



The situation of implementation of services for children with disabilities at the local level: Interventions guideline document, towards improvement of the social and health services for of people with disabilities.

Tirana, May 2018

TABLE OF CONTENTS

- I. Introduction
- II. The situation pertaining the social services for people with disabilities in 10 municipalities of the country.
- III. The situation pertaining the health services for people with disabilities in 10 municipalities of the country.
- IV. Relevant intervention at the central level to ensure quality social services for people with disabilities.
- V. Relevant intervention at the central level to ensure quality health services for people with disabilities.

I. INTRODUCTION

The 2011 Census in Albania revealed that 6.2% of the population over 15 years of age (2,084,137 persons) is affected by one form or another of disability. Recent State Social Services data indicate that there are 140,840 identified disabled people, of whom 67,741 are beneficiaries of disability payment and 73,099 are beneficiaries of payments due to being persons with labor-depriving disabilities. 14,578 children are registered as beneficiaries of disability payments. This figure represents roughly 2% of the number of children in the country (n = 738990).

The study conducted by World Vision Albania and Save the Children in Albania, which aimed at measuring the prevalence of disability among children, identified that 10.4% of children aged 2-17 years encounter at least a major difficulty in carrying out an activity or fail to do it at all. The study also showed that only 7.8% of children with disabilities in Albania receive specialized services from a social center. Other findings of this study, pertinent to the health and social protection sectors, are the following:

Prevalence is higher in low-income households. 66% of children with disabilities live in low income households, while 30% of them live in households with average monthly income.

- ✓ The level of unemployment of parents of children with disabilities is reportedly quite high. 58% of mothers and 33% of fathers are unemployed, or work part-time/seasonally. 78.8% of these families are composed of four to six members.
- ✓ 38.6% of parents of children with disabilities are dissatisfied with the expenditures incurred for them in order to receive the service, versus 17.7% of parents of children without or with mild functioning difficulties.
- ✓ 70.4% of parents of children with or without mild functional disabilities, point to the poor quality of health services as the reason why they abstain from accessing it.
- ✓ In 58.3% of the cases the family doctor is the one to refer the child with disabilities to a specialist.
- ✓ Access to social services, such as specialized centers, day care centers, mental health centers and residential social care centers, is reported in this research to be significantly low. Only 7.8% of children with disabilities have received a specialized social service.
- ✓ 55.0% of parents report that the costs of obtaining the service for these children are either unaffordable or completely unaffordable for them.
- ✓ The main reasons for abstaining from social services of parents are their inability to bear the financial costs incurred by receiving the service (88.9%); lack of transport (20.0%);

lack of community service (8.9%); rejection of the service (11.1%), and inadequate service quality (8.9%).

- ✓ 86.9% of parents find the financial assistance either insufficient or completely insufficient to make ends meet and to afford the costs of disability-related services.
- ✓ Most of the children assessed by the medical commission receive only a financial support, while only 13.6% of them claim to receive home care from a specialist doctor. Other forms of support such as specialized medical and educational services, those of rehabilitation and psychosocial are utilized by less than 4% of these children.
- ✓ 1 in 3 children with disabilities face discrimination in public services such as health or social services.

CONTEXT

Ratification by the Albanian government of the Convention on the Rights of Persons with Disabilities (CRPD) presents new obligations for the Albanian Government in terms of: (a) legal amendments; (b) administrative practices; (c) access to disability; (d) standards of a higher level of ensuring and protecting the rights and a better quality of life for persons with disabilities. In recent years, a number of laws and policies have been drafted in the country regarding the promotion and protection of persons with disabilities, such as the National Action Plan on People with Disabilities, 2016-2020¹, Social Protection Strategy (2015-2020)², Social Inclusion Policy Document (SIPD 2016-2020)³, Law on Inclusion and Accessibility (2014)⁴, Law on Social Care Services in the Republic of Albania (2016)⁵. All of these documents, to the extent that they deal with issues related to persons with disabilities, have in their essence the implementation of the guidelines set out in the Convention on the Rights of Persons with Disabilities, ratified in December 2012 by the Albanian Government. Despite the fact that the legislative framework has undergone some improvements over the years, it is important to remember that legal obligations belong with and should be implemented by all levels of government. However, the legal and political framework, the new approach and the norms of the CRPD, often remain unknown in some of the central-level segments, and more so at the local level.

Despite efforts and measures taken for change, the community of people with disabilities still faces difficulties, which prevent them from being citizens with equal rights and opportunities with the rest of society. Citizens with disabilities face many obstacles in their efforts to get

1. 1 DCM No. 483, dated 29 June 2016, "The National Action Plan for Persons with Disabilities, 2016-2020".
2. 2 DCM No. 1071, dated 23.12. 2015, "On the adoption of the National Social Protection Strategy, 2015-2010".
3. 3 Decision of the Council of Ministers no. 87, dated 3.2.2016, "On the Approval of the Social Inclusion Policy Document 2016-2020".
4. 4 Law no. 93/2014 dated 28.07.2014, "On the Inclusion and Accessibility of Persons with Disabilities".
5. 5 Law No. 121, dated 21.11.2016, "On Social Services in the Republic of Albania"

involved in the country's socio-economic, political and cultural life. The difficulties, inter alia, relate to: (a) the lack of accessibility and consequently inclusion in terms of their participation in low levels in all aspects of life; (b) low level of income; (c) lack of services related to rehabilitation and integration; (d) lack of services in the communities where they live; (f) Discrimination, Stigmatization and Prejudice.

World Vision Albania (WVA) in cooperation with the Albanian Disability Rights Foundation (ADRF), took the initiative to draft a set of Local Plans with the focus on disability in 10 municipalities of the country. The Local Plans were developed respectively for the Municipalities of Durrës, Vlora, Korça, Elbasan, Kurbin, Librazhd, Lezha, Kamza, Dibra and Shkodra. The number of people with disabilities, beneficiaries of the schemes of disability payment and those for labor-depriving disability in these 10 Municipalities was 49,595, of which 23,121 beneficiaries of disability payments and 26,474 beneficiaries as people with labor-depriving disability in. Of them, nearly a tenth are children (9.97%, n = 4,946)

The drafting of the local plans for the inclusion of people with disabilities, a specific intervention, is in line with the legal and political framework that the Albanian government has adopted and is trying to implement in order to improve the quality of life of people with disabilities in Albania. Also, these plans are an added value for the Social Plans, which are and are being drafted in many of the country's municipalities.

The main areas where the work was focused to design the plans were those of: a) Social Services; b) Health services; c) Education. For each area, administrative data was collected from local and regional government stakeholders as well as Centers providing services for people with disabilities, be they with state support, civil society or religious institutions. Based on the situation as well as the legal and political framework adopted by the Albanian government, the main interventions were proposed, which are mandatory to be implemented at local and regional level in order to fulfill the obligations assumed, and in order to realize the rights of persons with disabilities in the areas of Education, Social Services and Health Services. The purpose of this policy document is to provide a brief overview of the situation of persons with disabilities in the 10 municipalities above mentioned and to guide the future interventions in order to improve the situation in terms of inclusion in Education, Social and Health Services.

II. THE SITUATION PERTAINING THE SOCIAL SERVICES FOR PEOPLE WITH DISABILITIES IN 10 MUNICIPALITIES OF THE COUNTRY.

Below are summarized the main findings in the ten targeted municipalities regarding social services.

1. In all ten municipalities, that this document covers, there are no specific structures for identifying and guiding the needs for services for persons with disabilities, as well as for cooperation and coordination of the work with other local and regional institutions in charge of issues related to disability. With the exception of the Municipality of Elbasan, existing structures in other municipalities are guided only towards the preparation of documentation of disability pay applicants.
2. There is a lack of focal point for disability in all municipalities, contrary to the stipulation of legal provisions deriving from Law no. 93/2014 dated 28.07.2014 "*On the Inclusion and Accessibility of Persons with Disabilities*".
3. The number of services for people with disabilities in all of the 10 municipalities with which there was collaboration, is 39. Of these, 11 are services supported by central and local government, in some cases in cooperation with donors. 28 other services are provided by civil society organizations and faith based organizations. 1,287 people out of 49,595 were identified as people with disabilities (2.59%) and they receive services in all ten municipalities, of which 301 people receive employment and vocational training services and 986 others, daycare, residential, different types of therapy according to their needs, as well as support in the community. 52% of beneficiaries from the 39 services in these 10 municipalities, are children (n = 670). This number constitutes 13.5% of the total number of children identified and found with disabilities by MCDWD in these 10 municipalities (n = 4,946).
4. Out of the ten municipalities contacted, only four of the offer the service of Community Center for Mental Health (CCMH) and only in one of the municipalities, this service was active, together with a supported shelter for individuals with mental health problems. The number of treatment services in these Centers was 15,646. The number of treated children cases was 666.
5. As indicated above (only 2.59% of people with disabilities receive services and only 13.5% of identified children with disabilities, receive services), existing services are insufficient to cover the various needs of all categories of people with disabilities. Identification and early intervention services are completely lacking. Independent living services are very limited and the number of beneficiaries is minimal. Although in recent years there is an increase in the tendency to set up new community services for people with disabilities, their staff and infrastructure capacity is limited and consequently there is no coverage of the demands they receive in areas where they operate. Support services, including assistive technology, personal assistant, sign language translator,

Braille print and customized transport, are largely unrecognized and not applied in any of the 10 municipalities.

6. Budget outlooks for services, are limited and there are no plans or expectations for growth. Nonetheless, 11 of the 39 existing services are covered by local government/district funds.
7. None of the municipalities has a plan of measures to eliminate the barriers to information, communication and mobility for all groups of people with disabilities, and moreover a dedicated budget line in this regard, as defined in the Decision of the Council of Ministers (DCM) no. 1074 dated 23.12.2015 "*On the Determination of Measures to Eliminate Communication and Infrastructure Hurdles in the Delivery of Public Services for People with Disabilities*". Moreover, there is limited knowledge of the legal framework and new concepts that it introduces in this regard.
8. Staff at the local level is informed with delay or is completely uninformed about the legal and political framework pertaining disability. Exception here is the legal framework related to pecuniary benefits for which information is timely and complete.
9. There is no formal cooperation network among all institutions responsible for addressing disability issues at the local level (education, health, employment, vocational training, social services, housing, transport and infrastructure, service-providing organizations and organizations of people with disabilities).
10. Child Protection Units and authorities of Gender Equality and Domestic Violence, in the municipalities where they are established, do not have it as a part of their everyday work description the addressing and treatment of issues of children with disabilities and that of women with disabilities.
11. Statistics in all 10 municipalities are still collected in the same obsolete formats, regardless of the new data collection requirements that derive from Law no. 93/2014 dated 28.07.2014 "*On the Inclusion and Accessibility of Persons with Disabilities*" and DCM No. 798, dated 26.08.2015 "*On the types, periodicity and the manner of reporting the statistical data on disability by the relevant state bodies in both central and local level.*" Consequently, there is a lack of data showing the functioning of the disability payment beneficiaries and their needs for specialized services.
12. There is no systematic approach to capacity development of all staff and specialists working with disabled persons.

III. THE SITUATION PERTAINING THE HEALTH SERVICES FOR PEOPLE WITH DISABILITIES IN 10 MUNICIPALITIES OF THE COUNTRY.

Below are some of the issues identified in the domain of health services in all ten targeted municipalities.

1. With the exception of physiotherapy services, which operate in the regional hospitals, in all ten Municipalities were identified shortcomings in the provision of rehabilitation services for persons with disabilities.
2. Community Mental Health Centers (CMHC) have been established and they provide services only in four of the ten targeted municipalities. In 6 out of 10 municipalities, the CCMH are missing. The situation in this regard is at the level of an emergency.
3. At the local level, there is a lack of specialists/capacities in terms of identifying and early diagnosis of disabilities for children.
4. The legal framework that provides accessibility to the premises, communication, information and transportation, is unmodified in health centers and hospitals. Regional Health Directorate and all other health institutions, do not have a plan of measures to eliminate the barriers to information, communication and mobility for all disability groups, and moreover a dedicated budget line in this regard as defined in the DCM no. 1074 dated 23.12.2015 "*On the Determination of Measures to Eliminate Communication and Infrastructure Disadvantages in the Delivery of Public Services for People with Disabilities*". Moreover, there is limited knowledge of the legal framework and of the new concepts that it introduces in this regard.
5. Facilities of health institutions are not adapted to the accommodation of people with disabilities and to resolve their health needs.
6. Notwithstanding the obligations stipulated in the legal framework, no screening of all children in maternity is carried out to identify hearing impairments.
7. The statistics in all 10 municipalities are still collected via the same outdated formats, regardless of the new data collection requirements deriving from Law No. 93/2014, dated 28.07.2014 "*On the Inclusion and Accessibility of Persons with Disabilities*" and DCM no. 798, dated 26.08.2015 "*On the types, periodicity and the manner of reporting the statistical data on disability by the relevant state bodies in central and local level*"
8. With regard to capacity development, there is no positive progress in this respect. The organized trainings are made on annual basis, but not focused on disability. There is no plan or prospects in this regard for the staff of health institutions at all levels.

9. None of the targeted areas' expenditures on orthotics, prostheses, wheelchairs, hearing aids and other aids for people with disabilities are covered, and there is no database for children and adults with disabilities who need them.
10. Reimbursement of specialized dental services, especially for children with autism spectrum disorder and those with mental health disabilities, is lacking.
11. The staff of health center agrees to follow up on the cases of persons with severe disabilities through the provision of services at home, but no figures are provided for the number of persons who benefit from this service.

IV. RELEVANT INTERVENTION AT THE CENTRAL LEVEL TO ENSURE QUALITY SOCIAL SERVICES FOR PEOPLE WITH DISABILITIES.

The following interventions should be undertaken by the MHSP in order to improve the situation and to cover at a national level the needs for social services of children with disabilities.

1. The MHSP should take measures to establish a special structure for the Disability, which will spearhead the preparation, implementation and monitoring of the legal and political framework under the Convention on the Rights of Persons with Disabilities and that of the human rights.
2. MHSP should continuously guide and monitor the municipalities that appoint and maintain focal points that will coordinate the work with all relevant stakeholders for disability at the local level, as well as set up special structures for identifying and managing the cases of people in need, covering the needs for appropriate services for people with disabilities.
3. MHSP should develop annual plans to be followed and to be periodically reported, on the fulfillment of obligations in the implementation of legal and political documents affecting the lives of persons with disabilities in Albania.
4. MHSP should request from local government units to prepare annual disability-based plans, on the bases of legal and policy documents, and should monitor their implementation based on predefined indicators.
5. MHSP should provide training and information sessions for local government units pertaining any change in the legal and political framework, both specific and inclusive, which affects the lives of people with disabilities.
6. MHSP should require from all municipalities as well as institutions operating at the local level, accessibility plans and budgets allocated for this purpose and should monitor their implementation every year.

7. MHSP should ask the municipalities to plan the establishment of the necessary services for persons with disabilities in their territories; coordinate budgets with them as well as continuously monitor the enhancement and quality of services provided. Recommended services to be raised include: information and counseling for individuals with disabilities and their families, early identification, various therapies, life-skills training, family services, support for integration into mainstream school, resource schools and classrooms, transition from school to work services, personal assistant, lifelong assistance technologies, community residential services for adults with disabilities, community day services, vocational training services, employment services, personal care services, community integration (accompaniment, sign language interpreter, etc.). The aforementioned services are required under the DCM no. 483, dated 29 June 2016, "*The National Action Plan for Persons with Disabilities, 2016-2020*" and Law No. 121, dated 21.11.2016, "*On Services of Social Care in the Republic of Albania*"
8. MHSP should require all regional and local institutions to collect data and report in accordance with the DCM. No. 708 dated 26.8.2015 "*On the types, periodicity and the manner of reporting of disability statistics by the relevant state structures at central and local level*", which will provide clear primary data for persons with disabilities at the central and local level as well as conducting surveys dedicated to people with disabilities, mainly from the Institute of Statistics.
9. MHSP should prepare capacity development plans for staff at the central level, for both staff and specialists who work directly with the community of people with disabilities as well as those who should be part of the work plan of their community.

V. RELEVANT INTERVENTION AT THE CENTRAL LEVEL TO ENSURE QUALITY HEALTH SERVICES FOR PEOPLE WITH DISABILITIES.

The following interventions ought to be undertaken by MHSP in order to improve the situation and guide the needs for health services for people with disabilities throughout the country.

1. MHSP should prepare annual plans, focused on the implementation of the legal and policy framework, which aims at providing quality health services for all categories of persons with disabilities. Their implementation should be periodically monitored by the leadership of the ministry as well as by all departments or institutions in charge of their implementation.
2. MHSP should provide for the establishment of Community Centers for Mental Health in each municipality and, in addition, it should take measures for budget planning for other community services (currently not provided) that the community of individuals with mental health problems needs.
3. MHSP should provide for the establishment of prevention and rehabilitation services at the respective health institutions in each municipality/region.

4. MHSP should take measures to prepare health staff, in particular the medical staff of maternity hospitals, as well as the primary care staff, in administering the tests and protocols that aim at early identification of children with disabilities.
5. MHSP should accelerate the training processes for qualified physicians, focusing on the diagnosis and treatment of children with mental health problems in the communities where they live.
6. MHSP should take measures to enhance the capacity of health sector staff towards new approaches to the treatment of disabilities, from the perspective of human rights and the bio-psycho-social model.
7. MSHMS should cooperate, coordinate and streamline the work with all ministries of the line as well as other institutions in charge of the implementation of the Disability Action Plan. MoUs should be prepared, approved and monitored on a continuing basis.
8. MHSP should require from all municipalities as well as institutions operating at the local level, accessibility plans and budgets made available in this regard, and it should annually monitor their implementation.
9. MHSP should require from all regional and local institutions to collect data and report in accordance with the DCM. No. 708 dated 26.8.2015 "On the types, periodicity and manner of reporting of statistical data on disability by the relevant state bodies at the central and local level".
10. MHSP should take measures, through its subordinate bodies, to identify needs and undertake the necessary budgetary plans to meet the needs of assisting technology, such as prostheses, orthotics, hearing aids, wheelchairs, etc.
11. MHSP should allocate budgets for the refurbishment of premises for specialized dental interventions for individuals with intellectual disabilities and those with autism spectrum disorder.