Informal Care & Gender Equality in the Western Balkans
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Children with disabilities situation in Albania

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Albania is committed to protecting and promoting women and girls' rights and freedoms at home and abroad so that they can have their voice, choice and control over all aspects of their lives.

Equality recognizes diversity and seeks to offer the same opportunities and access to health treatment and social care regardless of race, colour, gender, age or mental or physical health, or any other factor which may make somebody different.

Albania has a solid legal and policy framework:
- Gender Equality Law (2008)
- Law for Protection from Discrimination (2010, revised in 2020)
- Law on Social Care Services (2016)
  - The purpose of this law is to determine rules on the provision and delivery of social care services which are useful for the well-being and social inclusion of individuals and families in need of social care.
  - The law clearly directs both central and local governments to cover social care services and the setting up of a Social Fund as a separate budget line to finance these services, to be transferred to local government units (LGUs).
Social Care and gender Equality in Albania

- In Albania the Social Care Services are part of the Social protection Program funded by the state budget.

- Currently there are gaps in coverage of all needs for services of the vulnerable groups at the national level.

- Specialized social care services are provided by NGOs or other partners. Services are mainly available in the large urban areas (90% of the services are available in urban areas) with a serious lack of services in rural areas.

- In difference from the social assistance (NE) scheme and disability benefits, (called “cash programs) the challenge here is related to the establishment of a system of social care services (care system) that can cover more broadly the needs of the vulnerable groups, in need for integrated and efficient social services.
Challenges related to Social Care in Albania

Policy challenges are related to the introduction of a functional and effective social care system, based on the principles of decentralization and deinstitutionalization, aiming at inclusion of vulnerable groups in the social protection programs.

1. The analyses and finding the most appropriate model for the decentralization of services, in harmony with the territorial reform currently under implementation in the country.

2. De-Institutionalization remains a challenge, since it requires the establishment of a network of territorial services, a re-structuring of processes and procedures for case management, and increasing capacities of the professionals.

3. The data of social care services could be integrated in an information management system, while facilitating the exchange of data with other services, but also improving the quality of activities, from planning to control.
PRINCIPLES OF SOCIAL CARE REFORM

Civil rights, equality, and non-discrimination: Every individual in need, despite his/her gender, religious belief, age, disability etc. is entitled to social protection.

- **Protection**: Particular groups, including children, should be subject to special protection based on their needs, and rights.
- **The right to life, survival and development**: 
- **Independence, autonomy, and respect for points of view**: Individuals are responsible for their lives. They should be encouraged to take decisions for their lives, within the norms places by the society.
- **Inclusion and integration**
- **Respect for the rights and needs**
- **Partnership**: coordination of central structures, regional and local governance, and other partners in the community
The overall objective was to contribute towards social inclusion of children with disabilities in two Municipalities of Albania (Lushnja & Patos), improving the quality of life as well as fostering social cohesion at local level by promoting the localization of Agenda 2030 and its objectives, in particular, the Leave no One Behind – LNOB principle at municipality level.

**Identified problems from previous studies:**

- Dissatisfaction with the infrastructural conditions of the educational institutions and their distance;
- Dissatisfaction with the child’s progress in school, the level of adaptation of teaching as well as the level of respect shown by the educational staff;
- Unaffordable necessary expenses that enable children to attend educational institutions, etc.
- High discrimination;
- Widespread underestimation of the abilities and potential of children with disabilities.
- Lack of knowledge of parents/legal guardian on how they can benefit from the social scheme.
Social mapping of the situation of children with disabilities and their personal assistants.

- Examination of the situation of children with disabilities in the municipality level through the methodology of Social Mapping.
- Documenting the needs for social and health services that the children with disabilities needs/compared with what they have
- Contribute to promote to the fulfillment of the SDGs

<table>
<thead>
<tr>
<th>Municipality</th>
<th>Boys</th>
<th>Girls</th>
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</thead>
<tbody>
<tr>
<td>Lushnja</td>
<td>141</td>
<td>98</td>
</tr>
<tr>
<td>Patos</td>
<td>48</td>
<td>35</td>
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Social mapping of the situation of children with disabilities and their personal assistants.

The research questions were:

- What is the socio-economic status of children and adults with disabilities and their families?
- What is the level of incomes of the families of the people with disabilities?
- How are the living conditions of the children and adults with disabilities?
- What is the level of risk and danger of children and adults with disabilities?
- What are the needs for social services of children and adults with disabilities? What is the overall condition of the children with disabilities?
- What conditions and social centres, as well as human resources are offered by the municipality?
- What is the short term and long term actions that municipality can take to tackle the problems?
LNOB group analysis

**LNOB risk factor geography**
The influence of geographical positioning on obtaining the necessary services!

**LNOB risk factor socio-economic status**
The socio-economic status of children with disabilities and their families!

**LNOB risk factor Discriminatio**
The degree of discrimination for children with disabilities and their families

**LNOB risk factor Vulnerability to shocks**
The impact and consequences of the COVID-19 pandemic on physical and mental health

**LNOB risk factor governance**
Involvement in local government for lobbying important issues related to the target group
Social Mapping methodology

- **In depth Interviews**: 11 interviews with stakeholders
- **Filed Survey**: 192 interviews with parents/guardians of children with disabilities

Desk Research

Secondary data analysis

- **Focus Groups**: 8 focus groups discussion with parents/guardians of children with disabilities and stakeholders.
- **Pilot Test**: 10 test interviews
- **Meetings with municipalities**: Periodic meetings throughout the development of social mapping
Findings from the social mapping

Most of the respondents live on below the average wage.

According to focus groups with parents of children with disabilities, this category is often discriminated against, in hospitals, on public transport, at school or even in society.

The COVID-19 pandemic has physically and mentally affected this category. Fear of deteriorating child health, isolation, lack of finances has exacerbated the situation in these families.

In Lushnjë municipality there is one center for children with disabilities, called Centre for Development for children with disabilities. This is a day centre which offers services for children with disabilities of different age groups ranging from 2 to 16 years and operates five days a week from Monday to Friday. There is no such center in Patos.

Although there are differences in percentage, most of the unemployed guardian parents are not registered in the labor office.

Both municipalities have drawn up social plans but could not implement them due to lack of budget.

Most of the primary, secondary, and high schools in both municipalities do not have the basic logistics for children with disabilities. And, this logistics is only about building the ramps.

Most of the houses meet the basic living conditions, while about 10% of the respondents' houses do not meet the basic living conditions.
Findings from the social mapping

Most of the respondents during the Social Mapping affirmed that their children do not benefit from the personal assistance service.

Parents with children 0-6 years old cannot take their children to nursery or kindergarten because the law does not provide for a supportive teacher or educator, and for this reason they are obliged to keep them at home.

100% of the parents received financial assistance from the state (KEMP) for the child but did not receive financial assistance as a Personal Assistant;

Most of the respondents’ homes do not have adequate access for children with disabilities.

There is no institution in the booth municipalities that provides professional care and support for food, clothing and health care if a child does not have the conditions for independent living;

Transport to receive services is missing. An exception is made here for 13 children with disabilities who receive services at the Horizont center thanks to the agreement with the Municipality of Fier. The municipality of Patos enables the transportation of children to and from the center;

During the COVID-19 the children with disabilities did not receive additional financial assistance from the state but food packages from the municipality.

The identified children face many problems in learning due to the lack of professional assistant teachers.
Recommendations for improvements of Social care
Mos of targeted children with disabilities in addition to the disability that accompanies them all their lives, they also have other health problems that come as a result. The lack of specialized medical services for their disability near residential centers aggravates the situation even more.

<table>
<thead>
<tr>
<th>Problem identification</th>
<th>Recommendation</th>
<th>Indicator</th>
<th>Key institutions</th>
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</thead>
<tbody>
<tr>
<td>Recommendation 1: Providing specialized medical services near residential centers.</td>
<td>• Identification of specialized medical services for which children with disabilities.</td>
<td>• Number of services added according to above.</td>
<td>• Ministry of Health and Social Protection</td>
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<tr>
<td>Recommendation 2: Cost refund in cases when these services must be obtained outside the municipality of Lushnja.</td>
<td>• Number of children with disabilities who have benefited from specialized medical services near residential centers.</td>
<td>• Number of children who benefits from Social Centers</td>
<td>• Municipality of Lushnja and Patos</td>
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<td>Recommendation 3: Increasing the capacities of the Lushnje Day Center for children with disabilities. Establishment of a day center for children with disabilities in Patos. The establishment of a residential center for the children of this target group who suffer from</td>
<td></td>
<td></td>
<td>• Ministry of Finance and Economy</td>
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<td>• Other stakeholders</td>
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SGD 3: Good Health and Well-Being:
**Target 3.8:** By 2030 achieve universal health coverage including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.
### Problem identification

Children with disabilities suffer the lack of proper logistics to access schools or kindergartens. Also, the lack of a sufficient number of assistant teachers makes their progress in school difficult and they often interrupt the learning. Children with disabilities in the schools of rural administrative units remain problematic.

### Recommendation

**Recommendation 1:** Equipping with proper logistics for access to school for children with disabilities. Construction of ramps in schools that lack this facility.

**Recommendation 2:** Review of the support curriculum for this target group and make available support teachers for each child with disabilities.

**Recommendation 3:** Revision of the law on the appointment of assistant educators for children who must attend kindergarten.

### Indicator

- Accurate identification of the number of support teachers;
- Number of support and specialized teachers for children with disabilities.
- Number of beneficiaries who receive this service in a proper and uninterrupted manner.
- Number of schools that meet the logistical criteria for children with disabilities.

### Key institutions

- Ministry of Education and Sports;
- Ministry of Finance and Economy;
- Regional Education Directorate of Lushnja and Patos;
- Schools of both municipalities

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**SDG 4: Ensure inclusive and quality education for all and promote lifelong learning**

**Target 4.1:** By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes

**Target 4.a:** Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all.
**Problem identification**

Families of children with disabilities have large shortages of financial income. As many services for children are missing, in 99% of cases one of the parents is forced to stay at home as unemployed. The financial assistance received by the state for children is quite low and does not meet basic needs. Also the number of parents who receive additional financial assistance as guardians is very low. After all, even in cases where parents receive financial assistance from the state, the years of service are not recognized as years of work for all categories of this target group. Thus missing the payment of basic needs.

**Recommendation**

**Recommendation 1:** Review the law and provide financial assistance to any parent who has children with disabilities and stays at home to care for them.

**Recommendation 2:** Review the amount of financial assistance for this target group.

**Recommendation 3:** Review of the law and recognition of years of service (of parents) for children for all categories of disability. Also determination of working hours.

**Indicator**

- Number of parents in the target group who will receive financial assistance from the state for child care.
- Changes in the legislation regarding the monthly fee that this target group benefits due to disability.
- Review of the law and recognition of years of service (of parents) for children for all categories of disability.

**Key institutions**

- Medical Commission for Assignment of Ability;
- Ministry of Health and Social Services;
- Ministry of Finance and Economy;
- Albanian Government;
- Other stakeholders

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**SDG 10: Reduced Inequalities**

**Target 10.1:** By 2030, progressively achieve and sustain income growth of the bottom 40 per cent of the population at a rate higher than the national average

**Target 10.2:** By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status.
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| Lack of logistics in means of transport is a major obstacle for children with disabilities. The lack of services near residential centers forces the families of this target group to undertake trips, often daily. But, both public and private transport do not provide the necessary conditions for these children. Also, the municipality of Lushnja does not provide organized transport for this target group for movements to receive services, thus increasing the costs of families of children with disabilities. | **Recommendation 1:** Obligation by the municipality for every public transport operator to meet the necessary conditions for children with disabilities.  
**Recommendation 2:** Provision in the annual budget of the municipality of Lushnja of a fund to cover transport for this target group, or the creation of organized transport according to administrative units. | - Number of public transport line operators that meet the necessary conditions for children with disabilities.  
- Budget line for transport organized by the municipality.  
- Number of children benefiting from the transport organized by the municipality | - Respective municipalities  
- Public Transport operators;  
- Ministry of Infrastructure and Energy.  
- Other stakeholders |

**SDG 11: Sustainable Cities and Communities.**  
**Target 11.2:** By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons.
Questions?

Thank you!