPRESENTATION IN ASSOCIATIONS

According to the Standard Rules of the United Nations, the state should encourage and support economically the creation and strengthening of the organizations of persons with disabilities, establish constant communication with them and ensure their participation in the drafting and implementation of development policies.

In Albania, there are a considerable number of such associations, whose establishment was allowed only after the political changes of 1991. The first to be set up was the National Association of the Blind, which was approved by the Ministry of Health in January 1991. Many of them are well structured, carry out their activity on a national level and have branches in various districts of the country. The National Association of the Work Invalids, for example, has branches and structures that operate in all the districts.

"...The Association considers as the success of its work its opposition to the law on custody. The law approved by parliament grants the family of the mentally disabled person who has the right of guardianship a monthly stipend of 2600 leks. The law excludes from the right of guardianship, (i) the families living in the town which have at least one member working or which benefits a pension by the state; and (ii) the families living in the town which have land in their ownership. The Association opposed these restrictions and the law was amended. At present all the families of the persons with mental disabilities that have the right of guardianship, have the legal right to benefit economic assistance. But despite the fact that the amendment was made since 2004, in real life it was implemented only partially, to the benefit of particular individuals..." (N. D. President of the Association "In help of mentally handicapped").

The focus of the work of these associations is the raising of the awareness of the public and making advocacy for a contemporary perception on disability, the identification of the needs and priorities for persons with disabilities, participation in the processes of the preparation of laws, the planning of the funds, the implementation and evaluation of services and so on. The associations have institutional contacts with the main state actors and are recognized and assessed by them as representatives of various groups of persons with disabilities. Cooperation with the Assembly of Albania where the Lobby of the Deputies for Disability and the process of the preparation of the National Strategy of Persons with Disabilities is considered one of the most typical positive examples of cooperation of these associations with the state structures. This cooperation with the structures of local authorities is considered to be at a very lower level due to the fact that the latter have no responsibility under the law regarding the problem of disability. The associations are also part of the international networks of organizations of persons with disabilities, maintaining constant links with them and taking an active part in the relevant international activity.

The representatives of the associations express the need for: (i) a better geographical extension of these associations, particularly in the rural areas, (ii) the strengthening of their capacities to identify, formulate and implement projects of services for persons with disabilities; (iii) the strengthening of the links among the associations themselves, particularly for undertaking common actions in support of persons with disabilities; (iv) the improvement of the reciprocal information system on their activity, and (v) considering them only as representatives of the persons with disabilities and the exclusive interlocutors of state structures, avoiding their replacement by other local or foreign NGOs.

11.

ROLE OF INTERNATIONAL DONORS

International, bilateral, and multilateral donors, or the foreign NGOs are considered to be the main contributors to the social integration of persons with disabilities. They have funded successful projects for the establishment and enhancement of the capacities of the associations of persons with disabilities, the drafting of legislation, policies and strategies, having a direct impact on the enhancement of the interest of the society and the decision makers regarding the problem of disability.

"...The Association is based on funds from international donors to implement various projects for raising the awareness of the public and integrating children with mental disabilities. The main project is a two year project funded by the European Union and it is implemented in five districts of Albania, Tirana, Fier, Pogradec, Elbasan, and Librazhd. Its results have been assessed as very positive and have been summed up by Inclusion International in all the countries of the South-Eastern Europe as a good example. The Association has set up three daily rehabilitation centers with funds by the international donors respectively in Tirana, Ballsh, and Poliçan. The latter two have been closed down now for lack of funds....". (N. D. President of the Association "In help of mentally handicapped").

"....The center has been financed for some years by international donors but the funds ended one year ago. During the last year, it has functioned with the voluntary contribution of the staff, with a reduced activity. Thus the number of children who come to this center has halved. The main reason for this is that the center cannot provide, like in the past, for the transportation of the children for lack of funds. It means they have to pay for a driver and the fuel because the center has its own van for transportation but it cannot use it. That is why at present it is frequented only by some children who may come themselves or accompanied by their parents. The staff of the center is likewise reduced....". (V. D. - Directress of the Life Training Center, Tirana).

"...If I had no motorbike, I would not be able to move about and meet my invalid friends at the center of paraplegic persons we are several of us who have motorbikes. But they cannot come there as often as they like because they have no money to purchase fuel. And without fuel we are doomed to remain shut at home. The

state does not provide us with any assistance to buy fuel. I read in a newspaper that a major international donor had started a program for training Albanian men to attend in the birth of their children. Since they are financing it, probably this is important, maybe it is a condition for Albania's membership into the European Union. However with that money all the paraplegics of Albania would resolve the question of fuel for five years. You cannot imagine how important this is for us..." (D. I. - 27 years).

The main characteristic of the projects funded by international donors is the clear tendency to pass from the humanitarian aid, mainly foodstuffs, clothes medicaments and special equipment, into development projects. Through their projects, they have created successful pilot models of daily and residential centers for persons with disabilities and are the only ones who have successfully implemented integration models through the creation of mixed classes, where students with disabilities learn together with able students.

To the perception of persons with disabilities, their families and the representatives of their associations on the aid of international donors are added also some critical considerations regarding the state institutions and the international donors themselves: (i) The aid given tends to support specific pilot projects that are not linked with one another, and is not coordinated by the state institutions in the context of a national reform in support of the persons with disabilities; (ii) Numerous examples of projects, now concluded, testify to a very low sustainability after the termination of their funds; (iii) In general, we note a low level of information exchange on the projects by various donors, their experience and results, and no initiatives taken by the institutions to generalize the good experience; and (iv) the role of state institutions for the coordination of aid of the international donors and its direction towards the most important priority projects is perceived as very small and insufficient.

ANNEX 1

INDIVIDUAL INTERVIEW GUIDE

PRINCIPLES

- The aim is to understand and interpret the different individual experiences giving access to people's own experiences;
- The interactive "face-to-face" communication is fundamental;
- It is important to be sensitive to the informants' responses;
- The interviewer should take the role of a student - someone who wants to learn from the informant who is the expert of his/her life situation;
- The interviewer should encourage the informants to *like* to tell about themselves;
- It is not necessary to follow the interview guide precisely from beginning to end and to respect the sequence of questions;
- Explain to the informants on the study's purpose and objectives, who is the initiator, how the results are going to be used, who will benefit from the study;
- The interviewer must take into consideration the informants demand for integrity and dignity and under no circumstance should the informant be forced or persuaded to answer questions;

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- 1 Introduce yourself and give the formal information about the study.
- 2 Ask the informant to tell about the reason for the disability, as well as the reason for the onset of the disability. Try to get the detailed story:

*Please describe or explain to me about your impairment;
What happened, when and how?
Why do you think this happened to you? (This question is an attempt to find out if the informant believes in "other" explanations – witchcraft, ancestors' anger, evil spirits etc).*

- 3 Ask the informant to describe his activities and tasks, the role and responsibility connected to:

*Household duties;
Participation in work or school;
Participation in social activities;
Private activities as hygiene, toilet, dressing etc.*

- 4 Invite the informant to tell about the daily activities, describing the activities from morning to evening:

*Arrange this according to the informant's age, sex, family position, role etc.
Encourage the informant to be specific and to illustrate by examples;
What additional responsibilities would he have if it were not for the disability?
Would the activities be done differently if he was not disabled?
Is this what others in the neighborhood usually do?*

- 5 Relate the activities to the bodily and/or mental functioning:

*Ask the person to describe how the disability affects the performance of the activities;
Ask the person to describe any assistance given and by whom the assistance is given;
If the person does not participate in some of the activities, ask the person to reflect on why he does or does not participate in the activities;
Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned.*

practical arrangements at work, in school, at home) and the efforts made in connection with these adjustments.

- 7 Ask the family members to describe how they take care of the disabled family member:**
How does the situation with disabled family member affect their family life?
In what way does the disability affect some of the household members' ability to work, access to employment, go to school or participate in social activities?
Ask them to reflect on why the situation is like this.
- 8 Access to health care and medical services:**
What kind of health services and/or medical care has the person received, or not received, because they have a disability?
Ask for experiences regarding: modern health care, traditional health care, self care in the family.
- 9 Participation in organizational activities:**
What kind of social and/or organizational activities does the person participate in?
Tell about what happened last time they had a meeting.
- 10 Invite the informant to talk about the future:**
What are the dreams and plans regarding education/schooling, employment/economic support, having a family?
How does he think the living situation will be in approximately ten years from now?
What are his chances of achieving these goals?
What would be the hindrances?
- 11 Reactions to disability**
Ask the informant to explain about his reaction to being/ becoming disabled;
Ask for their experiences with other persons' behavior, reactions and knowledge to the fact that he is disabled;
Ask if he knows or gets together with other persons with disabilities in the village or the community.
- 12 Ask the head of the family to tell about the family:**
How many family members, and how many disabled members (age, sex) are there?
How are the consumed goods obtained?
How does the family get their income?
Is the income sufficient to support the family?

Are there enough persons in the households to care for the disabled member and to support the family?

Do family members have to quit a job or not work in the field because of the need to care for person with disability?

Concerning housing, is their accommodation similar/worse/better than the other community member's accommodations?

What is the informant's opinion about the family's social ranking/class?

How does the disability affect the family life in all?

13 Level of fulfillment of International Standards related with the disability

14 Note age, gender, and sometimes name, of the informant:

Biographical data are often given quite early in the interview as a natural part of the conversation. It is not always wise to open the interview situation with these questions because: (i) this information is not directly related to the reason for the interview and may therefore be disturbing when it comes to the importance of getting a good start; and (ii) opening an interview by noting personal data may under some circumstances be interpreted as an inquiry.

15 Closing the interview: Acknowledge the informant's cooperation, time spent and information shared.

GENERAL INFORMATION

Some general information on the situation for people with disabilities in national and local levels must be collected considering the following questions:

What are the main problems related to disability in the country and local levels?

Are there people who do not have access to schools, jobs, public buildings and other public or common goods?

What kind of consequences does this have for those who do not have access?

What do you know about the living conditions for people with disabilities in the are/district?

What is done to improve the living conditions?

What is your opinion on participation and integration in the community/society for persons with disabilities?

Illustrate with examples on what has been done in their own community/village/school

