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POLICY PAPER AND RECOMMENDATIONS

on social inclusion
of people with disabilities
and mental disorders
in Kosovo





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Based on the results of discussions of Working Group meetings held in the framework of the SOCIETIES project

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DISCLAIMER:

The SOCIETIES project is funded within the European Union's Civil Society Facility and Media Programme 2014-2015 - Support to regional thematic networks of Civil Society Organizations.

The opinions expressed in the document herewith are based on the discussions and the references provided by the participants of the working group meetings held during the project, and thus do not necessary represent the opinions of the supporting institutions, including European Union, SOCIETIES project, Caritas Kosova, or other partner organizations in the project.

Introduction

Caritas Kosova, jointly with 15 partner organizations, has implemented the SOCIETIES project - **Support of CSOs in Empowering Technical Skills, Inclusion of People with Disabilities and EU standards in South East Europe**. This four year project funded by the European Commission (2015 / 370-229) is being implemented since 2016 in five countries of Southeast Europe with the support of experts from Italy and Bulgaria. The project involves 7 national Caritas organizations: Caritas Kosova, Caritas Albania, Caritas Montenegro, Caritas Bosnia and Hercegovina, Caritas Serbia, Caritas Italy and Caritas Bulgaria.

The project aims to contribute to strengthening the capacity of civil society organizations in Southeast Europe to influence decision-making processes and the promotion of social policies through participation in public debate and dialogue with authorities.

The primary data and recommendations presented in this document are based on eight meetings of the Social Inclusion Working Group that was created within the SOCIETIES project with a number of 30 participants representing various institutions at the central and local level as well as Civil Society Organizations (CSOs). Secondary data have been collected prior to the working group meetings gathered based on previous assessments, institutional and civil society reports, schools, and legal documents and reports.

Caritas Kosovo will present the conclusions and recommendations from this document at the National Forum “Social Inclusion of Persons with Disabilities and Persons with Mental Health Disorders”, organized within the SOCIETIES project, on 7 June 2019 in Prishtina. The final document will include concrete recommendations for improving the situation of persons with disabilities and mental health disorders, which will be presented to all actors involved in the field of disability and mental health as a contribution to the creation of policies, regulations and the improvement of practices in the field of social protection of these vulnerable categories.

The data presented in this document are a summary of the daily experiences and challenges of practitioners and experts of the field and they do not present a problem analysis in a broader context.

Profile of PWDs in Kosovo

The number of persons with disabilities in Kosovo is unknown. While data has been gathered in the last few years, there is no accurate number that can support data-driven decision-making because multiple definitions of disability are in use by multiple institutions and stakeholders. The identification of persons with disabilities follows the medical model and is based on a medical opinion regarding impairment, rather than a holistic assessment, that takes into consideration the assessment of multiple professionals from a variety of disciplines/sectors. Existing legislation regulating the identification of disability does not focus on children; it is almost always used in terms of monetary benefit – social assistance scheme. Children with disabilities are mostly identified when they reach school age and attempt to enroll in school, at which time intervention is already too late to have a lasting impact on their development¹.

The 2011 Kosovo Population and Housing Census gathered data related to disability by utilizing a set of questions that tried to quantify the number of persons reporting a long-standing difficulty, rather than asking about disability². The questions involved identifying 1) deafness or severe hearing impairment; 2) blindness or severe visual impairment; 3) condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting; 4) learning or intellectual disability; 5) a long-standing psychological or emotional difficulty; and 6) other, including any long-standing illness. According to the results of the 2011 Kosovo Population and Housing Census, the number of children ages 0 to 14 years old with one or more long-standing difficulties reported is 3,298. There are 1,555 children ages 15-19 years old with one or more difficulties reported, and 1,639 young adults ages 20-24 also with one or more difficulties reported. The numbers increase significantly between the ages of 55 and 69 and then decline once again. In all categories, the number of reported males is higher than females; while the most represented category of long-standing difficulty is the conditions that substantially limit one or more basic physical activities.

Overview of PWD situation in Kosovo

Implementation of the legal framework and access to public services

Kosovo authorities have been engaged on establishing the necessary legal infrastructure and policies for the protection and promotion of the rights of persons with disabilities, both in the central and local level of governance³. However, according to the EC Kosovo Report 2019, little progress has been made on the rights of persons with disabilities and their integration in society remains a challenge due to limited support, inadequate health services and poor access to existing services. The legal framework on mental health is also incomplete. Implementation of the Law on Blind Persons and the Law on the Status of the Rights of Persons with Paraplegia and Tetraplegia is limited. The same applies for the 2013-2023 Strategy on the rights of persons with disabilities⁴.

1 UNICEF(2017). Situation Analysis: Children with Disabilities in Kosovo.

2 Kosovo Agency of Statistics (2011) Kosovo Population and Housing Census 2011 – Final results. Census Project Multi-Donor Trust Fund. Prishtina, Pg. 118.

3 Office for Good Governance. National Strategy on the Rights of Persons with Disabilities in the Republic of Kosovo (2013).

4 European Commission. Kosovo Report (2019)

There is not a comprehensive law on disability; while specific laws, e.g. Law for Blind persons, are not really favorable for specific groups. Ministry of Labor and Social Welfare has foreseen drafting the concept document on the comprehensive law for persons with disabilities to advance the legal framework.

Despite the issue of the implementation of the existing national legislation, physical access to public buildings, including schools, and transport remains limited for persons with disabilities. Consequently, physical access was emphasized as a barrier also on accessing public service.

Recommendations:

- Organize advocacy activities with relevant institutional stakeholders on higher implementation of the existing legal framework;
- Organize advocacy activities with relevant institutional stakeholders on taking concrete actions for improving the physical infrastructure for better access to public services by PwD.

Provision of specialized services and long-term care

Many of the support services required for ensuring independent living of PwDs are not available in Kosovo. Specialized rehabilitation services, i.e. psychologist, social worker, speech therapist, physiotherapist, are provided by local CSOs with very limited capacities due to financial restraints.

According to the EC Kosovo Report 2019, inclusive planning and budgeting for appropriate interventions and service delivery should be pursued for both adults and children.

On the other hand, regarding long-term care and accommodation, Kosovo remains as one of the best practices in the region with 19 mental health and social care institutions: 9 social care institutions/community houses, 9 mental health institutions/integrated-community houses and 1 special institution. Currently it is of concern the limited capacities for accommodation considering the overload, while Elderly House has age admission criteria (e.i. 65 and above). In addition, there are available daily accommodation options run also by CSOs. However, family members require a long-term solution for people with disabilities and mental health problems, while the issue of accommodation and long-term care creates many barriers during the provision of assistance. Particularly challenging remain cases of persons with disabilities under the care of elderly family members who require immediate institutional attention and a durable solution.

Recommendations:

- Providing or contracting specialized services for people with disabilities and mental health disorders by respective institutional authorities;
- Organize advocacy activities to discuss adequate solutions for persons with disabilities under the care of elderly caregivers who are not capable of providing the proper support;
- Increase financial support to scale up community-based social services.

Social welfare services

There are few issues to be addressed related to the provision of social assistance to people with disabilities. The amount of the assistance can hardly contribute to the survival of the families of PwD who are usually living in very poor socio-economic conditions. In addition, there are different standards for categories in need on determining the provision of assistance, which creates barriers on fair treatment.

Bureaucratic procedures for re-applying for social assistance every six months remains challenging for majority of cases of persons with disabilities; it remains a difficulty for families or caregivers considering their socio-economic condition and the physical infrastructure to access public buildings. There are interruptions also on the provided social assistance – there are periods of time when they receive the assistance and other periods they do not.

In addition, CSOs have highlighted the need to be reviewed the decisions of the Appeals Commission/Ministry of Labor and Social Welfare considering the potential disharmony with the needs of the persons with disabilities.

Recommendations

- Review procedural issues and complaint process for social assistance:
 - *Address the legal gaps on determining the actions regarding specific cases in close consultations with local authorities/first-line workers and civil society organizations, e.g. in cases of death while in family housing;*
 - *Review bureaucratic procedures for re-applying for social assistance every six months, which remains challenging for majority of cases of persons with disabilities;*
 - *Review the decisions of the Appeals Commission for paraplegic cases, where were observed that the decision made is in disharmony with the needs of the person, e.g. not assigning a guardian though it is needed.*

Health services and long-term treatment

The health care system in Kosovo does not mainstream disability throughout its plans of action. Screenings, early identification and intervention of children at risk of delay or disability, do not exist and the medical model of disability has been perpetuated by medical professionals.

Health services for psychiatric cases are provided; though the treatment remains short-term considering that the referral chain ends in the mental health centers.

Shelter houses for such categories are more than needed. In terms of health services, it is required more cooperation between Psychiatry Unit, Centers for Social Affairs, Primary Health Care Centre, Mental Health Centre and non-governmental organizations providing specific specialized services.

In addition, additional expenses are required for severe cases; though no additional institutional support is provided considering their specific needs.

Recommendations:

- Advocate for additional assistance to cover the health needs of severe cases with disability or mental health disorders.
- Create a strategy among local stakeholders for provision of specialized health services for persons with physical and mental disabilities.

Access of children with disabilities in educational system

Approximately 800 million young children worldwide are affected by biological, environmental and psychosocial conditions that can limit their cognitive development. In Europe, it is estimated 15 million children with special educational needs at⁵. On the other hand, only 10% of children with disabilities benefit from the appropriate access to health, education and social services⁶. On social inclusion, the municipalities do not have an integrated interdepartmental approach to service coverage, so as to take appropriate account of the needs of the most vulnerable groups, in particular children. Kosovo needs to ensure that children with disabilities are able to attend public schools alongside their peers. More efforts are needed to provide children with disabilities with access to quality education. The first cohort of 54 assistants for children/students with special needs graduated in June 2018. At present there are only 83 support teachers for children with disabilities; they are engaged and paid by families, rather than the education system⁷.

Identifying the cases of children with disabilities not enrolled in the education system remains the initial challenge of the educational institutions. In addition, children with disabilities pursue education with private assistants considering that schools do not offer supporting teachers. Schools also are limited on possessing adequate infrastructure as well as recourse rooms and didactic materials necessary for the development of children with disabilities. Teaching staff needs capacity building activities on disability and inclusive education, while the absence of individual teaching plans presents a challenge to be further addressed.

Authorities should increase efforts to integrate children with disabilities effectively into educational institutions and take into consideration their needs throughout their education.

Recommendations:

- Establish a field team to identify cases of children with disabilities not enrolled in the educational system as well as school drop-outs;
- Increase the number of teaching assistants in educational processes for children with disabilities enrolled in mainstream schools to support their educational needs;
- Establish resource rooms equipped with didactic materials and assisting technology in all schools;
- Compile individual teaching plans for each child with disabilities;
- Organize capacity building activities for teaching staff on disability and inclusive education;
- Contract additional specialized services (e.g. Psychologist and Speech Therapist) necessary for the advancement of children;
- Increase awareness of community regarding early childhood education;
- Increase awareness among peers, parents and teaching staff on disability and mental health disorders.

⁵ European Commission (2013). Support for Children with Special Educational Needs.

⁶ Coalition of NGOs for Child Protection – KOMF (2017). Child Protection Index 2.0: Measuring government efforts to protect girls and boys.

⁷ European Commission. Kosovo Report (2019)

Inter-institutional cooperation and role of CSOs

Horizontal and vertical inter-institutional cooperation was highlighted among all working group meetings. In general, there is a lack of coordination and proper cooperation between institutions at local and central level as well as between institutional authorities and CSOs as service providers for persons with disabilities and mental health problems.

In addition, *intervention challenges* were brought by all service providers with specific emphasizes on Centers for Social Affairs. There are few municipalities that have drafted municipal regulations and action plans to effectively utilize all resources for provision of services; though the majority has reported the need for improvement of cooperation and coordination levels between all actors involved, institutional or civil society.

First line workers have also reported *lack of adequate human resources*, i.e. psychologists and social workers; which creates barriers on assisting cases in need due to excessive workload or provision of adequate assistance accordingly. Centers for Social Affairs are continuously challenged with the limitations on assisting their cases due to lack of *an emergency fund for interventions*. Furthermore, *inadequate working conditions* were highlighted by practitioners representing both, local institutions as well civil society.

Poor consistency on provision of services due to the lack of financial resources was reported by CSOs. There is no sustainability on the provision of existing services considering that the support from local authorities is not consistent. Although exists the Regulation MF-NR-04/2017 on Criteria, Standards and Procedures on Public Funding of NGOs, the financing procedures and methods do not secure the consistency in services. Despite the call for applications invites 1-year projects, considering the length and delay of procedures, they are able to support only few months for the implementation year. Considering the financing issues, daily centers usually provide services with lower working hours.

Recommendations:

- Improve the inter-institutional coordination and increase the support for local level institutions:
 - *Improve the inter-institutional coordination between central (ministries) and local level (municipal);*
 - *Provide Centers for Social Affairs (CSA) with a specific fund for emergent interventions;*
 - *Provide CSAs with adequate human resources (e.g. psychologists, social workers and other mental health professionals) and working conditions;*
 - *Initiate drafting municipal Regulations and Action Plans for PwD.*
- Determination of minimal standards, CSO licensing and financing as well as improvement of cooperation between institutions and civil society.
 - *Improve the cooperation with CSOs in terms of licensing for social services and financing their activities, especially in cases of services not provided by institutional authorities;*
 - *Increase the current limited municipal budget for local CSOs activities working with disability and mental health.*

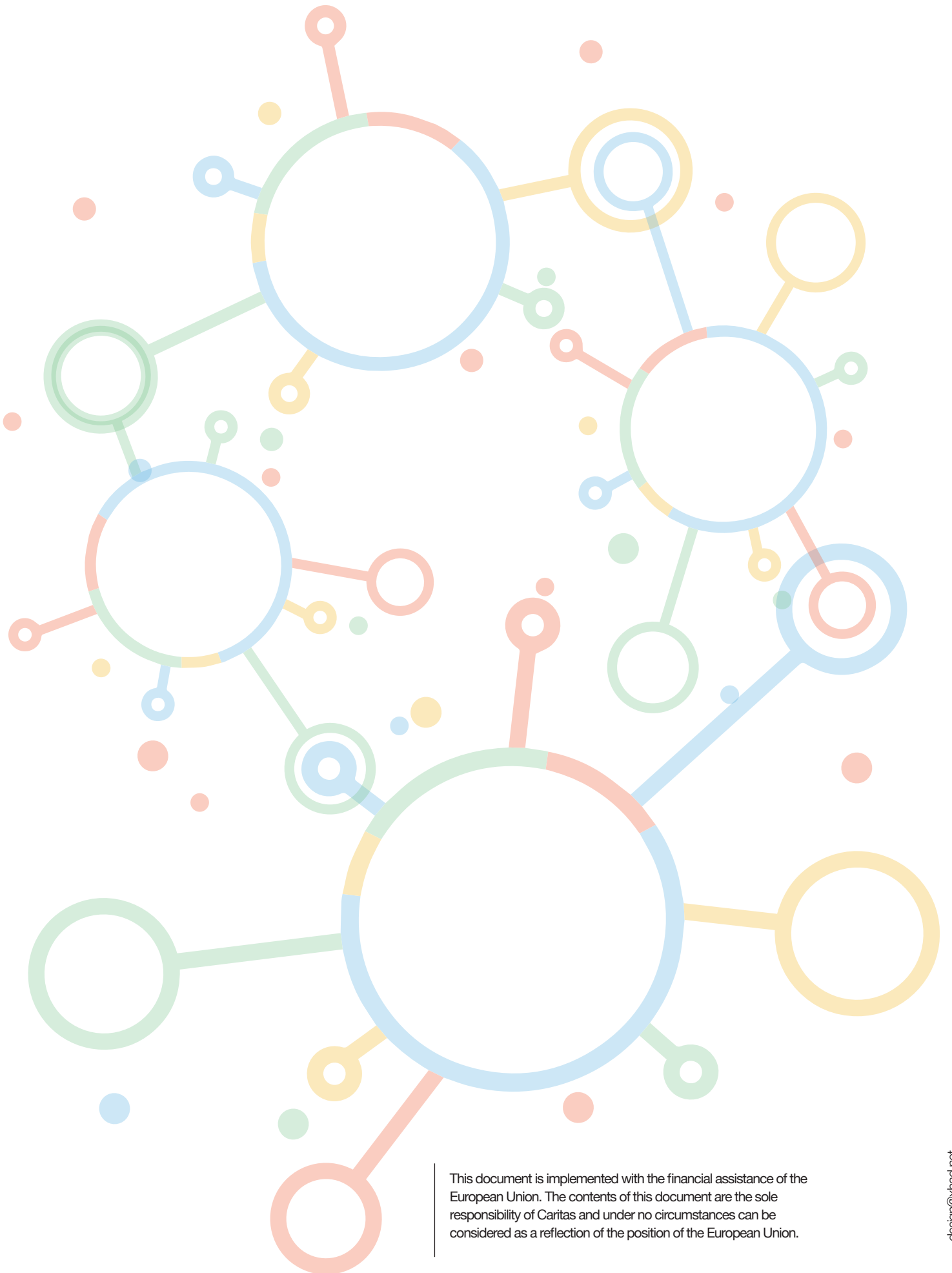
Prejudices and stigma

There is an overall tendency of the society to neglect and repress disability and mental health issues. The issues of prejudices and stigma remain of significant nature while providing assistance. There is a general perception among community that PWDs and persons with mental health disorders are incapable of dealing with daily life demands or working and participating in the social life. Persons with light mental developmental delays are not accepted in various vocational trainings; while others remain isolated due to stigma and negative social beliefs. In addition, persons with intellectual impairments remain as the category with at least attention by society in terms of provision of services. Negative perceptions are also present among officials who provide their services.

The prejudices and stigma are present not only in the community; it is also common among the family members as well as in the school settings among peers, teachers and parents.

Recommendations:

- Raising awareness among family members regarding the disability and early treatment as well as counseling parents or caregivers on treatment of disability;
- Advocating for effective and efficient intervention procedure in cases of referral
- Raising awareness among public opinion on disability and mental health as well as the abilities and skills of people belonging to such categories;
- Initiate a network of CSOs to implement joint awareness raising and advocacy activities; it cannot be achieved at the level of projects only.
- Strengthening the capacities of relevant institutional stakeholders and CSOs on fund raising and project implementation.



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