**English**

**Questionnaire onthe provision of support to persons with disabilities**

1. Please provide information on the following services that are available for persons with disabilities in your country, including data on their coverage, geographic distribution and delivery arrangements, funding and sustainability, challenges and shortcoming in their implementation:
2. Personal assistance;
3. In-home, residential and community support;
4. Support in decision-making, including peer support; and
5. Communication support, including support for augmentative and alternative communication.

Spina Bifida Federal Association of Sudan (SBFA) cares for children of spina bifida and hydrocephalus and provides them with all services they need. SBFA is the only service provider to this type of disability in Sudan. SBFA is member of International Federation of Spina Bifida and Hydrocephalus Associations (IF). IF is the only organization that supports us. IF supplies SBFA with shunts, catheters, cones and some funds which covers part of our expenses. According to our records we receive about 400 cases every year but other cases go to private clinics and some even go abroad. People in remote areas who got their own beliefs use local medicines and usually babies die.

The first step in treatment is explaining to parents the causes of the problem and the medical procedures and how to keep babies clean including the use of catheters and cones. In case the baby needs physiotherapy we advise parents where to go. In our awareness campaigns we emphasize the importance of folic acid and fortunately it is available in most clinics free of charge.

1. Please explain how persons with disabilities can access information about the existing services referred to in question one, including referral procedures, eligibility criteria and application requirements.

Usually parents know about our services from hospitals and clinics. Some get information through media and volunteers who do awareness campaigns. Doctors and paramedics refer them to us to get the necessary information and free shunts for surgeries and come back for training on how to use catheters through professional nurses. Now we are about to open one-stop center in Soba Teaching Hospital which is part of University of Khartoum to save parents the trouble of visiting different places.

1. Please elaborate on how these services respond to the specific needs of persons with disabilities throughout their life cycle (infancy, childhood, adolescence, adulthood and older age) and how is service delivery ensured in the transition periods between life cycle stages.

Since we have started our activities in 2007 we have no experience yet with people who are above thirty. We have 20 young people who are doing fine and they have been trained to look after themselves and help us in educating their age mates on spreading the prevention message and their experiences.

1. Please provide information on the number of certified sign language interpreters and deafblind interpreters available in your country.

We are not in position to respond to this question, although there are centres for such cases.

1. Please provide information on the existence of any partnership between State institutions and private service providers (e.g., non-governmental organizations, for-profit service providers) for the provision of support to persons with disabilities.

We have partnership with government, hospitals, universities, media and other relevant institutions. Now we are working with other disability organizations to form Sudan Disability Network to coordinate our efforts. We have partnerships with youth initiatives in other parts of the country.

1. Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of support services.

There is people with disabilities council that is doing this job in addition to DPOs and the network will play part in monitoring and there is Ministry of Social Affairs.

1. Please provide any other relevant information and statistics (including surveys, censuses, administrative data, reports, and studies) related to the provision of support to persons with disabilities in your country.

N/A