



**The UN  
Standard Rules on the  
Equalization of Opportunities  
for Persons with Disabilities:**

NGO Responses to the  
Implementation of the Rules on  
Medical Care, Rehabilitation, Support Services  
and Personnel Training

**I. Summary**



Disability and Rehabilitation Team  
Management of Noncommunicable Diseases Department  
Noncommunicable Diseases and Mental Health Cluster  
**World Health Organization**

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## ACKNOWLEDGMENTS

The present report was based on the information provided by non-governmental organizations (NGOs) responding to the questionnaire sent by WHO in May 1999. The questionnaire, developed at the request of the Special Rapporteur on Disability of the UN Commission for Social Development, was designed to monitor the implementation of the health component of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, in accordance with the United Nations General Assembly Resolution 48/96. Some preliminary results have been included in the report of the UN Special Rapporteur to the UN Commission for Social Development in February 2000 and 2002.

We wish to express our gratitude to Professor Usha S. Nayar, Deputy Director, Tata Institute of Social Sciences, Mumbai, India, and Chairperson, Technology And Social Health (TASH) Foundation, Mumbai, India, who has analyzed the responses and written this report with great competence and commitment.

Many thanks are extended to our donor governments in Italy, Norway and Sweden without whose support this report would not have been possible.

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## **SUMMARY**

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## Preface

WHO undertook this survey in cooperation with the office of the UN Special Rapporteur on Disability as a part of continuous monitoring of the Standard Rules. There is also an increasing demand for information on disability issues and a need to reflect trends and developments in this domain.

The present Report is an analysis of information collected in 1999 by means of a questionnaire sent to the NGOs<sup>1</sup> working in the field of disability in the member States of the WHO. The information focuses on issues related to four of the 22 Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Rule 2 on Medical Care, Rule 3 on Rehabilitation, Rule 4 on Support Services, and Rule 19 on Personnel Training.

The questionnaire was designed and finalized in April 1999. It was sent to the selected NGOs of the member countries with a request to complete the questionnaire in order to help WHO identify the official policy of the country. For this, they were requested not to give their personal opinion but to quote the official opinion.

The objectives of the study were:

- To identify various government policies regarding medical care, rehabilitation, support services and personnel training,
- To identify various strategies adopted and problems encountered when working in the field of medical care and rehabilitation of persons with disabilities.

This survey was undertaken to meet the increasing demand for information of this nature and the need for reflecting on trends and developments in this domain. A total of 128 NGOs from 83 Member States responded. A classification according to socio-economic criteria of the NGOs responding to the questionnaire is presented in Table A<sup>2</sup>.

**Table A: Socio-economic classification of government responses**

<b>Classification</b>	<b>No. of responses</b>	<b>Percentage</b>
Developed market-economy countries	17	20.5
Developing countries: Least developed countries	19	22.9
Developing countries: Other developing countries (excluding least developed countries)	39	47.0
Economies in transition	8	9.6
<b>Total</b>	<b>83</b>	<b>100.0</b>

<sup>1</sup> The selected NGOs belong to the international organizations represented in the Panel of Experts, i.e. Disability Persons International (DPI), Inclusion International (ILSMH), Rehabilitation International (RI), World Blind Union (WBU), World Federation of the Deaf (WFD), World Network of Users and Survivors of Psychiatry (WNUSP).

<sup>2</sup> The classifications used in this report are based on the classification of 1st May 1998 used by the United Nations. This classification is an update of the classifications used by the United Nations in the *World Economic and Social Survey 1997*. The groupings are employed for analytical purposes only and do not have any official status.

## 4-Summary

Table B shows region-wise classification of NGOs included in the analysis. There were a total of 128 NGOs, of which 45 NGOs (35.2%) were from the European Region, a quarter (25%) from the African Region, 23 (18%) were from the American Region, 11 (8.6%) from the Western Pacific Region, 8 (6.2%) from the Eastern Mediterranean Region and 9 (7%) from the South East Asian Region. These NGOs represented 83 member countries of the WHO.

**Table B: Regional distribution of WHO member states**

<b>Region</b>	<b>No. of Countries</b>	<b>No. of NGOs</b>	<b>Percent NGOs</b>
African	23	32	25.0
American	15	23	18.0
Eastern Mediterranean	7	8	6.2
European	26	45	35.2
South East Asian	6	9	7.0
Western Pacific	6	11	8.6
<b>Total</b>	<b>83</b>	<b>128</b>	<b>100.0</b>

The survey, for the first time has attempted to bring together information on the status of the persons with disability, worldwide. Some countries were represented by more than one NGO and thus many questions had multiple answers given by NGOs depending on their involvement in a particular type of work and the area of disability.

The Standard Rules establish that solutions must be sought not only at the individual level, but also in society that hinders real participation (barriers in the physical environment, legislation, education etc.). The policies should aim at enabling persons with disabilities to be included in society, meaningfully, and to adapt to the environment suitably so that the needs of persons with disabilities are met for maximum social interaction. To reach the objective of Equalization of Opportunities some basic preconditions must be fulfilled. For instance, provision of qualified medical care, provision of rehabilitation services wherever necessary, as well as elimination of discrimination against persons with disabilities.

This Report is an overview of the present Regional situation with respect to the level of implementation of the four Standard Rules under review here. Policy makers, administrators, program implementers and rehabilitation specialists for planning and implementation of programs related to disability can use this information.

### **Methodological Considerations**

Presenting a global perspective is a challenging task for any researcher. Standardization of definitions and classifications to fit into a questionnaire applicable in different social, cultural and administrative settings to draw meaningful analyses is commendable. Many basic concepts, such as medical care system, prevention of impairment and rehabilitation services, required for the survey have different interpretations in different countries. The policies regarding these concepts also vary. There is also a difference in significance attached to policy statements.

A critical balance was maintained while analyzing this type of data to take care of diversity among the countries and within the country between NGOs. The overall results indicate that

there are disparities among the countries and the type of services provided. Certain groups of persons with disability are neglected in quite a few countries. The governments, municipalities, and NGOs need better and coordinated efforts to provide services to persons with disability. Finance and financial subsidies are the critical areas where the social insurance schemes offer more options to the persons with disability. Administrative differences in certain countries such as Singapore, where there is no district or province, made regional interpretations inconclusive for questions such as availability of medical/paramedical staff at each level. Therefore, caution was taken while interpreting the data, keeping in mind the socio-cultural and political variations of the countries within the Region. Another area, which was difficult to analyze, was the total reliance on the information given by an NGO. There was a tendency to know more about the specific disability in the area of their work rather than an overall view of various types of persons with disabilities in the country. As a result, underestimation could not be avoided, particularly when one NGO report has been taken to represent the entire country. However, the Comparative Report of the NGOs and government would give a more realistic view of the policy and implementation of the four rules.

Despite the difficulties, the effort to interpret all the data collected from various sources is nonetheless worthwhile, since it enables countries to make useful comparisons and to share information on policy and practice. Such data are needed to plan both general socio-political measures to optimize the environment for persons with disabilities and more individual support services.

The study aims primarily to identify tendencies and patterns. However, the cross-national character of this study is limiting, giving only an approximate picture of the present condition, worldwide, for persons with disabilities. The tendencies and patterns, old and new, will indicate the trend.

The survey results can act as a powerful stimulus towards reforms and guidelines to review the neglected areas. The previous survey<sup>3</sup> was widely used and thus has generated a great deal of positive feedback.

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<sup>3</sup> *Government Action on Disability Policy*, Office of the United Nations' Special Rapporteur on Disability, Stockholm, 1997. This survey concentrated on four other Rules, namely, Rule 15 on Legislation, Rule 5 on Accessibility, Rule 18 on Organizations of Persons with Disabilities and Rule 17 on Coordination of Work. Therefore, an overall comparison between these two studies cannot be easily done.

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## MEDICAL CARE

The basic information on medical care was whether the medical care system provides services to persons with disabilities. According to the opening paragraph in the Rule on Medical Care, “States should ensure the provision of effective medical care to persons with disabilities.” The first question indicates the extent to which states comply with this rule. Medical care is provided to persons with disabilities in almost all the countries.

**Table 1**

**Question 1: Medical care system providing services to persons with disabilities in the country**

Services to persons with disabilities	No. of NGOs	Percentage
Yes	119	93.0
No	9	7.0
<b>Total</b>	<b>128</b>	<b>100</b>

Table 2 shows that in over half the countries there is no tendency to provide medical care services outside the general medical care services.

**Table 2**

**Question 1a: Treatment given to certain groups of persons with disabilities outside the general medical care services in the country**

Treatment given	No. of NGOs	Percentage
Yes	54	45.4
No	65	54.6
<b>Total</b>	<b>119</b>	<b>100.0</b>

The first paragraph in the Rule on Medical Care is, “States should work towards the provision of programs for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects.” The most commonly included program in the medical care system is treatment of impairment. In most of the countries, medical care system includes prevention of impairment, early detection and diagnosis, and rehabilitation techniques. Counseling for parents and referrals is not as common as the other programs.

**Table 3**

**Question 2: Programs included in the medical care system**

Programs	No. of NGOs	Percentage
Prevention of impairment	101	78.9
Early detection & diagnosis	98	76.6
Treatment of impairment	114	89.1
Rehabilitation techniques	101	78.9
Necessary referrals	86	67.2
Counseling for parents	84	65.6
None	1	0.8
<b>Total = 128*</b>		

\* Multiple responses

According to the first paragraph in the Rule on Medical Care on the provision of programs for early detection, assessment and treatment of impairment, “States should ensure full participation of persons with disabilities, and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level”. Table 4 summarizes the degree of involvement of organizations of persons with disabilities in planning and evaluation of these programs. Over half of the countries reported that organizations of persons with disabilities are ‘sometimes’ involved in the planning and evaluation of these medical care systems. Around 15 percent NGOs stated that ‘often’ organizations of persons with disabilities are involved in the planning and evaluation of medical care systems, while as many as 30 percent NGOs stated that these organizations are ‘never’ involved.

**Table 4**

**Question 3: Degree of involvement of organizations of persons with disabilities in planning and evaluation of these programs**

Degree of involvement	No. of NGOs	Percentage
Always	1	0.8
Often	20	15.6
Sometimes	69	53.9
Never	38	29.7
<b>Total</b>	<b>128</b>	<b>100.0</b>

Early detection of impairment is done at all the three stages in various degrees; the least is at four to seven years (Table 5). While six NGOs reported that early detection is not done at all, one NGO stated that it is done at the prenatal stage as well. Early detection needs to be conducted at all the three stages equally well till the child is seven years old since some disorders would manifest when the child is older.

**Table 5**

**Question 4: Age at which early detection methods for children with disabilities are performed**

Age of children	No. of NGOs	Percentage
Prenatal	1	0.8
0-6 months	81	63.3
6 months-3 years	82	64.1
4-7 years	64	50.0
None	6	4.7
<b>Total = 128*</b>		

*\*Multiple responses*

The paragraph 3 of the Rule on Medical Care ensures that infants and children with disabilities are given the same level of medical care within the same system as other members of the society. The question 5 asks just that and, if it was not within the same system, then

why not. As Table 6 shows, infants and children are provided with medical care within the same system as other infants and children as reported by over three-fourths of the NGOs.

**Table 6**

**Question 5: Medical care for children with disabilities within the general medical care system**

Medical care within the same system	No. of NGOs	Percentage
Yes	98	76.6
No/no response	30	23.4
<b>Total</b>	<b>128</b>	<b>100.0</b>

The reason, as reported by NGOs from a third of the countries which do not provide medical care within the same system as other infants and children, was mostly lack of a specific program. Other reasons reported were difficulties in the families due to economic constraints, lack of training, societal attitudes and lack of staff.

**Table 7**

**Question 5a: Reasons for not treating children with disabilities within the same system**

Reason	No. of NGOs	Percentage
Lack of specific programs	25	83.3
Lack of staff	11	36.7
Lack of training	14	46.7
Societal attitude	12	40.0
Difficulties in the families due to economic constraints	17	56.7
Other	5	16.7
<b>Total = 30*</b>		

\* Multiple responses

Next, it was asked whether persons with chronic disabilities are provided with regular medical treatment to preserve or improve their level of functioning and, if not, why. According to paragraph 6 of the Rule on Medical Care, “States should ensure that persons with disabilities are provided with regular medical treatment and medicine, they may need to preserve or improve their level of functioning.” About one-third of the NGOs reported that persons with chronic disabilities are not provided with regular medical treatment to preserve or improve their level of functioning.

**Table 8**

**Question 6: Provision of regular medical treatment to preserve or improve level of functioning**

Regular medical treatment	No. of NGOs	Percentage
Yes	89	69.5
No	39	30.5
<b>Total</b>	<b>128</b>	<b>100.0</b>

Countries that do not provide persons with disabilities with regular medical treatment to preserve or improve the level of functioning, have given the main reason to be lack of specific programs followed by difficulties in the families due to economic constraints. Other less frequent reasons given were lack of training, lack of staff, and societal attitude.

**Table 9**

**Question 6a: Reasons for not providing regular medical treatment**

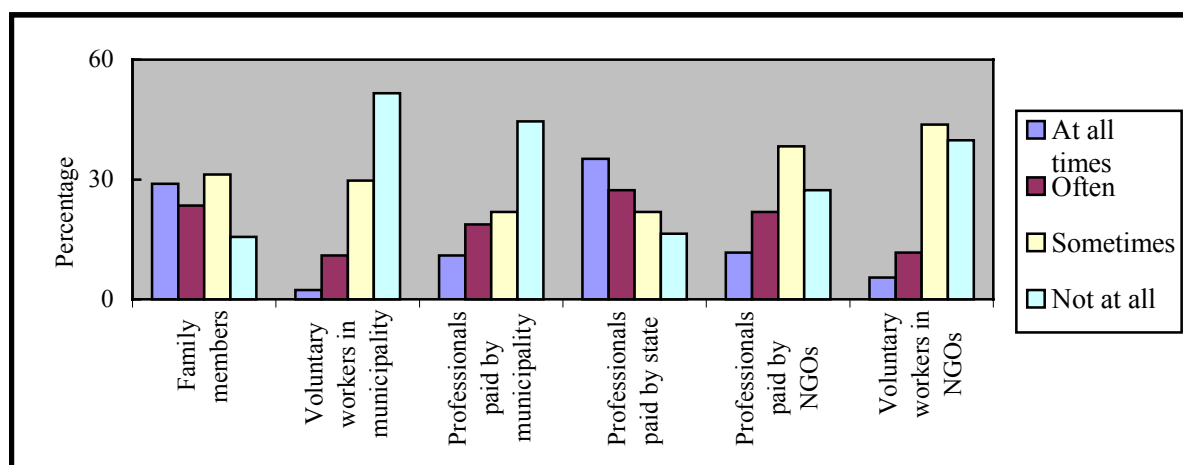
Reason	No. of NGOs	Percentage
Lack of specific programs	34	87.2
Lack of staff	16	41.0
Lack of training	17	43.6
Societal attitude	16	41.0
Difficulties in the families due to economic constraints	25	64.1
Other	7	17.9
<b>Total = 39*</b>		

\* Multiple responses

The first paragraph in the Rule on Medical Care states that, “A multidisciplinary team of professionals should run the provision of programs, and furthermore, that such programs should ensure full participation of persons with disabilities and their families at the individual level and of organizations of persons with disabilities at the planning and evaluation level.” The aim of this analysis was to identify the groups in society with the responsibility of providing medical care and to find out whether the society undertakes the economic responsibility of providing medical care to citizens with disabilities or whether this responsibility is laid upon civil society members and as a consequence, whether medical care is provided by professionals. Figure 1 summarizes this. Mostly family members and professionals paid by the state are involved in providing medical care ‘at all times’. Professionals paid by NGOs and voluntary workers in NGOs are mostly ‘sometimes’ involved. The ‘least’ involved is the municipality, while the family members are almost ‘always’ involved.

**Figure 1**

**Question 7: Level of involvement of medical care providers**



An attempt was made to determine the sources of financing medical care. Table 10 indicates that medical care subsidy is commonly provided through social insurance schemes. The government ministries provide this in over a third of the countries. But mostly the persons with disabilities themselves pay for their medical care fully or partially. A few other schemes also exist.

**Table 10**

**Question 8: Payment for medical care subsidies**

<b>Payment for medical care</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Provided free of charge by government	50	39.1
Paid by social insurance scheme	74	57.8
Paid fully by patients	45	35.2
Paid partially by patients	79	61.7
Other	21	16.4
<b>Total = 128*</b>		

\* Multiple responses

In countries where social insurance schemes provide medical care subsidy, mostly children are covered. All adults and the elderly are also covered, but to a lesser extent. ‘Working adults only’ was stated by about 43 percent of NGOs.

**Table 11**

**Question 9: Groups covered by social insurance schemes**

<b>Groups</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Children	61	82.4
All adults	47	63.5
Working adults only	32	43.2
Elderly	50	67.6
<b>Total = 74*</b>		

\* Multiple responses

Over half the NGOs stated that the social insurance schemes cover between 61-100 percent of the population. Whereas, less than 40 percent of the population coverage was reported by over one-third of the NGOs.

**Table 12**

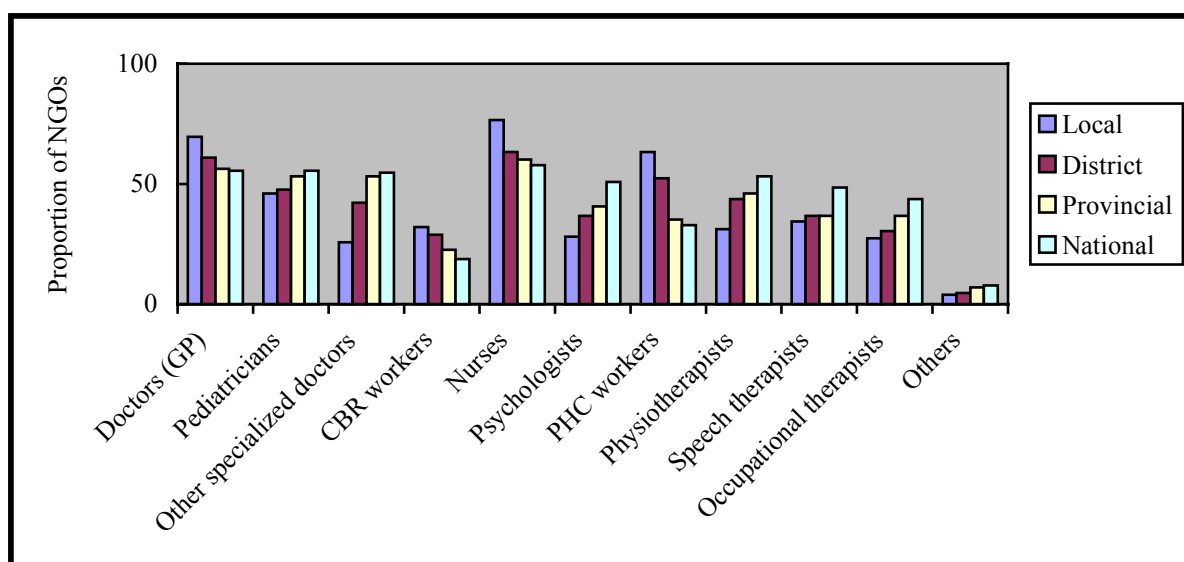
**Question 10: Extent of the population covered by social insurance schemes**

<b>Population covered (%)</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Less than 20	10	13.5
21-40	14	18.9
41-60	6	8.1
61-80	7	9.5
81-100	33	44.6
No response	4	5.4
<b>Total</b>	<b>74</b>	<b>100.0</b>

The importance of adequately trained and equipped medical and paramedical staff is stressed in two paragraphs in the Rule on Medical Care. According to Paragraph 4, “States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.” And Paragraph 5, “States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.”

Medical and paramedical staff available at different levels is shown in Figure 2. Doctors and nurses are very well represented at all the levels. Pediatricians are also well represented at all levels, but to a lesser extent. CBR workers are least available. At the local level, other specialized doctors, psychologists, physiotherapists, speech therapists and occupational therapists are less available. Inaccessibility of these services inconvenience persons with disabilities, particularly when they have to commute long distances repeatedly. The lack of availability of psychologists at the local and district levels would restrict counseling to be an ongoing process, since practically it would be difficult to access them. CBR workers are mostly available only at the district level and not at other levels. Wide variation exists in the availability of staff connected with therapy. The trend shows a decline for doctors, CBR workers, nurses, and PHC workers from local to national level, while it increases for other medical and paramedical staff.

**Figure 2**  
**Question 11: Availability of medical and paramedical staff at all levels**



The second paragraph in the Rule on Medical Care states, “Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.” Table 13 shows that medical care services reach the villages and the poor in urban areas in most of the countries.

**Table 13****Question 12: Provision of medical care services in village and poor urban areas**

<b>Services in villages and poor urban areas</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Yes	115	89.8
No	13	10.2
<b>Total</b>	<b>128</b>	<b>100.0</b>

The subsequent question notes the type of services provided in these areas. Table 14 shows that by far the most frequent form of service is primary health care. Community based rehabilitation and other types of approaches such as outreach and public health centers reach the villages and the urban poor.

**Table 14****Question 12a: Type of services provided in villages and in poor urban areas**

<b>Type of service</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Primary health care	107	92.9
Community based rehabilitation	37	39.3
Other	11	10.7
No response	1	3.6
<b>Total = 116*</b>		

\* Multiple responses

The services provided to facilitate information and communication between persons with disabilities and staff in health care is given in Table 15. The most frequent service given to facilitate information and communication between persons with disabilities and the staff in health care is easy reading information. Less frequently provided is information in Braille, sign language interpretation, and information on tape. This reveals that provision of facilities for providing information and communication between persons with disabilities and health care personnel is inadequate. Persons with all types of disabilities are also not provided with facilities for facilitating communication.

**Table 15****Question 13: Type of services provided to facilitate information and communication between persons with disabilities and the staff in health care**

<b>Type of services</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Information in Braille	48	37.5
Information on tape	40	31.3
Sign language interpretation	49	38.3
Easy reading information	53	41.4
No response/none	40	31.3
<b>Total = 128*</b>		

*Multiple responses*

## REHABILITATION

“WHO estimates that more than 300 million people worldwide are disabled, over 70% of whom live in developing countries. Only about one to two percent of persons with disabilities in the developing world have access to rehabilitation and majority of them are relegated to the margin of society. Over the past decade, WHO has been promoting community based rehabilitation as a way to increase access to rehabilitation and promoting equalization of opportunities for the social integration of persons with disabilities into the community and society. This approach employs resources within the family and community, along with support from the referral system.”

The opening paragraph in Rule 3 on Rehabilitation says, “States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.” National rehabilitation programs exist for persons with disabilities in over half the countries.

**Table 16**

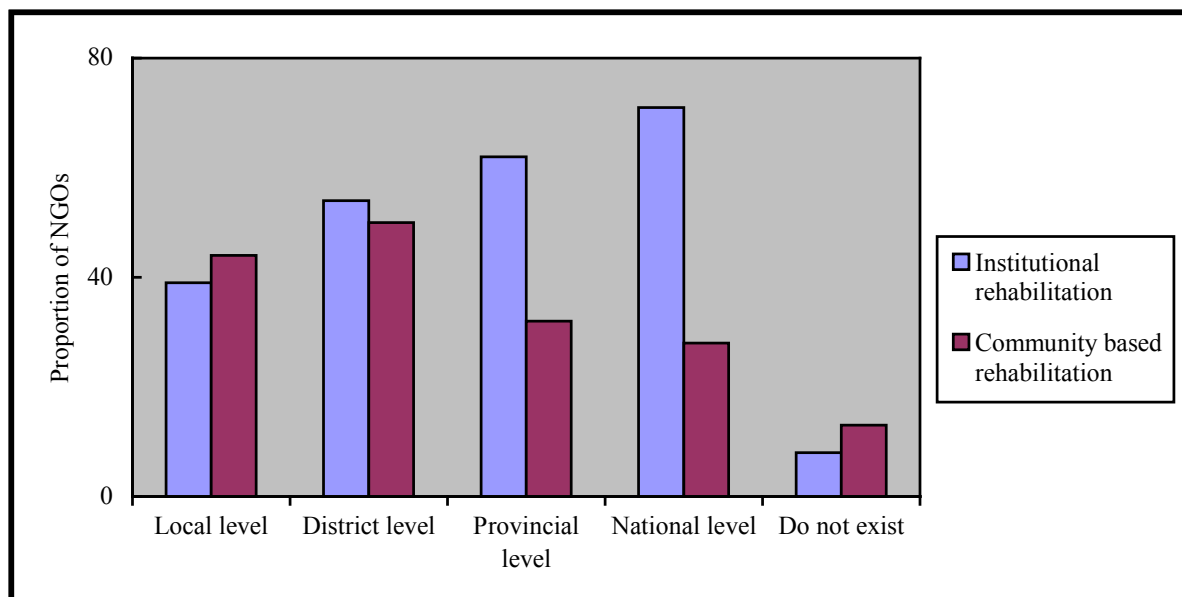
**Question 14: National rehabilitation programs available for persons with disabilities**

<b>Rehabilitation programs</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Do not exist	61	47.7
Exist	67	52.3
<b>Total</b>	<b>128</b>	<b>100.0</b>

Paragraph 5 in the Rule on Rehabilitation states, “All rehabilitation services should be available in a community where the person with disability lives. However, in some instances, in order to attain a certain training objective, special time limited rehabilitation courses may be organized, where appropriate, in residential form.” In this regard, the NGOs have reported that while more of community based rehabilitation is available at the local and district levels, it is more of institutional rehabilitation at the provincial and national levels. Wide variation is found at the provincial and national levels in the availability of institutional and community based rehabilitation. Rehabilitation programs are least available at the local level. Only a few countries do not have rehabilitation programs.

**Figure 3**

**Question 15: Level at which institutional and CBR programs are available**



Wherever rehabilitation is available, it mostly reaches less than 20 percent of the population with disabilities. Nearly ten percent NGOs stated that it reaches 81-100 percent of the population. The population coverage is low.

**Table 17**

**Question 16: Percentage of persons with disabilities receiving rehabilitation**

Population receiving rehabilitation (%)	No. of NGOs	Percentage
Less than 5	34	26.6
6-20	26	20.3
21-40	10	7.8
41-60	7	5.5
61-80	10	7.8
81-100	12	9.4
Not applicable/no response	29	22.7
<b>Total</b>	<b>128</b>	<b>100.1</b>

According to Rule 3 on Rehabilitation, “All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.” Largely persons with mobility impairment, persons with severe sight impairments, and persons with intellectual disabilities are provided with rehabilitation and to a lesser extent persons with hearing impairments and persons with hearing disabilities also receive rehabilitation services. The disability groups with least access to rehabilitation are persons with intellectual disabilities, persons with learning difficulties, persons with disabilities due to chronic diseases, persons with disabilities owing to mental illness and persons with multiple/severe disabilities. Thus, this implies that disability groups do not receive rehabilitation equally well and that although all the disability groups receive rehabilitation, the population coverage does not correspond to the groups covered.

**Table 18****Question 17: Type of disability groups receiving rehabilitation**

<b>Disability groups</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Persons with mobility impairment	115	89.8
Persons with hearing impairment	100	78.1
Persons with hearing disabilities	97	75.8
Persons with severe sight impairment	107	83.6
Persons with intellectual disabilities (mental handicap)	104	81.3
Persons with learning disabilities (e.g. dyslexia)	87	68.0
Persons with disabilities owing to chronic diseases (e.g. epilepsy)	83	64.8
Persons with disabilities owing to mental illness (e.g. schizophrenia)	86	67.2
Persons with multiple/severe disabilities	83	64.8
None/no response	4	3.1
<b>Total = 128*</b>		

\* *Multiple responses*

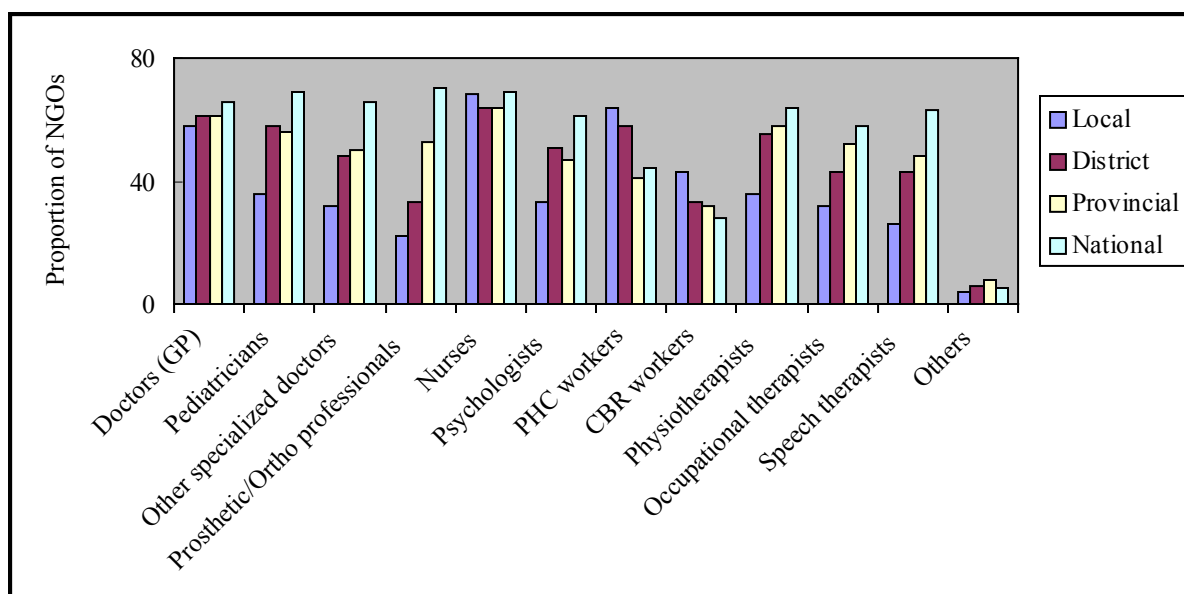
As indicated in paragraph 3 in the Rule on Rehabilitation, all persons with disabilities should have access to rehabilitation, irrespective of age. It is revealed in Table 19 that all age groups are included in the rehabilitation services in three-fourths of the countries.

**Table 19****Question 18: All age groups included in rehabilitation services**

<b>All age groups in rehabilitation services</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Included	95	74.2
Not included	33	25.8
<b>Total</b>	<b>128</b>	<b>100.0</b>

Professional groups involved in providing rehabilitation services are shown in Figure 4. Doctors and nurses are available at all levels for rehabilitation, whereas the CBR workers are the least available. There is a general increasing trend in the availability of all medical and paramedical staff, except for nurses, PHC workers and CBR workers, from the local to the national level. This variation is particularly wide for pediatricians, other specialized doctors, prosthetic/orthotic professionals, physiotherapists, occupational therapists and speech therapists.

**Figure 4**  
**Question 19: Availability of medical and paramedical staff in rehabilitation at all levels**



Paragraph 5 in the Rule on Rehabilitation requires that, “All rehabilitation services should be available in the local community where the person with disabilities lives.” Tables 20 and 21 indicate the availability of rehabilitation services at the community level and the way these services are organized. As is shown in Table 20, these rehabilitation services are available in most countries.

**Table 20**  
**Question 20: Rehabilitation services at community level**

Rehabilitation services	No. of NGOs	Percentage
Exist	96	75.0
Do not exist	32	25.0
<b>Total</b>	<b>128</b>	<b>100.0</b>

These rehabilitation services are mostly available through NGOs; about 65 percent NGOs have reported this. They are also provided through primary health care and community based rehabilitation. Hospitals and other institutions also provide rehabilitation services at the community level.

**Table 21**  
**Question 20a: Organization of rehabilitation services at community level**

Rehabilitation services provided through	No. of NGOs	Percentage
Primary health care	46	47.9
Community based rehabilitation	44	45.8
Non-governmental organizations	62	64.6
Other	7	7.3
No response	3	3.1
<b>Total = 96*</b>		

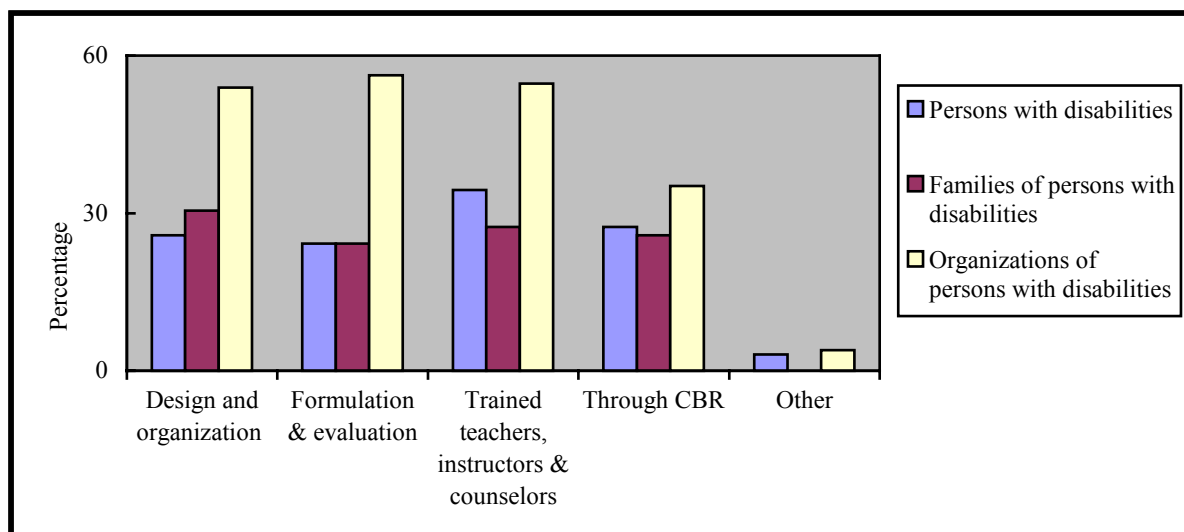
\* Multiple responses

The extent of participation of persons, families and organizations involved in the area of disabilities, is presented in Figure 5. The importance of this is amply provided in three paragraphs in Rule 3 on Rehabilitation:

- “Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.”
- “Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counselors.”
- “States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programs.”

As shown in Figure 5, organizations/agencies of persons with disabilities participate in the provision of rehabilitation through design and organization of rehabilitation programs, formulation and evaluation and as trained teachers, instructors and counselors, to a lesser extent also through CBR. Persons with disabilities and families of persons with disabilities are also involved in these activities but to a much lesser extent. This indicates that participation in rehabilitation programs by key persons is low. The participation in community based rehabilitation is the least. For programs to be more effective there is a need to involve persons with disabilities as well as families of persons with disabilities as a demonstration to persons with disabilities and their families or care takers on coping with disabilities and other related issues. Involvement of all these groups needs to be increased in the provision of community based rehabilitation.

**Figure 5**  
**Question 21: Participation in rehabilitation services**



## SUPPORT SERVICES

According to the fourth paragraph of the Rule on Support Services, “States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.” Table 22 shows the sources of financing assistive devices and equipment. Finance for assistive devices and equipment is almost equally shared by the government ministries and NGOs and persons with disabilities themselves and to a lesser extent also by social insurance schemes. About 30 percent of persons with disabilities pay fully for the assistive devices and equipment. The least involved are the municipalities.

**Table 22**

**Question 22: Arrangements for financing assistive devices and equipment**

Source of finance	Fully	Partially	Not at all
Government ministries	17.2 (22)	56.3 (72)	25.8 (33)
Municipalities	9.4 (12)	33.6 (43)	56.3 (72)
Social insurance scheme	10.9 (14)	50.0 (64)	38.3 (49)
Persons with disabilities	30.5 (39)	57.8 (74)	20.3 (26)
NGOs	16.4 (21)	62.5 (80)	27.3 (35)
Other	3.1 (4)	7.8 (10)	78.9(101)
No response	1.6 (2)	1.6 (2)	1.6 (2)
<b>Total = 128*</b>			

\* Multiple responses

Note: Figures in brackets are number of NGOs.

Table 23 shows that social insurance schemes make payments for the assistive devices and equipment, covering all children, all adults, and the elderly. Over half the NGOs stated that all adults and the elderly are covered. Children are covered the most than any other group, stated by over 61 percent NGOs.

**Table 23**

**Question 23: Groups covered by social insurance schemes for providing assistive devices**

Groups	No. of NGOs	Percentage
Children	47	61.8
All adults	38	50.0
Working adults only	36	47.4
Elderly	39	51.3
No response	7	9.2
<b>Total = 76*</b>		

\* Multiple responses

Paragraph 2 of the Rule on Support Services stresses that, “States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.” Nearly three-fourths of the NGOs stated that their government is involved in the provision of assistive devices.

**Table 24****Question 24: Government involvement in the provision of assistive devices**

<b>Government involvement</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Exists	95	74.2
Does not exist	33	25.8
<b>Total</b>	<b>128</b>	<b>100.0</b>

The nature and extent of involvement in providing assistive devices differs. The governments are usually involved in the provision of information about the availability of assistive devices and distribution followed by development and production and their maintenance and repair. Some other ways of providing assistive devices also exist.

**Table 25****Question 24a: Type of involvement in the provision of assistive devices**

<b>Type of involvement</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Development and production	47	49.5
Distribution	55	57.9
Maintenance and repair	46	48.4
Information about availability	56	58.9
Other	9	9.5
<b>Total = 95*</b>		

\* *Multiple responses*

According to the first paragraph of Rule 4 on Support Services, “States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of the persons with disabilities, as important measures to achieve the equalization of opportunities.” Table 26 shows that the most commonly provided assistive device by the government is prostheses/orthoses followed by wheel chairs and crutches. To a lesser extent hearing devices and visual devices are provided, there is an indication that the visually impaired are less catered for, than the hearing disabled. Devices for daily living and computers are the least provided items. Most of the governments are involved in providing assistive devices to persons with mobility impairment.

**Table 26****Question 25: Type of assistive devices and equipment provided by the government**

<b>Type of assistive devices/equipment</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Prostheses/Orthoses	82	86.3
Wheel Chairs	77	81.1
Crutches	78	82.1
Hearing Devices	70	73.7
Visual Devices	61	64.2
Devices for daily living	42	44.2
Computers	23	24.2
Other	2	2.1
<b>Total = 95*</b>		

\* *Multiple responses*

According to paragraph 6 of the Rule on Support Services, “States should support the development and provision of personal assistance programs and interpretation services, especially for persons with severe and/or multiple disabilities. Such programs would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and leisure-time activities”. Personal assistance is important to a disabled person; it gives the person psychological and emotional support. Most of all it ensures safety, particularly in countries where the system is not yet designed to be disabled-friendly. Table 27 shows that personal assistance is provided in some countries. It is not provided in about one-third of the countries. Understandably, personal assistance is not provided so extensively, for the high costs involved in doing so.

**Table 27**  
**Question 26: Provision of personal assistance**

<b>Personal assistance</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Provided	88	68.8
Not provided	40	31.3
<b>Total</b>	<b>128</b>	<b>100.0</b>

Mostly, personal assistance is provided at home, may be rendered by the relatives, followed by school, social services, health care services and work places. It is least provided during leisure. This implies that persons with disabilities are not encouraged to be employed, as without personal assistance it would be difficult for most of persons with disabilities to function.

**Table 28**  
**Question 26a: Localities/activities where personal assistance is provided**

<b>Localities/Activities</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Home	59	67.0
School	55	62.5
Work	44	50.0
During leisure	7	8.0
Health service	51	58.0
Social service	48	54.5
Other	16	18.2
<b>Total = 88*</b>		

\* *Multiple responses.*

Table 29 shows that in all the countries, the most common method of financing personal assistance is partially through the government, NGOs and the persons with disabilities themselves. Social insurance schemes were the other less common sources of finance. The least involved were the municipalities. In a few countries, other arrangements also existed.

**Table 29****Question 27: Arrangements for financing personal assistance**

Source of finance	Fully	Partially	Not at all
Government ministries	17.4 (16)	68.5 (63)	39.1 (36)
Municipalities	13.0 (12)	34.8 (32)	55.4 (51)
Social insurance schemes	12.0 (11)	37.0 (34)	57.6 (53)
Persons with disabilities	38.0 (35)	59.8 (55)	27.2 (25)
NGOs	22.8 (21)	59.8 (55)	40.2 (37)
Other	2.2 (2)	1.1 (1)	87.0 (80)
<b>Total = 92*</b>			

\* Multiple responses

Note: Figures in brackets are number of NGOs.

Support is provided to families of children with disabilities in most countries. Support is not provided in a third of the countries.

**Table 30****Question 28: Support provided to families of children with disabilities**

Support	No. of NGOs	Percentage
Provided	89	69.5
Not provided	39	30.5
<b>Total</b>	<b>128</b>	<b>100.0</b>

Largely, the government ministries and NGOs finance support to the families of children with disabilities. While persons with disabilities themselves provide full or partial financial support to families of children with disabilities, the municipalities also do so partially. Social insurance schemes provide support in a few countries.

**Table 31****Question 28a: Arrangements for financing support to the families**

Source of finance	Fully	Partially	Not at all
Government ministries	13.0 (12)	58.7 (54)	30.4 (28)
Municipalities	7.6 (7)	40.2 (37)	54.3 (50)
Social insurance schemes	8.7 (8)	29.3 (27)	60.9 (56)
Persons with disabilities	19.6 (18)	44.6 (41)	42.4 (39)
NGOs	17.4 (16)	48.9 (45)	39.1 (36)
Other	1.1 (1)	1.1 (1)	44.6 (41)
<b>Total = 92*</b>			

\* Multiple responses

Note: Figures in brackets are number of NGOs.

According to 65 percent NGOs interpreter services are provided in their country, whereas the remaining NGOs have reported the absence of such services in their country.

**Table 32****Question 29: Provision of interpreter service**

<b>Interpreter services</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Provided	83	64.8
Not provided	45	35.2
<b>Total</b>	<b>128</b>	<b>100.0</b>

Interpreter services are most commonly available in schools. Interpreter services are not offered extensively at work places, social service centers, health service centers, homes and during leisure. A few countries provided these services in other places such as on TV. Generally, the interpreter services are poorly provided. This needs to be improved if persons with disabilities have to interact effectively and be with the mainstream, particularly at health services.

**Table 33****Question 29a: Localities/activities where interpreter service is provided**

<b>Localities/Activities</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Home	6	7.2
School	67	80.7
Work	33	39.8
Leisure	23	27.7
Health service	25	30.1
Social service	37	44.6
Other services in society	25	30.1
<b>Total = 83*</b>		

\* Multiple responses

Table 34 shows that there is very little financial assistance available for acquiring interpreter services through the governments, municipalities, and NGOs. Some NGOs have reported that the government does pay fully at times for the interpreter services. Persons with disabilities themselves mostly pay partially for interpreter services. Social insurance schemes are the least involved.

**Table 34****Question 30: Arrangements for financing interpreter service**

<b>Source of finance</b>	<b>Fully</b>	<b>Partially</b>	<b>Not at all</b>
Government ministries	20 (24.1)	32 (38.6)	35 (42.2)
Municipalities	6 (7.2)	17 (20.5)	60 (72.3)
Social insurance schemes	2 (2.4)	8 (9.6)	74 (89.2)
Persons with disabilities	16 (19.3)	29 (34.9)	44 (53.0)
NGOs	17 (20.5)	38 (45.8)	33 (39.8)
Other	2 (2.4)	4 (4.8)	42 (50.6)
<b>Total = 83*</b>			

\* Multiple responses

Note: Figures in brackets are number of NGOs.

Persons with disabilities and/or their organizations are involved in the planning of support services as stated by over half the NGOs, while the other half stated that either they are not involved or there is no response from them to this question.

**Table 35**

**Question 31: Involvement of persons with disabilities and/or their organizations in the planning of support services**

<b>Involved</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Yes	72	56.3
No/no response	56	43.8
<b>Total</b>	<b>128</b>	<b>100.1</b>

## PERSONNEL TRAINING

An important tool to ensure quality and effective professional care for persons with disabilities is to train the personnel involved. WHO has noted this as, “Over the years, this priority has been refined and expanded. It now not only includes human resource planning but also consideration of the optimal mix of different categories of health professionals to deliver the most effective service of an acceptable quality. WHO has also successfully promoted the incorporation of sound educational principles to ensure relevant training curricula and effective learning.” The first paragraph of the Rule on Personnel Training suggests, “States should ensure that all authorities providing services in the disability field give adequate training to their personnel.” Over half of the government ministries have a mechanism to ensure that all authorities/agencies providing services in the field of disability give training to their personnel (Table 36). A large number of countries do not have such a mechanism (reported by about 47 percent NGOs). This is regrettable since it implies that a large proportion of persons with disabilities do not get care from trained personnel, thus reducing the quality of care and the effectiveness of the disability program.

**Table 36**

**Question 32: Training ensured to professionals in the disability field**

<b>Training</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Ensured	68	53.1
Not ensured	60	46.9
<b>Total</b>	<b>128</b>	<b>100.0</b>

In countries where training is ensured, it is mostly through the policies adopted by the government ministries and through supervision of training curriculums for medical and paramedical staff. Other methods are also used in some countries to ensure professionalism.

**Table 37**

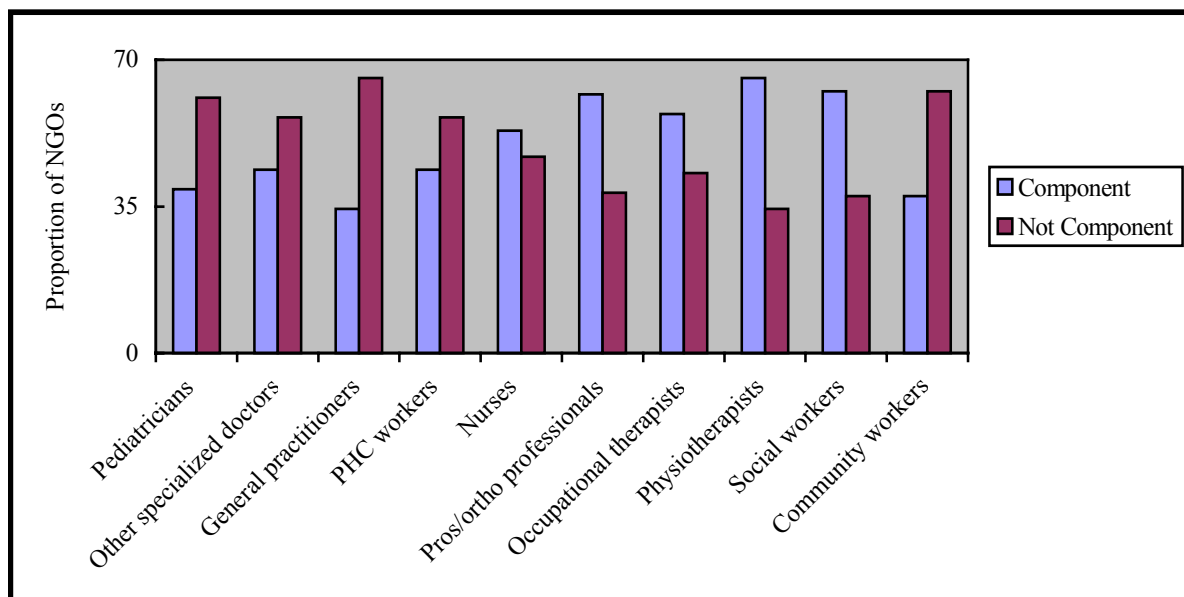
**Question 32a: Methods to ensure training of professionals**

<b>Method to ensure training</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Policy adopted by government ministries	47	69.1
Supervision of training curriculums	39	57.4
Other	12	17.6
<b>Total = 68</b>		

In support of the second paragraph of the Rule on Personnel Training, “In the training of the professionals in the disability field, as well as in the provision of information on disability in general training programs, the principle of full participation and equality should be appropriately reflected”, an item on training curriculum was included in the questionnaire. Figure 6 shows that largely disability issues are a component in the training curriculums of prostheses/orthotic professionals, occupational therapists, physiotherapists, and social workers. To some extent, nurses also have disability as a component in their training program. General practitioners, pediatricians and community workers have the least training on disability issues.

Disability issues are not a component in most of the training curriculums of the medical and paramedical staff. Some of the medical and paramedical staff such as, nurses at all the levels and PHC staff at the grassroots level, are involved largely in providing services to persons with disabilities. It is important for pediatricians to have disability as a component since they are the specialists dealing with children when the disability is diagnosed. Nurses are mostly involved at all levels in providing medical care and rehabilitation therefore, there is a need for disability issues to be included in all training curriculums for nurses. It is rather discerning that these groups of personnel lack formal training in the care of persons with disabilities.

**Figure 6**  
**Question 33: Disability issues in the training curriculum**



According to the third paragraph of the Rule on Personnel Training, “States should develop training programs in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programs.” Staff training programs are developed to some extent in consultation with organizations of persons with disabilities. The programs would be more successful if they were involved in the training programs.

**Table 38**  
**Question 34: Training programs developed in consultation with organizations of persons with disabilities**

Organizations	No. of NGOs	Percentage
Consulted	37	28.9
Not consulted	91	71.1
<b>Total</b>	<b>128</b>	<b>100.0</b>

Table 39 shows that persons with disabilities are involved in staff training programs, to some extent. They need to be more involved if the programs are to become more effective and meaningful to persons with disabilities themselves.

**Table 39****Question 35: Involvement of persons with disabilities in staff training programs**

<b>Persons with disabilities</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Involved	51	39.8
Not involved	77	60.2
<b>Total</b>	<b>128</b>	<b>100.0</b>

In countries where persons with disabilities are involved, they are usually involved as advisers followed by teachers and the least as instructors (Table 40).

**Table 40****Question 35a: Role of persons with disabilities in staff training programs**

<b>Role</b>	<b>No. of NGOs</b>	<b>Percentage</b>
Teachers	27	52.9
Instructors	23	45.1
Advisers	36	70.6
<b>Total = 51*</b>		

\* *Multiple responses*

## CONCLUSIONS

Medical care is provided to persons with disabilities in most of the countries, the tendency is to provide these services outside the general medical care services. The medical care system does not include all the programs. Referrals and counseling to parents is weakly established. The organizations of persons with disabilities need to be more extensively involved in the planning and evaluation of the medical care system. Early detection of diseases leading to disabilities is mostly done during the early years. This needs to be increased to seven years of age so that detection continues when almost all such diseases would occur. Most countries do not provide regular medical treatment to preserve or improve the level of functioning of persons with chronic disabilities. Involvement of the municipality and NGOs in providing medical care needs to be increased. Services to facilitate information and communication between persons with disabilities and others are available to a limited extent.

Subsidies for medical care, support services, personal assistance, support to families and for interpreter services, are mostly provided by the government followed by NGOs. Social insurance schemes and municipalities need to share economic resources by providing more financial subsidies.

All medical and paramedical staff is available at all levels to differing extents in providing medical care. Doctors and nurses are usually well available at all levels. Overall, the least available are CBR workers. The general pattern in the availability of staff was the decrease from the national level to the local level, except for PHC workers and CBR workers. Staff availability was found to be better for medical services than for providing rehabilitation.

This analysis showed that medical and paramedical staff is not adequately trained, as indicated by their curriculum, which mostly does not include disability as an issue. This indicates that personnel who are involved in the field of disability are not trained professionals, persons with disabilities are, and therefore, not getting the benefit of trained personnel. Thus, implying that programs for persons with disabilities are not being effectively implemented. This also brings into question the quality of care being provided in most of the countries.

More involvement of organizations of persons with disabilities and a greater role of persons with disabilities is required in staff training programs for successful program implementation. Organizations of persons with disabilities participate in the rehabilitation program more than persons or families of persons with disabilities in providing medical care. For programs to be more effective there is a need to involve persons with disabilities as well as families of persons with disabilities as a demonstration to persons with disabilities and their families or care takers on coping with disabilities and other related issues.

Provision of rehabilitation is not widespread. While institutional based rehabilitation is more available at the provincial and national levels, it is community based rehabilitation at the local and district levels. Almost all types of disabilities and age groups are included in the rehabilitation program in most of the countries. However, persons with mobility impairments are taken care more than persons with other types of disabilities/impairments.

Although in most of the countries the government is involved in the provision of assistive devices and equipment, their involvement is not extensive. The services such as personal assistance and to a lesser extent, interpreter services exist. It is mostly in one or two sectors, such as personal assistance, which is mostly available at home, while interpreter services are available in schools. There is scope to increase these services for all activities. The poor availability of these may also be due to lack of resources or the reason that informal and voluntary support is provided in most cases.

Although this analysis was drawn from reports of NGOs, it is conclusive in indicating that persons with disabilities are a neglected group worldwide, and more needs to be done particularly in the areas of rehabilitation and training of personnel.