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MONITORING REPORT

TRANSPARENCY AND ACCESSIBILITY IN THE HEALTH AND EDUCATION SYSTEM

Tirana 2024





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CONTENT

I. Introduction

9

1.1. Health Care Services Operator

9

1.2. The General Directorate of Pre-University Education

11

II. Monitoring Methodology

14

III. Transparency in the Regional Directorates of the Health Care Service Operator

20

3.1. The proactive transparency monitoring findings

20

3.2. The reaction to official requests for information (reactive transparency)

22

IV. Transparency in the Regional Directorates of Pre-University Education

22

4.1. The proactive transparency monitoring findings

22

4.2. The reaction to official requests for information (reactive transparency)

24

V. Accessibility in health institutions

24

- 5.1. The opening up of health institutions to the public and the accessibility of information** 26
- 5.2. Physical access and adequate infrastructure** 28
- 5.3. Communities' challenges** 29
- 5.4. Complaint mechanisms** 32

VI. Accessibility in educational institutions

35

- 6.1. Opening up educational institutions to the public and information accessibility** 37
- 6.2. Physical access and adequate infrastructure** 39
- 6.3. Communities' challenges** 40
- 6.4. Complaint mechanisms** 44

VII. Conclusions and recommendations

47

ACRONYMS

DRAP	Drejtoria Rajonale e Arsimit Parauniversitar (Regional Directorates of Pre-University Education)
DRF	Drejtoria Rajonale e FSDKSH/Fondit (Regional Directorate of FSDKSH /Fund)
DROSHKSH	Drejtoria Rajonale e Operatorit të Shërbimeve të Kujdesit Shëndetësor (Regional Directorate of the Health Care Services Operator)
DPAP	Drejtoria e Përgjithshme e Arsimit Parauniversitar (General Directorate of Pre-University Education)
FSDKSH	Fondi i Sigurimit të Detyrueshëm të Kujdesit Shëndetësor (Compulsory Health Insurance Fund)
HIV	Human Immunodeficiency Virus
KMD	Komisioneri për Mbrojtjen nga Diskriminimi (Commissioner for Protection from Discrimination)
LGBTI+	Lesbian, gay, bisexual, transgender, intersex and more
MSHMS	Ministria e Shëndetësisë dhe Mbrojtjes Sociale (Ministry of Health and Social Protection)
OSHKSH	Operatori i Shërbimeve të Kujdesit Shëndetësor (Health Care Services Operator)
PEI	Plani Edukativ Individual (Individual Educational Plan)
QSUNT	Qendra Spitalore Universitare “Nënë Tereza”
ZVA	Zyrat Vendore Arsimore (Local Education Office)
ZVAP	Zyrat Vendore e Arsimit Parauniversitar (Local Offices of Pre-University Education)

I. Introduction

Transparency in the health and education system is very important, as it makes it possible for institutions that should be closer to citizens to be more responsible in their activity and decision-making. When institutions are transparent, it becomes easier to identify problems directly related to corruption, nepotism, mismanagement or favoritism of various kinds. When information about performance, results and decision-making processes is available, citizens are more likely to believe that these institutions are acting in their best interest. Transparent systems allow for continuous monitoring and the evaluation of performance. By making data on results, resource allocation and service delivery publicly available, stakeholders can identify areas for improvement and implement the changes needed to improve the quality of services provided. Access to information empowers individuals and communities to make informed decisions about their health and education.

Also, access to information in the education and health sector means easy access to information about services, results, policies and practices. This includes making available to the public in a proactive way not only the categories of information provided by law no. 119/2014 “On the right to information”, such as data of the Coordinator for the Right to Information, the annual budget, procurement contracts, updated legislation, services offered, etc., but also other important data that directly affect the improvement of the quality of services to citizens.

In order to fully monitor the level of transparency of health and educational institutions, it is important to briefly explain what services these institutions offer and how they are organized.

1.1 Health Care Services Operator

The Health Care Services Operator (OSHKSH) was established in 2018 by a Decision of the Council of Ministers no. 419, dated 4.7.2018, “On the creation, organization and operation of the Health Care Services Operator”. It is tasked with providing primary and hospital care services in accordance with needs, standards, protocols and defined

requirements, guaranteeing the full, quality and timely provision of the services and the efficient use of human and financial resources and of assets and materials, in accordance with the legislation in force for the health care system and hospital service.

The operator's activity extends throughout the territory of the Republic of Albania and is organized at/in:

- Regional level through regional directorates;
- Direct service delivery units, which include local health care units, health centers/clinics and health facilities with beds/hospitals.

The regional directorates of the Health Care Services Operator (DROSHKSH) are divided into four regions, with headquarters in Shkodra, Tirana, Vlorë and Elbasan.

- The Regional Directorate of the Operator of Health Care Services in Shkodra includes the districts of Lezha, Shkodra and Kukes.
- The Regional Directorate of the Operator of Health Care Services in Tirana includes the districts of Durrës, Tirana and Dibra.
- The Regional Directorate of the Operator of Health Care Services in Vlorë includes the districts of Fierë, Vlorë and Gjirokastra.
- The Regional Directorate of the Operator of Health Care Services in Elbasan includes the districts of Korça, Elbasan and Berat.

Each of the four regional directorates reports to the General Director of the Operator and has under their dependence the units of direct provision of services, which include the directorates of public health and health education, primary service directorates, hospital service directorates and support service directorates.

The regional directorates of the Health Care Operator perform the following tasks¹:

¹ Regulation no. 18, dated 17.01.2019, "For the approval of the internal regulation on the way of organization and operation of the Health Care Services Operator".

- a. Plan the needs for primary health care, public health and hospital services in the territory they cover;
- b. Guarantee that health services are provided within standards, on time, within the budget and with the required quality in the territory they cover;
- c. Coordinate, monitor and ensure the provision of primary health service and public health near the places of residence of all citizens;
- d. Carry out procedures for the management of human resources in the primary health system, the public and hospital health system (needs planning, recruitment, training, etc.) for the relevant region;
- e. Cooperate with the regional directorates of the Compulsory Health Insurance Fund (FSDKSH) on issues related to health care financing;
- f. Monitor implementation of norms and standards related to the coverage of the population with family doctors and nurses in the primary and hospital health care system in their jurisdiction, and plan their needs;
- g. Control and monitor the realization of indicators of the quality of medical service in the primary and hospital health care system under their jurisdiction;
- h. Step-by-step check the progress of investment implementation in accordance with preventive [**correct term?**] projects under their jurisdiction;
- i. Review the use of secondary incomes and reallocations within the budget for health service providers under their jurisdiction and forward them to the Central Operator for approval in principle. After receiving approval in principle from the Central Operator, they send them to the Regional Directorate of FSDKSH / Fund (DRF) for approval;
- j. Coordinate work between all subordinate structures;
- k. Organize work for the provision of basic public health services and other auxiliary services according to the package of public health services.

1.2 The General Directorate of Pre-University Education

Albania has not only conducted territorial reform in the health sector but also in education. Through a Decision of the Council of Ministers no. 99, dated 27.2.2019, "On the creation, organization and operation of the General Directorate

of Pre-University Education”, the General Directorate of Pre-University Education (DPAP) was created.

Also foreseen was the creation of regional directorates with at least 4,000 employees each. The task of the General Directorate is to provide and ensure a quality educational service in all pre-university educational institutions in the Republic of Albania in accordance with policies and national strategies, and the curriculum, with the aim of developing and fully and comprehensively educating the pupils.

The regional division model of pre-university education directorates is similar to that of the Health Care Services Operator. Their locations are in the cities of Lezha, Durres, Fier and Korca².

- The Regional Directorate of Pre-University Education in Lezha includes the Local Offices of Pre-University Education (ZVAPs): Lezha, Kurbini, Mirdita, Shkoder, Malesi e Madhe, Vau i Dejes, Puka-Fushe Arrez, Kukes, Has and Tropoja.
- The Regional Directorate of Pre-university Education in Durres includes the ZVAPs: Bulqiza, Diber, Durres, Kamez, Kavaja, Klos, Kruja, Mati, Rrogozhina, Shijak, Tirana and Vora.
- The Regional Directorate of Pre-University Education in Fier includes the ZVAPs: Fieri, Divjaka, Mallakaster, Tepelena-Memaliaj, Lushnja, Patosi, Selenica, Gjirokaster-Libohova, Finiq-Dropull, Vlora-Himara, Rroskoveci, Permet-Kelcyre and Saranda-Delvina-Konispol.
- The Regional Directorate of Pre-University Education in Korca includes the ZVAPs: Dimal, Belsh, Librazhd, Kolonja, Polican, Pogradec, Kucova, Peqin, Perrenjas, Devoll, Berat, Cerrik, Gramsh, Maliq, Skrapar-Polican, Korca-Pustec and Elbasan.

The Regional Directorates of Pre-University Education (DRAPs) are responsible for the operation and smooth running of the Local Offices of Pre-University Education and educational institutions within their jurisdiction, ensuring the quality of the pre-university education service at the regional level.

The Regional Directorates of Pre-University Education perform the following tasks:

² By order no. 68, dated 05.4.2019, of the Prime Minister, “On the approval of the Structure and Organization of the General Directorate and Regional Directorates of Pre-University Education.”

- a) Manage, supervise, evaluate and control pre-university educational institutions, ensuring their activities comply with the laws and by-laws in force;
- b) Ensure implementation of the curriculum, methodologies and standards;
- c) Supervise the daily activity and functioning of educational institutions, the fulfilment of administrative duties and the regularity of the teaching process;
- d) Assess needs and problems during the provision of the educational service and propose solutions;
- e) Provide technical expertise in the design of teaching methodologies, practices and techniques that improve the quality of teaching;
- f) Monitor the qualifications of the teaching staff for the curriculum, methodologies and standards determined by the responsible institution;
- g) Guarantee the good administration of human resources for public institutions of pre-university education, as well as their distribution, depending on abilities, the contribution of everyone, and the principles of justice and meritocracy;
- h) Guarantee the establishment of teachers' professional networks, as well as spread the successful practices and experiences of teachers;
- i) Are responsible for the recruitment of teachers through the national portal "Teachers for Albania", following the relevant competition procedures, processing and analyzing the data and announcing the results;
- j) Guarantee the good administration of financial resources and their allocation in accordance with the legal framework in force and the needs of educational institutions;
- k) Organize and support psychosocial services in public pre-university educational institutions;
- l) Request maintenance of the infrastructure of educational institutions from local self-government units;
- m) Monitor the selection, distribution and equipping of students with textbooks;
- n) Support and administer the development of national and international exams and assessments in pre-university education system;
- o) Collect and process statistical data from the educational institutions in their jurisdiction;
- p) Evaluate and examine the requirements of the ministry responsible for education for the fulfilment of the infrastructure criteria for the opening of educational institutions and the exercise of activity in the field of pre-university education;
- q) Provide services to citizens;

- r) Provide legal assistance and judicial representation for the local offices of education under their jurisdiction,, as well as financial and support services that have not been delegated to the local offices of education by the DPAP;
- s) The directors of the regional directorates appoint directors of public educational institutions according to the relevant instruction of the minister.

II. Monitoring Methodology

This monitoring aims to assess the transparency of the health and education system at regional level. For this reason, referring to the aforementioned legal analysis, there are eight monitored public authorities. Four are regional institutions of the health system and four are regional institutions of the educational system. The monitoring includes three components: proactive transparency monitoring; FOI requests; and conducting focus groups and in-depth interviews.

In the first component, proactive transparency monitoring, 26 indicators have been selected for monitoring. Information that must be published on the website is grouped into seven categories: “Proactive Transparency, “Ethics and Integrity”, “Financial Transparency”, “Performance Indicators”, “Patient and Student Rights”, “Services Provided” and “Public Participation”.

Pondering [consideration? weighing?] of Indicators: Each indicator is considered based on a specific weight, from 1 to 5, based on its importance within the transparency assessment. For example, having an official website is rated 5, since it is the most easily accessible instrument for obtaining the necessary information and documentation from citizens. Information on internal regulations is rated 3, as this does not have the same importance for citizens.

Table No. 1: *The component indicators of each category of the first component and the specific weight of each indicator.*



Proactive
transparency

1	Official website of the regional directorate	5
2	Appointment of a coordinator for the right to information	3
3	Publication of data of the coordinator for the right to information on the official website or in the premises of the regional directorate	3
4	Publication of the transparency program of the regional directorate	5
5	Publication of the register of requests and responses for the right to information	3
6	Front desk or secretarial service for patients/students.	5



Ethics and Integrity

7	Approved code of ethics	4
8	Approved internal regulation	3
9	Regulation for the processing of personal data	5
10	Approved Integrity Plan	4
11	Anti-corruption coordinator	2



Financial
Transparency

12	Financial information, including budgets, current and capital expenditures, funding sources, contracts, etc.	5
13	Annual financial report of the regional directorate	3
14	Publication of service fees on the Internet, or in the premises of the regional directorates	5



Performance
Indicators

15	Regional strategies of public health and pre-university education	4
16	Licensing standards.	3
17	Establishment and communication of clear indicators and standards on school performance, health care outcomes, and medical procedures	3
18	Annual performance reports of units depending on regional directorates	3



Patient and student rights

19	Informing patients and students about their rights, including the right to receive health and educational services, the right to privacy, informed consent, access to their data, the right to information, the right to data confidentiality, etc	5
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Services provided

20	A list of services provided, including application forms, application duration, appeals procedures	5
21	The recruitment criteria for doctors, nurses, and teachers	5
22	List of doctors providing services in health care units and their CVs/List of teachers and their CVs	4
23	Opening hours to the public, hours for providing various services and relevant tours	5



Public Participation

24	Policies to encourage public participation in decision-making processes related to education and health	1
25	Calendar of meetings with patient associations, school senate, parents' meetings, etc.	2
26	Clear procedures for receiving patient and student complaints as well as clear procedures for addressing them.	5

However, it is not enough just to weigh the indicators; in the case of evaluating proactive transparency it is important also to evaluate the level of information accessibility. To assess the accessibility of the documentation, we must see if the information is easily found in the transparency program's rubric. If the indicator's information or document is published on the website and can be fully accessed through the transparency program, the transparency of this indicator is evaluated with six points. If the indicator's information or document is published on the website but cannot be accessed through the transparency program according to legal requirements (it is not linked within the relevant fields), the transparency of the indicator is evaluated with four points. Where the indicator's information or document is partially published on the website, the transparency of the indicator is evaluated with two points. Where the indicator's information or document is not published on the site, the transparency of the indicator is evaluated with zero points.

Table No. 2: *The evaluation of the indicators*

The level of access to documentation/information	Points
Published in full online and accessible (linked) through the transparency program	6
Published in full on the site but not accessible (not linked) through the transparency program	4
Fully displayed at a stand or near the premises of the Regional Directorate	4
Partially published on the website	2
The documentation is not published	0

The second component is about sending requests for information to the Coordinator for the Right to Information at each regional directorate. Requests for information are simple requests, which aim to collect some basic statistical data. But they serve more as an exercise to understand the application of the right to access to information of a public nature and the level of transparency of institutions in the case of a request for information. Based on Law No. 119/2014 “On the right to information”, as amended, the institution must answer within 10 working days, otherwise it is considered as rejected information.

A request for information can be sent electronically or by mail to the above-mentioned regional directorates, addressed to the Coordinator for the Right to Information or on behalf of the institution.

Below is a list of requests for information of a public nature for which cases of restriction of the provision of information cannot be applied according to Article 17 of Law No. 119/2014, “On the right to information”, as amended.

Requests for information sent to the regional health care service directorates contained the following questions:

- What is the number of doctors and nurses currently employed near all health care units covered by the relevant regional directorate?

- What is the number of new doctors and nurses employed in 2021-2023?
- What is the number of doctors and nurses who left in 2021-2023?
- What is the number of beds near all health care units divided by each respective unit in the jurisdiction of the Regional Health Care Service Directorate?
- What specialties are offered in the units of direct provision of health care services according to the relevant units in the jurisdiction of the Regional Directorate of Health Care Service?
- Are radiological examinations offered at the direct delivery units of health care services in the jurisdiction of the Regional Directorate of Health Care Service? If so, in which health care units?

Requests for information sent to the regional directorates of pre-university education contained the following questions:

- How many special needs assistant teachers does the Regional Directorate of Pre-University Education employ?
- How many children are taught by these assistant teachers?
- How many hours a week do assistant teachers have?
- Is there a ranking of the performance of pre-university educational institutions? If so, make available a copy of the most recent performance report.
- How much money was spent in the last budget year for heating the schools of the regional directorate of pre-university education?
- How much money was spent in the last budget year for recreational activities/community schools with students?

The third component has to do with the development of focus groups and in-depth interviews conducted with representatives of civil society, journalists and representatives of regional directorates to discuss important issues which, through the sharing of experiences, will contribute to analysis of the main problems of transparency and accessibility in the regional health and education sector.

Twelve in-depth interviews and eight focus groups were conducted.

In-depth interviews included activists and journalists engaged in education and health issues, as well as representatives of organizations working for the rights of people with disabilities, the LGBTI+ community, Roma and Egyptian minorities, women, children, etc., who work in Tirana, Shkoder, Vlora and Elbasan.

The focus groups consisted of about six to 10 participants and took place in six cities. During the focus group sessions, moderators lead the discussion by asking open-ended questions and by encouraging participants to share their thoughts, opinions and experiences regarding the transparency and accessibility of health and education system institutions.

The four focus groups that dealt with the health system that took place in Tirana, Fier, Shkoder and Elbasan consisted of representatives of organizations dealing with patient rights, organizations of patients with different pathologies, representatives of minorities, activists and journalists dealing with social issues.

In these focus groups, issues related to the standards of health care service delivery were discussed, for example on: the disinfection of health care units, the sanitary service, suitable work premises, suitable beds for patients, certified radiological equipment, patient information on rights and services, specialties offered in the territory covered by the regional directorate, list of doctors, their CVs, investments made in the last year by the regional directorate, etc.

The four focus groups that dealt with the education system and that took place in Tirana, Berati, Lezha and Fieri consisted of representatives of associations of parents and/or parents of children with disabilities, representatives of minorities and various activists in the field of education.

In these focus groups, issues related to investments made in the units of the pre-university education system, the progress of the school reconstruction process for those regions affected by the earthquake of 2019 were discussed. Other important issues that were addressed in the focus groups were the measurement of the performance of the educational system, data collection from the educational units, the adjustment of the needs assessment process and the problems encountered during the provision of the educational service, as well as some proposals for their solution.

III. Transparency in the Regional Directorates of the Health Care Service Operator

3.1 The proactive transparency monitoring findings

In order to monitor the proactive transparency of the Regional Directorates of the Health Care Service Operator, the methodology shown above was followed. Online research showed that none of the Regional Directorates of Shkoder, Tirana, Vlora and Elbasan have their own official websites but are an integral part of the official website of the General Directorate of the Health Care Service Operator. The lack of a dedicated website for each directorate not only hinders proactive transparency monitoring but above all makes access to information difficult.

Indeed, in the legal framework and in the practice already established by the Commissioner for the Right to Information and Protection of Personal Data, there is no legal obligation for regional branches/regional directorates of a public authority to have an official website internet different from that of the General Directorate. The law on the right to information also does not specify as a “public authority” the regional directorates of a central public authority. There is a consolidated stance of the Office of the Commissioner for the Right to Information and Protection of Personal Data³ that the central public authority should adopt, review and implement a single transparency program valid for the whole institution, including the head office and regional directorates/branches.

Also for the appointment of the Coordinator for the Right to Information, the Commissioner’s Office has taken a similar stance to the one above, instructing the public authorities to appoint a coordinator responsible for the entire institution, including the head office as well as the regional directorates⁴.

³ Udhëzuesi “Autoritetet publike në zbatim të Ligjit për të Drejtën e Informimit”, 2016 https://idp.al/wp-content/uploads/2024/04/Udhezues_kush_eshte_AP.pdf

⁴ Udhëzuesi “Autoritetet publike në zbatim të Ligjit për të Drejtën e Informimit”, 2016 https://idp.al/wp-content/uploads/2024/04/Udhezues_kush_eshte_AP.pdf

As per above, the official website and Transparency Program of the General Directorate of the Health Care Service Operator⁵ were monitored, in which documents reflecting the activity of the regional directorates are published. From this monitoring, the information that was published on the official website of the General Directorate was evaluated with positive points according to the defined methodology.

Table No. 3: *The level of transparency of the Regional Directorates of the Health Care Service Operator*

	Average level of transparency	Proactive transparency	Ethics and Integrity	Financial Transparency	Performance indicators	Patient rights	Services provided	Public Participation
DROSHKSH Shkoder	19%	52%	26%	0%	26%	0%	20%	0%
DROSHKSH Tirana	19%	52%	26%	0%	26%	0%	20%	0%
DROSHKSH Vlora	19%	52%	26%	0%	26%	0%	20%	0%
DROSHKSH Elbasan	19%	52%	26%	0%	26%	0%	20%	0%

From the results presented in the table above, it can be seen that the average level of transparency for the Regional Directorates of the Health Care Service Operator is minimal, reaching over 50% in only one category; in some indicator categories it is 0%.

The above findings show that the most populated categories with information are “Proactive Transparency” (since a Coordinator of the Right to Information has been appointed, the data of the coordinator has been published, the Transparency Program and the register of requests and responses have been published) and the category of “Ethics and Integrity” (since the “Regulation of Internal Organization on the Organization and Functioning of the Health Care Services Operator”⁶ has been published, which contains the obligations of regional operators as well as the rules of ethics of the Operator’s employees). Categories that are less transparent are “Patient rights” and “Public

⁵ Check <https://oshksh.gov.al/programi-i-transparencas/>

⁶ Order no. 18, dated 17/01/2019 of the Ministry of Health and Social Protection <https://oshksh.gov.al/wp-content/uploads/2019/06/rregullorja-e-operatorit-1.pdf>

participation”, which are the most important categories for this sector.

3.2 Reaction to official requests for information (reactive transparency)

Referring to the above methodology, an official request for information was sent to all institutions. A request for information was sent by email to the Regional Directorates of the Health Care Service Operator on 19.06.2024. Only the DROSHKSH of Vlora responded within the legal deadline and made available all the required documentation. The DROSHKSH of Tirana made available all the required documentation but beyond the legal deadline. Of the other two directorates, the DROSHKSH Elbasan and Shkodra, neither responded.

IV. Transparency in the Regional Directorates of Pre-University Education

4.1 Proactive transparency monitoring findings

In order to monitor the proactive transparency of the Regional Directorates of Pre-University Education, the same methodology was followed as for the monitoring of the regional directorates of the health system.. The official website of the regional directorates was first searched on the Internet. In this case, the Regional Directorates of Pre-University Education in Lezha, Durres, Fieri and Korca have a dedicated interface inside the official website of the General Directorate of Pre-University Education⁷. However, the information published on these interfaces is very

⁷ Check: <https://lezhe.arsimiparauniversitar.gov.al/>, <https://durres.arsimiparauniversitar.gov.al/>, <https://fier.arsimiparauniversitar.gov.al/>, <https://korce.arsimiparauniversitar.gov.al/>

limited. For this reason, the Transparency Program of the General Directorate of Pre-University Education⁸ was also monitored.

In the case of the Regional Directorates of Pre-University Education, the findings show that these institutions have only partially fulfilled their legal obligation to publish information proactively. As presented in the following table, the average level of transparency for all four regional directorates of pre-university education is minimal, reaching above 50% only in one category of indicators; in three cases, the value was 0.

Table No. 4: *Level of transparency of the Regional Directorates of Pre-University Education*

	Average level of transparency	Proactive transparency	Ethics and Integrity	Financial transparency	Performance indicators	Student's rights	Services provided	Public Participation
DRAP Lezha	17%	82%	18%	6%	0%	0%	0%	10%
DRAP Durres	17%	82%	18%	6%	0%	0%	0%	10%
DRAP Fieri	17%	82%	18%	6%	0%	0%	0%	10%
DRAP Korca	17%	82%	18%	6%	0%	0%	0%	10%

The above findings show that the categories most populated with information are “Proactive Transparency” (since there is an individual interface of each regional directorate, a Coordinator of the Right to Information has been appointed, the data of the coordinator has been published and also the Program of Transparency and the register of requests and responses) and the category “Ethics and Integrity” (since the “Regulation on the organization and operation of the DPAP”⁹ acronym in Albanian, which contains the obligations of the operators, has been published).

⁸ Check <https://arsimiparauniversitar.gov.al/transparenca/>

⁹ Check <https://arsimiparauniversitar.gov.al/rregullore-per-organizimin-dhe-funksionimin-d-p-a-p/>

The categories that are less transparent are “Performance indicators”, “Student rights” and “Services provided”.

4.2 Reaction to official requests for information (reactive transparency)

Referring to the above methodology, an official request for information was sent to all institutions. A request was sent to the regional directorates of pre-university education by mail on 25.06.2024. All DRAPs responded with the exception of Durres DRAP. Fieri and Korca DRAP responded within the legal deadline and made available all the requested information with the exception of information related to the budget, arguing that they do not have such information. Lezha DRAP made the requested information available but beyond the legal deadline (the response date was 19.07.2024).

V. Accessibility in health institutions

Accessibility in health facilities is essential to ensure that all individuals receive the care they need and also equal treatment. This includes, but is not limited to, physical accessibility or infrastructure to enable physical access, such as wheelchair ramps, accessible examination rooms, and other facilities that serve people with disabilities.

Also important is the accessibility of information and communication, to ensure that patients and citizens can understand and interact with health service providers. This includes designing the website and information to be usable and accessible by all. Programs and services dedicated to responding to the needs of patients of vulnerable groups such as LGBTI+, Roma and Egyptian minorities and those with disabilities, are also essential for creating a safe and equal environment in health institutions. To be as accessible as possible, the institution should also guarantee clear procedures for complaints, to enable patients to express and address their concerns.

Difficulties in accessing health institutions disproportionately affect vulnerable groups, exacerbating existing inequalities. For example, LGBTI+ individuals may experience discrimination in health settings when faced with untrained and unprofessional service providers; members of Roma and Egyptian minorities may also face prejudice and culturally insensitive behavior; people with disabilities often encounter physical and technological barriers that prevent them from accessing the necessary service independently. These challenges hinder access to health services for these groups, and may lead to delays or insufficient care, worsening the health status of patients.

The right to health care is a basic human right and its denial has significant legal and social consequences. Denial of access to health services constitutes a violation of Albanian law, which guarantees equal rights in health care, based on non-discrimination¹⁰. Beyond the legal consequences, denial of access with discriminatory consequences undermines the principles of equality and inclusion, creating negative social consequences and feeding cycles of poverty and social exclusion for already marginalized communities.

This also damages public trust by negatively affecting perceptions of health sector institutions. When patients perceive that health services are not inclusive or accessible, they are less likely to seek care, which can lead to worsening health conditions and increased health care costs in the long term, as well as an added financial burden to provide health care in the private sector. Furthermore, the public may lose confidence in the health system's ability to provide fair and equitable treatment, which may have consequences for social cohesion and the legitimacy of public institutions. The data show that the level of public distrust in public health institutions is worrying; in 2023, 49.7% of Albanian citizens said they did not trust these institutions, while 51.1% were dissatisfied with their services¹¹. For 65% of citizens, poor quality and standard healthcare is among the three main reasons for their feeling of insecurity in the country, along with criminality (72%) and workplace insecurity (30%)¹².

Therefore, guaranteeing comprehensive and quality health services is not only a legal obligation and a social need but

¹⁰ Law No. 10107, dated 30.3.2009 on Health Care in the Republic of Albania

¹¹ Institute for Democracy and Mediation (2024) Trust in Government 2023 <https://idmalbania.org/sq/besimi-ne-qeverisje-2023-sondazhi-vjetor-i-opinionit-publik-ne-shqiperi/>

¹² Ibid.

also a critical factor in maintaining the credibility of health institutions.

5.1 Opening up health institutions to the public and the accessibility of information

As noted in section III, the level of transparency in the Regional Directorates of the Health Care Service Operator in Shkoder, Tirana, Vlore and Elbasan is generally low, with an average of 19%. Of particular concern is the lack of transparency of information regarding patient rights (0%), public participation (0%) and services provided by institutions (20%). These are categories that directly affect the public’s ability to access and interact with health institutions and hold them accountable.

Monitoring on the ground showed that two of the four regional directorates displayed the rights of patients in their premises, while three of the four had a functional “front desk” service, which aims to facilitate information and communication with citizens. However, study participants noted that despite posting patients’ rights, there is low engagement from patients due to the complexity of the legal language or general apathy about their rights¹³.

In the perception of the participants, despite steps taken towards the decentralization of decision-making in the health sector, these institutions in reality continue to function as extensions of the central government.

Another perception shared by the participants in the study was related to the lack of independence of the regional directorates in communicating with the public and in providing the information requested by it. In their experience, information was controlled by the Ministry of Health and Social Protection and provided only with the latter’s

¹³ Focus group discussion with organizations of patients with different pathologies, Fier, 18/06/2024

approval¹⁴, creating a gap in transparency and accountability.

Regarding the accessibility of the information made public, the institutions do not have an official website, Transparency Program, Coordinator for the Right to Information or a register of dedicated requests and responses. According to best practices, official websites need to be as accessible as possible and be adapted for people with disabilities, e.g. have necessary features, such as screen reader compatibility, alt texts for images, voice-to-text translation, or navigation aids. Lack of these features makes it difficult or impossible for people with disabilities to access information independently, manage appointments or access their medical records. However, it should be underlined that the lack of accessibility of information does not only affect people with disabilities but also the elderly, those who live in remote areas or do not have access to the Internet service, as well as citizens with a limited digital knowledge.

Despite these challenges, there are also good examples of cooperation. Some representatives of the civil society organizations that participated in the study noted that they have cooperation agreements with the regional directorates of OSHKSH, which have helped to speed up responses, especially in relation to health care centers. This points to a more collaborative approach when clear agreements exist, resulting in faster and more effective information and communication. However, the latter must be guaranteed equally to all citizens. From the point of view of the participants in the study, the high number of citizen complaints in this sector was seen as an indicator of dissatisfaction with the health system¹⁵.

¹⁴ Focus group discussion with journalists, Tirana, 06/24/2024

¹⁵ Ibid.

5.2 Physical access and adequate infrastructure

Guaranteeing physical accessibility in health institutions is a basic requirement to ensure equal access to health for everyone, including people with disabilities. The necessary infrastructure includes elements such as simplified directions, ramps, lifts, blind bars, widened doors, adapted toilets, etc.

Denial of reasonable accommodation is considered a form of discrimination according to Albanian law on protection against discrimination¹⁶. This includes the obligation of the state to make necessary and appropriate changes or adjustments to address the special needs of certain groups so that they can enjoy and exercise their rights equally.

Lack of equal access to these services and facilities continues to create significant disparities between different socio-economic groups and geographic areas, limiting their inclusion and integration into the health system.

The field monitoring carried out for this study showed that only two of the four Regional Directorates of OSHKSH were equipped with basic elements of physical access, such as ramps and elevators. Study participants also reported cases where ramps are present but do not have the right parameters to be functional. In some cases, the slope of the ramps is inappropriate, creating great difficulties for users¹⁷. A lack of elevators makes it impossible for many individuals with disabilities to access services offered on upper floors. These concerns were confirmed by two-thirds of the study participants.

Another issue they highlighted was the lack of simplified instructions and special signs for the visually impaired, such as braille, tactile signs and guide strips, auditory cues or sign language interpreters for deaf individuals, which

¹⁶ Law No. 10 221, dated 04.02.2010 on Protection from Discrimination

¹⁷ Interview with H.M, First Association of Tetraplegics, Vlora, 05/06/2024

are essential for orientation and independent movement within health institutions¹⁸. In a 2020 recommendation from the Commissioner for Protection from Discrimination to the Ministry of Health and Social Protection (MShMS), the lack of assistive technology equipment was described as evident, which includes assistive devices for everyday life, education, information and communication technology, orientation and mobility, as well as assistive devices for people with impaired vision¹⁹. The participants in the study highlighted also the lack of equipment and apparatus in emergency departments in some regions, as well as non-adapted facilities in toilets, which do not meet the needs of patients with special needs.

To sum up, ensuring equal physical access to health facilities is needed to guarantee equal treatment of all individuals, regardless of disability or special needs.

5.3 Communities' challenges

In the Albanian legal system, the right to health care from the state is a constitutional right²⁰. Denying access to health services constitutes a violation of the law on health care, which guarantees equal rights in health care, based on non-discrimination²¹. However, in practice, some citizens, especially those belonging to vulnerable groups, face challenges in enjoying this right. Some of these challenges are already acknowledged in the political and strategic framework for the Roma, Egyptian, LGBTI+ and disabled communities.

Roma and Egyptians in Albania face serious obstacles in accessing public services, especially health care, due to

¹⁸ Interview with J.F, Albanian Blind Association, Tirana, 07/06/2024

¹⁹ Recommendation no. 420, dated 06/03/2020 of the Commissioner for Protection from Discrimination https://www.kmd.al/wp-content/uploads/2021/02/06.03.2020_Rekomandim-per-sigurimin-e-pajisjeve-tifloteknike-per-te-verber_MShMS.pdf

²⁰ Constitution of the Republic of Albania

²¹ Law No. 10107, dated 30.3.2009 on Health Care in the Republic of Albania

lack of personal documents and civil registration, lack of information and lack of understanding of administrative procedures, as well as ongoing stigmatization and discrimination. A study has shown that 59% of Roma do not have health cards, significantly limiting their access to health services²².

These problems are recognized in the National Action Plan for Equality, Inclusion and Participation of Roma and Egyptians, according to which these communities continue to face obstacles in accessing health care on an equal basis. According to the Plan, poor housing conditions, low levels of education and health-related knowledge, physical distance from health care centers and experiences of discrimination exacerbate problems. Also, the lack of health mediators is another obstacle that makes access difficult for those members of the community who do not speak Albanian²³.

On the other hand, the LGBTI+ community in Albania faces challenges in accessing health care, experiencing discrimination and stigmatization in medical facilities. A survey shows that 16% of participants who have received health care in recent years have experienced discrimination from medical personnel during their visits either because of their sexual orientation or gender identity²⁴. According to the same source, 30% of the participants expressed the feeling of dissatisfaction and fear of discrimination or prejudice while receiving health services. This has led 64% of members of the LGBTI+ community to avoid sexual and reproductive health visits over a period of four years. Also, 3% reported having undergone unwanted childhood medical interventions on their intersex bodies. Discrimination in receiving services against the LGBTI+ community was also highlighted during an interview, where a case of non-treatment of the patient by the family doctor, for which the Commissioner for Protection from Discrimination had found evidence of discrimination²⁵, was highlighted.

²² Porta Vendore (2021) Study in 14 municipalities, 66% of Roma unemployed and 59% without access to healthcare <https://portavendore.al/2021/01/31/studimi-ne-14-bashki-66-e-romeve-te-papune-dhe-59-pa-akses-ne-shendetesi/>

²³ National Action Plan for Equality, Inclusion and Participation of Roma and Egyptians in the Republic of Albania 2021-2025 <https://shendetesia.gov.al/wp-content/uploads/2022/03/PLANI-KOMB%C3%8BTAR-I-VEPRIMIT-P%C3%8BR-BARAZI.pdf>

²⁴ Joint written contribution of the Alliance Against Discrimination of LGBTI People and ILGA on the position of LGBTI people within the 4th cycle of the universal periodic review of the Republic of Albania, 2024

²⁵ Interview with A.A, Alliance Against Discrimination of LGBTI people, Tirana, 13.06.2024

Beyond direct discrimination, the lack of specialized services for transgender people, such as hormone therapy or surgical interventions for gender reassignment, remain major concerns for this community. Also, the lack of retroviral medications for people with HIV for long periods and the lack of access to certain tests, such as CD4, negatively affect the health and quality of life of these patients²⁶. All these services or treatments have very high financial costs and not providing them in the public health system burdens individuals disproportionately.

Many of these challenges faced by the LGBTI+ community in accessing health care are recognized in the National Action Plan for LGBTI+ People, which provides, among other things, measures to guarantee their equal access to health services²⁷.

For people with disabilities, some of the challenges identified by the National Plan for People with Disabilities relate to the lack of facilities in health institutions, the lack of wheelchairs, the lack of support with assistive technology and the lack of accessible transportation²⁸.

Regarding the provision of health care at home, the participants in the study underlined that efforts to improve the situation through government projects are limited by insufficient funding and have only been extended to certain regions.

All these problems highlight the urgent need for reforms in the health sector to ensure equal access and appropriate treatment that addresses the specific needs of vulnerable communities.

²⁶ Joint written contribution of the Alliance Against Discrimination of LGBTI People and ILGA on the position of LGBTI people within the 4th cycle of the universal periodic review of the Republic of Albania, 2024

²⁷ National Action Plan for LGBTI People 2021-2027 <https://shendetesia.gov.al/wp-content/uploads/2022/01/LGBTI-NAP-2021-2027-AL-final.pdf>

²⁸ National Plan for Persons with Disabilities 2021-2025 <https://shendetesia.gov.al/wp-content/uploads/2021/11/Plani20Komb%C3%ABtar20p%C3%ABr20Personat20me20Aft%C3%ABsi20t%C3%AB20Kufizuar202021-2025-4.pdf>

5.4 Complaint mechanisms

In order to improve the accessibility and quality of services, health institutions should have appropriate complaint mechanisms. These should include clear, public and easy-to-understand processes, as well as support for those who need help accessing them.

According to the participants in the study, complaint mechanisms in the field of health in Albania are not sufficiently known by citizens and in general there is a lack of information on the websites of the institutions. Monitoring carried out in the field showed that two of the four OSHKSH Regional Directorates had posted posters containing information about complaint procedures.

According to the participants in the study, citizens in some cases direct their complaints to the relevant ministry. In cases where the problem has not been solved, other mechanisms that have been used are the Commissioner for Protection from Discrimination, or the courts. In this respect, due to the need for legal assistance, they often need the support of lawyers or specialized civil society organizations. The latter have successfully represented several cases in court that resulted in compensation decisions for hemophiliacs who were denied appropriate medical treatment²⁹, and children with hearing problems for whom cochlear implants were not performed³⁰.

The report of the Commissioner for Protection against Discrimination for the year 2023 highlighted some of the main problems encountered during the examination of cases where discrimination was claimed due to health status. These included problems with the reimbursement for medications for patients suffering from serious illnesses, the calculation of the amount of pensions by the Social Insurance Institute, lack of financial support for families in

²⁹ Check: Together for Life <https://www.togetherforlife.org.al/gjykata-demshperblen-pacientin-me-hemofili-together-for-life-perfaqesoi-ligjerisht-ceshtjen/>

³⁰ Ibid: <https://www.togetherforlife.org.al/te-drejtat-e-pacienteve-tfi-fiton-te-gjiitha-ceshtjet-ne-gjykate/>

need by local government institutions as well as the termination of employment due to health problems³¹. The Commissioner's reports from previous years showed a number of complaints about the lack of medication treatment in public hospital institutions for children suffering from leukemia and the lack of reimbursable medication for people suffering from hemophilia³².

In this context, the Commissioner made several discrimination decisions against the Ministry of Health and Social Protection and the "Mother Teresa" University Hospital Center (QSUNT). One of the cases treated was related to not providing the right amount of Factor IX medication for a patient with hemophilia³³. Despite being aware of the situation, complaints and a request for a response by the Commissioner for Protection from Discrimination, the Ministry of Health and Social Protection and the University Hospital Center in Tirana did not take measures to ensure the medication in the right amount.

This lack of treatment hastened the partial invalidation of the patient who submitted the complaint. The Commissioner's decision emphasized that health care is a right that cannot be conditioned by the limited state budget and that the state is obliged to provide health care for people with disabilities, guaranteeing free benefits of health services and medications needed for this category of people. Therefore, the claim of the institutions regarding budget restrictions was not accepted by the Commissioner, who found severe discrimination due to disability and ordered the responsible institutions to take immediate measures to deal with it. In conclusion, the Commissioner recalled previous cases handled by this institution, underlining that discrimination against hemophiliac patients by the Ministry of Health and Social Protection and the Tirana University Hospital Center had continued for some time.

³¹ 2023 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2024/03/Raporti-i-KMD-2023.pdf>

³² 2021 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2022/04/Raporti-KMD-2021-versioni-perfundimtar.pdf>

³³ The Decision No. 144, dated 05. 08. 2021 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2021/08/Vendim-nr.-144-date-05.08.2021-D.-N.-kunder-Ministrise-se-Shendetesise-dhe-Mbrojtjes-Sociale-dhe-Qendres-Spitalore-Universitare-Nene-Tereza-T.pdf>

In another case, the Commissioner found severe discrimination against children with leukemia from these two institutions, due to their health condition, age and economic condition³⁴. This case was related to the lack of chemotherapy drugs for children with leukemia. Not taking the right dose and the time of the treatment, in relation to the vulnerability of the disease, can have serious consequences for the health of these children and reduce their chances of survival. In this case, the Commissioner for Protection from Discrimination assessed that the actions and inactions of the Ministry of Health and Social Protection and the Tirana University Hospital Center were characterized by negligence, lack of cooperation and avoidance of responsibility, exposing children with leukemia to unfair and discriminatory treatment. This discrimination was aggravated by the failure of procurement procedures for the necessary drugs, which the Commissioner considered unreasonable and insufficient as a justification for the non-provision of drugs by the state.

This decision of the Commissioner also underlined that the drugs that were the object of the complaint were only for hospital use, and so should not be found in the open pharmaceutical network. Despite their confirmed absence during the year 2020-2021, QSUNT data showed that 72 children with leukemia had received chemotherapy treatment at the onco-hematology service during that year. According to the Commissioner, this fact shows that health care, which should have been free and guaranteed by the state, had not been such, but had burdened the finances of families who privately obtained the necessary drugs for chemotherapy treatment. According to the decision, the lack of medicines and the impossibility of obtaining them due to their economic situation disproportionately affected children from families in a poor economic situation³⁵. It should be underlined that, in Albania, concerns about access to drugs and health treatment for cancer patients remain acute. Several cases of corruption related to drugs exposed at the oncology hospital at QSUNT triggered civil protests during 2024, manifesting massive dissatisfaction among

³⁴ Decision No. 161, dated 01.09.2021 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2021/09/Vendim-Nr.-161-date-01.09.2021-Shoqata-Together-for-Life-kunder-Ministrise-se-Shendetesise-dhe-Mbrojtjes-Sociale-dhe-Q.S.U-Nene-Tereza-Diskriminim.pdf>

³⁵ Decision No. 161, dated 01.09.2021 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2021/09/Vendim-Nr.-161-date-01.09.2021-Shoqata-Together-for-Life-kunder-Ministrise-se-Shendetesise-dhe-Mbrojtjes-Sociale-dhe-Q.S.U-Nene-Tereza-Diskriminim.pdf>

the public³⁶.

The reports of Albania's Supreme Audit Institution³⁷ also confirm a series of problems in this area, including a lack of reimbursement for medicines in pharmacies and hospitals, inappropriate management of the list of reimbursable medicines, irregularities in the reimbursement of medicines, the orientation of patients to certain pharmacies for the purpose of private benefit, as well as the reduction of the drugs' consumption due to their unavailability.

In conclusion, the level of effectiveness and the difficulties in accessing the complaint mechanisms in the health services in Albania, as evidenced in the above cases, prove there is an urgent need for improvement, and for increasing the awareness of and support for citizens to protect their rights.

VI. Accessibility in educational institutions

Accessibility in educational institutions and the services provided by them is essential to ensure that all students have equal opportunities to exercise their right to education. For these environments to be accessible, among other things, certain physical infrastructure is needed, such as ramps, elevators and suitable facilities, but also quality psycho-social services, as well as access to effective complaint mechanisms to address concerns. Among other things, the website, the communication channels of the institution, the official information and school materials should be designed to be usable and accessible by everyone. Programs and services dedicated to the needs of

³⁶ Citizens.al (2024) Korrupsioni në spitalin Onkologjik çon qytetarët në protestë! <https://citizens.al/2024/06/27/korrupsioni-ne-spitalin-onkologjik-con-qytetaret-ne-proteste/>; Citizens.al (2024) Hetimet e Prokurorisë zbuluan se mjekët e Onkologjikut shisinin ilaçet, pacientët pa kurën e duhur <https://citizens.al/2024/06/25/hetimet-e-prokurorise-zbuluan-se-mjeket-e-onkologjikut-shisinin-ilacet-pacientet-pa-kuren-e-duhur/>

³⁷ Citizens.al (2024) KLSH: Shëndeti i pacientëve është cenuar nga mungesa e barnave <https://citizens.al/2024/07/15/klsh-shendeti-i-pacienteve-eshte-cenuar-nga-mungesa-e-barnave/>

students from vulnerable groups, such as LGBTI+, Roma and Egyptian minorities and students with disabilities, are also essential for creating a safe and equal environment in educational institutions.

The lack of accessibility of educational institutions disproportionately affects vulnerable groups who face specific challenges, including discrimination, social isolation and lack of necessary resources and support. For example, LGBTI+ students may face a lack of inclusive curricula or support services, while minority students may encounter, among other things, language barriers. Students with disabilities, on the other hand, often face physical and technological barriers (denial of reasonable accommodation) that do not allow them to fully participate in educational activities. These challenges not only hinder their educational journey but also contribute to further exclusion and marginalization.

Discrimination in the field of education has important legal and social implications. For example, the denial of reasonable accommodation in the case of people with disabilities is considered a form of discrimination according to Albanian law on protection from discrimination³⁸. This includes the obligation of the state to make necessary and appropriate changes or adjustments to address the special needs of certain groups, so that they can enjoy and exercise their rights equally with others. According to this law, the government also has the duty to take measures to ensure the education of the entire population, in particular, taking measures in favour of women and girls, minorities, people with disabilities, as well as persons who are, or are more likely to be, an object of discrimination, as well as ensuring the right to education in minority languages and in appropriate ways for people with disabilities³⁹.

Beyond the legal consequences, denying access with discriminatory consequences undermines the principles of equality and inclusion, creating negative social consequences and perpetuating cycles of poverty and social exclusion for already marginalized communities.

Also, public trust is damaged, by negatively affecting perceptions of educational institutions. When students and their parents perceive that schools are not inclusive or appropriate, they are less likely to engage with these institutions

³⁸ Law No. 10 221, dated 04.02.2010 on Protection from Discrimination

³⁹ Ibid

and may seek alternatives, which leads to further segregation and inequality. Moreover, the public may lose faith in the ability of the education system to provide equal opportunities for all, which may have long-term consequences for social cohesion and the legitimacy of these institutions. The data show that the level of public distrust in public education institutions in general (including pre-school) is worrying; in 2023, 44.4% of Albanian citizens expressed that they did not trust public education institutions, while 40.4% were dissatisfied with the services of these institutions⁴⁰. Therefore, guaranteeing comprehensive and quality educational services is not only a legal obligation and social need, but a critical factor in maintaining the credibility of educational institutions.

6.1 Opening up educational institutions to the public and information accessibility

As noted in section IV, the overall level of proactive transparency for each of the eight DRAPs in Lezha, Durrës, Fieri, Korça is low, at 17%. Of particular concern is the lack or low level of transparency in the categories related to student rights (0%), services provided by the institution (0%) and public participation (10%). These are categories that directly affect the public's ability to access and interact with educational institutions and hold them accountable.

The monitoring carried out in the field for the purposes of this study showed that three out of four DRAPs offered “front desk” services in their premises, in order to facilitate information and communication with citizens.

In the perception of the participants in the study, despite steps taken to decentralize decision-making in the education sector through regional operators, the latter in fact function as extensions of central government at local level. This is also reflected in the approach taken to proactive transparency, since none of the regional directorates has a dedicated Transparency Program, Coordinator for the Right to Information or register of requests and responses – all

⁴⁰ Institute for Democracy and Mediation (2024) Trust in Governance 2023 <https://idmalbania.org/sq/besimi-ne-qeverisje-2023-sondazhi-vjetor-i-opinionit-publik-ne-shqiperi/>

of which are focused on the General Directorate of Pre-University Education.

To confirm this perception, during the interviews, the lengthy procedures for obtaining permission to carry out activities in schools, which must be approved by the Ministry of Education and Sports, was discussed. According to the interviewees, bureaucracy and delays in the approval of the permit prevented the realization of activities in some cases⁴¹. Beyond the requirements for the approval of certain permits, the participants said they witnessed a lack of independence from the regional directorates in terms of communicating with the public or providing the information they had requested. Also in this aspect, they perceived that the information was controlled/concentrated at the Ministry of Education and Sports and was only given with the approval of the latter. However, some participants in the study highlighted some good cases of cooperation and the approval of permission to access schools for activities, facilitated thanks to cooperation agreements between organizations and the institution⁴².

Regarding the accessibility of information made public, the official (inter)faces of the institutions are not adapted to be used by people with disabilities. To ensure accessibility for these categories, designs⁴³ with features such as screen reader compatibility, alt text for images, voice-to-text translation, or navigation aids that would facilitate use by individuals who are blind, visually impaired, or deaf are needed. These are all features that these websites lack. It should be emphasized that the lack of access to information published on the Internet does not only affect people with disabilities but also the elderly, those who live in remote areas or do not have access to the Internet, as well as citizens with limited digital literacy.

⁴¹ Interview with M.V, Roma Women’s Rights Center, Tirana, 06/07/2024

⁴² Interview with G.S, The Social Justice Organization, Tirana, 10/06/2024; Interview with A.U., Shoqata Gruaja tek Gruaja, Shkoder, 05/06/2024

⁴³ Check Web Content Accessibility Guidelines (WCAG) <https://www.w3.org/WAI/WCAG20/versions/guidelines/wcag20-guidelines-20081211-a4.pdf>

6.2 Physical access and adequate infrastructure

Guaranteeing physical accessibility in educational institutions is a basic requirement to ensure equal access to education for everyone, including people with disabilities. The necessary infrastructure includes elements such as simplified directions, ramps, lifts, blind bars, widened doors, adapted toilets, etc. Despite its great importance, in practice this necessary infrastructure is often missing. The participants in the in-depth interviews (about two-thirds of them) said that few facilities are offered in educational institutions for people with disabilities, while one-third of them said that some institutions have ramps but no elevator. This shows that even in those cases where steps have been taken to ensure physical access, they are often not sufficient to guarantee full use of the educational environment.

In the experience of one participant in the study, no school or DRAP that he had visited had all the necessary conditions to be accessible by people with disabilities. According to him, even where schools are equipped with ramps at the entrance, there is no further access to the classrooms⁴⁴. Other participants in the study also identified cases where ramps were not present but were not built with the right parameters to be functional. For example, ramps that are too steep or long may be unusable for individuals in wheelchairs. Even more widespread is the lack of elevators, adapted toilets, or signals that assist people with hearing and vision problems (braille or tactile information).

However, during the focus group discussions, participants confirmed that some schools and ZVAs are properly equipped with ramps, but this is missing in the Regional Directorates⁴⁵. This was also confirmed by the monitoring carried out in the field for this study. Participants in the discussions with the focus groups mentioned also that the Regional Directorates are located relatively far away for many citizens, which also affects the issue of access, especially for communities living in rural or remote areas.

Despite the problems related to accessibility for people with disabilities, one-quarter of the participants in the study

⁴⁴ Interview with G.S, The Social Justice Organization, Tirana, 10/06/2024S

⁴⁵ Focus group discussion with the Roma and Egyptian community, Berat, 14/06/2024

positively evaluated the fact that this issue has been taken into consideration during the reconstruction of some schools and other educational institutions.

6.3 Communities' challenges

The legal and political framework for education in Albania⁴⁶⁴⁷ pays special attention to the support of vulnerable groups, including children with disabilities and Roma and Egyptian children. The right to education without discrimination on the basis of gender, race, skin colour, ethnicity, language, sexual orientation, political or religious beliefs, economic or social status, age, residence, disability or other reasons is guaranteed by the Constitution and relevant legislation⁴⁸.

Inclusion and the provision of equal opportunities for students are among the basic pillars of the functioning of the education system, according to the Law on the Pre-University Education⁴⁹. The latter envisions the provision of special care for students from families in need, students with disabilities and those with learning difficulties. In addition, the National Education Strategy⁵⁰ foresees financial support for Roma, Egyptian and students of other vulnerable groups, aiming to reduce inequalities in education and facilitate the integration of these groups in the education system. However, despite the existence of these policies aimed at providing additional support to students who face special challenges, during discussions with the participants in the study, the opinion that prevailed is that there has been little progress in implementation⁵¹.

⁴⁶ Law No. 69/2012 On the Pre-university Education System in the Republic of Albania

⁴⁷ The National Education Strategy 2021-2026 <https://arsimi.gov.al/wp-content/uploads/2021/05/Draft-Strategjia-per-Arsimin-2021-2026.pdf>

⁴⁸ Law No. 69/2012 On the Pre-university Education System in the Republic of Albania

⁴⁹ Ibid

⁵⁰ The National Education Strategy 2021-2026 <https://arsimi.gov.al/wp-content/uploads/2021/05/Draft-Strategjia-per-Arsimin-2021-2026.pdf>

⁵¹ Focus group discussion with the Roma and Egyptian community, Berat, 14/06/2024

An important issue that disproportionately affects the children of the Roma and Egyptian communities is dropping out of school. A large number of Roma and Egyptian pupils drop out of compulsory education as a result of discriminatory attitudes, lack of support and bullying at school, but also due to the need to help their parents in income-generating activities.

A significant number of children from these communities do not complete basic education, and only a symbolic percentage of them enroll in upper secondary schools⁵². This situation highlights a deep gap in educational opportunities between these communities and the wider population. The gap between Roma and non-Roma communities in compulsory education in Albania reaches 31%, with only 66% of Roma children enrolled⁵³.

According to the participants in the study, due to the magnitude of this problem, institutions are often reluctant to provide accurate data on the participation of Roma and Egyptian children in schools, even when the information is requested officially by civil society organizations⁵⁴. This lack of transparency makes it difficult to effectively monitor and address the situation.

Another challenge faced by these communities is the low level of information on the procedures for enrolling children in kindergarten/school. According to study participants, parents from these communities are often not involved in school boards and lack access to information provided by educational institutions. This prevents the enrolment of children and can lead to exclusion from education, especially for children of early age. Enrolment of Roma and Egyptian children in schools is also significantly affected by the economic situation of the family and whether or not they benefit from the abolition of kindergarten and school registration fees. For the latter, in 2021, the Commissioner for Protection from Discrimination made a recommendation to the municipalities to take positive measures to exempt families in need and children coming from families belonging to Roma and Egyptian community from kindergarten

⁵² The National Education Strategy 2021-2026 <https://arsimi.gov.al/wp-content/uploads/2021/05/Draft-Strategjia-per-Arsimin-2021-2026.pdf>

⁵³ National Action Plan for Equality, Inclusion and Participation of Roma and Egyptians in the Republic of Albania 2021-2025 <https://shendetesia.gov.al/wp-content/uploads/2022/03/PLANI-KOMB%C3%8BTAR-I-VEPRIMIT-P%C3%8BR-BARAZI.pdf>

⁵⁴ Interview with M.V, Roma Women's Rights Center, Tirana, 06/07/2024

registration fees⁵⁵. Another obstacle to attending school is transport, which remains a challenge for many Roma and Egyptian families living in the suburbs and far from educational institutions⁵⁶.

Students with disabilities also face a number of specific challenges. These include the lack of qualified assistant teachers, their constant changes, insufficient hours dedicated to children with disabilities, the lack of books, lack of school materials adapted to their needs or support technology, as well as the lack of adapted exams, despite the existence of individual educational plans (PEI)⁵⁷⁵⁸.

However, participants in the study also identified positive cases of professional and experienced assistant teachers who have managed to provide quality support to students with disabilities. Also, from the answers given to the requests for information from the 3 DRAP of Lezha, Fieri and Korca, it was evident that the instruction to assign assistant teachers for students with disabilities has generally been respected⁵⁹. However, in practice, this is often not sufficient to address the individual needs of each student, especially where schools do not have sufficient resources to provide specialized support.

According to the National Action Plan for Persons with Disabilities, another problem that negatively affects school attendance is the lack of means of transport adapted for children with disabilities. Although the legislation⁶⁰ provides

⁵⁵ Recommendation No. 1742 prot., dated 22. 12. 2021 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2022/01/Rekomandim-per-regjistrimin-pa-pagese-ne-kopshte-dhe-cerdhe-te-femijeve-te-komuniteteve-rome-dhe-egjiptiane-drejtuar-Bashkive-te-RSH-se.pdf>

⁵⁶ ECRI (2020) Report on Albania Sixth Monitoring Cycle <https://rm.coe.int/report-on-albania-6th-monitoring-cycle-translation-in-albanian-/16809e8240>

⁵⁷ Interview with Z.K, MEDPAK, Tirana, 06/06/2024

⁵⁸ Focus group discussion with parents of children with disabilities, Tirana, 24/06/2024

⁵⁹ Instruction No. 26, dated 25.11.2019 of the Ministry of Education, Sports and Youth <https://arsimi.gov.al/ep-content/uploads/2019/12/Udhezimi-nr.-26-dt.-25.11.2019.pdf>

⁶⁰ Decision of the Council of Ministers no. 682, dated 29.7.2015 https://arsimi.gov.al/wp-content/uploads/2018/02/Vendim_i_KM_682_29.07.2015_Per_perdorim_fond_per_transpo_e_mesuesve_dhe_nxnesve..pdf

for the state budget to cover transportation costs for students of pre-university education with disabilities, there is no official data on the number of children with disabilities who need to receive free transportation, as well as the number of children with disabilities who benefit from this service⁶¹. The action plan also underlines the need to implement standards of physical accessibility and that of information and communication in educational institutions.

Access to effective social services is also very important for students with disabilities, especially in cases where it is completely impossible for them to access an educational institution. In these cases, the assistant teacher, in cooperation with the mobile services of the social assistance operators, should provide the services at home, ensuring educational continuity and adapted support⁶².

The lack of effective psycho-social support remains a common problem for all students from vulnerable groups, including LGBTI+ youth, who face specific challenges related to social acceptance and inclusion. According to a survey, about 30% of LGBTI+ people have not completed compulsory education due to discrimination and economic challenges. They face frequent bullying and social pressure, which results in dropping out of school. According to the same source, 63% believed that teachers and school headmasters are not informed on LGBTI+ issues and 93% thought that teaching materials do not contain accurate and unbiased information about the LGBTI+ community⁶³. Some of these challenges are also recognized in the National Action Plan for LGBTI+ People in Albania. This provides, among other things, measures to reduce inequalities and discrimination against LGBTI+ persons in education⁶⁴.

⁶¹ National Action Plan for Persons with Disabilities 2021-2025 <https://shendetesia.gov.al/wp-content/uploads/2021/11/Plani20Komb%C3%ABtar20p%C3%ABr20Personat20me20Aft%C3%ABsi20t%C3%AB20Kufizuar202021-2025-4.pdf>

⁶² Instruction No. 26, dated 25.11.2019 of the Ministry of Education, Sports and Youth <https://arsimi.gov.al/ep-content/uploads/2019/12/Udhezimi-nr.-26-dt.-25.11.2019.pdf>

⁶³ Joint written contribution of the Alliance Against Discrimination of LGBTI People and ILGA on the position of LGBTI people within the 4th cycle of the universal periodic review of the Republic of Albania, 2024

⁶⁴ The National Action Plan for LGBTI People in Albania 2021-2027 <https://shendetesia.gov.al/wp-content/uploads/2022/01/LGBTI-NAP-2021-2027-AL-final.pdf>

6.4 Complaint mechanisms

In order to improve the accessibility and quality of services, educational institutions should have appropriate complaint mechanisms to allow students and/or parents to submit complaints. These should include clear, public and easy-to-understand processes, as well as support for those who need help accessing them.

But complaint mechanisms in the field of education in Albania are little known by citizens, according to the participants in the study, and in general there is a lack of relevant information about them on the institutions' websites. However, monitoring carried out in the field for this study noted that three out of four DRAPs has put posters in their premises containing information about the complaint procedures.

According to the participants in the study, citizens in some cases direct their complaints to the relevant ministry or to the courts and often need assistance from specialized civil society organizations to follow these processes.

Another mechanism is the Commissioner for Protection from Discrimination (KMD). His reports for the years 2022 and 2023⁶⁵ show that a significant number of complaints in the field of education are related to the establishment of exclusionary criteria for certain categories of students in higher education institutions, the exclusion from the 9th grade of children with disabilities, the exemption from paying the registration fee for children of the Roma and Egyptian community in kindergartens and nurseries, etc. In previous years' reports, there are also complaints regarding the appointment of assistant teachers for children with disabilities, their physical access to educational institutions⁶⁶, as well as segregation in schools⁶⁷. The main causes of discrimination alleged in complaints forwarded to Commissioner for Protection from Discrimination include disability, educational status, economic status and race.

⁶⁵ 2023 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2024/03/Raporti-i-KMD-2023.pdf>

⁶⁶ 2020 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2021/03/Raporti-Vjetor-i-KMD-2020.pdf>

⁶⁷ 2021 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2022/04/Raporti-KMD-2021-versioni-perfundimtar.pdf>

However, it is important to note that the number of discrimination cases in the field of education is lower compared to other fields. In 2023, out of a total of 359 cases dealt with, only 14 were in the field of education, compared to 144 in the field of employment and 201 cases in the field of goods and services.

An important example of the handling of complaints in the field of education is the case of Avdiu and Others vs. Albania⁶⁸, also presented to the European Court of Human Rights. This case concerned the alleged discrimination of Roma children in a primary school in Morava, Berat, where Roma students were segregated in a special school, “Avdyl Avdya”. After a complaint was filed, the Regional Education Directorate of Berat acknowledged the existence of the segregation of Roma students in the “Avdyl Avdya” school and the need to address the situation. The directorate claimed that the free transportation of children to the “Shaban Sollaku” school was not possible because the minimum distance for free transportation of students to the school was not met. After another complaint was filed, the Commissioner for Protection from Discrimination determined that the complainants had been discriminated against by the Ministry and the Directorate of Education because of their race in the field of education. The Commissioner ordered the implementation of the necessary steps, including the closure of the school and free transport for Roma children to an integrated school. After that, the students were welcomed and started regularly attending the “Shaban Sollaku” integrated school, and the Ministry approved the closure of the “Avdyl Avdya” school. Transport was provided by public authorities and parents were reimbursed for transport costs by the municipality. As a result, the European Court of Human Rights assessed that the Albanian authorities had accepted the violation of the complainants’ rights and had undertaken steps to correct the situation⁶⁹.

In another case⁷⁰, the use of several complaint mechanisms by citizens is evidenced, including the Ministry of

⁶⁸ European Court of Human Rights, Application no. 49516/17 Mariglen Avdiu and Others against Albania <https://hudoc.echr.coe.int/fre#%7B%22fulltext%22:%5B%22avdiu%22%2C%22itemid%22:%5B%22001-225553%22%5D%7D>

⁶⁹ 2023 Annual Report of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2024/03/Raporti-i-KMD-2023.pdf> ; European Court of Human Rights, Application no. 49516/17 Mariglen Avdiu and Others against Albania <https://hudoc.echr.coe.int/fre#%7B%22fulltext%22:%5B%22avdiu%22%2C%22itemid%22:%5B%22001-225553%22%5D%7D>

⁷⁰ Decision no. 101 dated 26/05/2022 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2022/06/Vendim-nr.-101-date-26.05.2022-S.-L.-kunder-ZVAP-Divjake-dhe-shkolles-Mihal-Nako-Divjake-Diskriminim.pdf>

Education and Sports, the Commissioner for Protection from Discrimination and a public denunciation in the media. In the case in question, the Commissioner found discrimination by the ZVAP of Divjaka and the High School “Mihal Nako” Fierseman, Divjaka, which had decided to stop the compulsory basic education of a student with disabilities, contrary to the legal provisions on pre-university education.

The student was refused registration in the ninth grade, even though he was a student of the school, without taking measures for his evaluation in the multidisciplinary commissions of the ZVAP or of the school. According to the Commissioner, these educational institutions had neglected the highest interest of the child and the obligations of the Albanian government for the elimination of all barriers and the inclusion of persons with disabilities in the public education system, placing the student in discriminatory conditions. Also, in the decision it is evident that after the public complaint made by the student’s family through an investigative TV show and the intervention of the Ministry of Education and Sports, it was possible for him to return to school and continue his studies. The Commissioner decided that ZVAP and the relevant school should take measures to support and eliminate all barriers and include persons with disabilities in the public education system. It should be underlined that the problem of discrimination of students with disabilities through the refusal of registration in public and professional education institutions or the interruption of their education is also evident in other decisions of the Commissioner⁷¹⁷².

These issues highlight, among other things, a series of challenges faced by citizens, the need to improve access to complaint mechanisms, and reinforce the importance of addressing rights violations in the field of education.

⁷¹ Decision no. 32, dated 03/02/2022 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2022/02/Vendim-nr.-32-date-03.02.2022-A.Z-kunder-Shkolles-se-Mesme-Teknike-Pyjore-Kole-Margjini-Shkoder-Diskriminim.pdf>

⁷² Decision no. 67, dated 18/03/2024 of the Commissioner for Protection from Discrimination <https://www.kmd.al/wp-content/uploads/2024/03/Vendim-nr.-67-date-18.03.2024-M.H-kunder-Shkolles-Aleks-Buda-Tirane-Diskriminim.pdf>

VII. Conclusions and recommendations

Based on the findings of this monitoring of the four Regional Directorates of the Health System and four Regional Directorates of Pre-University Education, and with the aim of improving their level of transparency and accessibility, the main issues and relevant recommendations are listed below:

- From the monitoring of the official websites, it is observed that the four Regional Directorates of the Health Service Operator in Shkoder, Tirana, Vlora and Elbasan do not have official websites or a dedicated section as part of the main page of the General Directorate. The four Regional Directorates of Pre-University Education in Lezha, Durrës, Fieri and Korça have a dedicated interface inside the official website of the General Directorate of Pre-University Education. In both cases, none of the regional directorates has a dedicated Transparency Program, a dedicated right to information coordinator or a dedicated request and response register. Although the Commissioner's Office is in favor of a transparency program and a unique coordinator for the entire institution, including a head office and regional directorates, it would be much more effective for citizens if each regional directorate had its own website, dedicated transparency program and dedicated coordinator who will receive requests for information and answer them, coordinating with the coordinator of the General Directorate.
- A problem encountered during the monitoring is that each of the official websites was monitored several times after the official website of the General Directorate of Pre-University Education (including the interfaces of the four regional directorates) was out of order for two weeks. For this reason, it is recommended that the regional directorates take technical organizational measures so that their online presence is optimal and guarantee accessibility to the public.
- Given that transparency has an important role in both the health and educational systems, to promote trust and accountability, it is important that all documents of these institutions are easily accessible to patients, students or citizens. In the health care system, transparent practices ensure that patients are fully informed about their treatment options, costs or other informational documents. Similarly, in education, transparency increases the effectiveness of teaching by providing clear information about the curriculum, performance indicators and educational results. This allows parents and students to understand the strengths and

weaknesses of the system, leading to better allocation of resources and educational strategies. For these reasons, the information published by the regional directorates should be as complete, updated and easily accessible as possible.

- Regional directorates must find innovative mechanisms to distribute as much and as quickly as possible public information related to proactive transparency, ethics and integrity, financial transparency, performance reports, patient student rights, services provided and mode of public participation. These mechanisms can be (in addition to the dedicated official website) smartphone applications, the provision of services on the unique government portal e-Albania, publications in dailies or various media, etc.
- Regional directorates must publish information needed to ensure proactive transparency, where the necessary elements, but not limited to them, are: Coordinator for the Right to Information, his/her electronic address, the address of the institution, working hours, request for information forms, description of how to make a request for information, etc., dedicated transparency program; a register of requests and responses for the right to information of the regional directorate; provision of a front desk or secretarial service for patients/students, service hours, possible shifts, etc.;
- Information on the ethics and integrity of employees is important, as it helps the employees of the regional directorates to provide quality healthcare and education while improving the health and educational results of the local population. For these reasons, the approval and publication are recommended of the Code of Ethics of the regional directorate; the regulations for the implementation of the legal framework; the regulations for the processing of personal data; the Integrity Plan and the data of the anti-corruption coordinator. Since transparency is considered one of the main tools in the fight against corruption, it is recommended that they publish: information on the incomes and expenses of regional directorates, such as financial information, including budgets, expenses, donations and funding sources, contracts, etc.; the annual financial report of the regional directorate; the service fees, published online or in the premises of regional directorates, etc.
- Performance measurements of the public health and education service are essential. These indicators help assess whether sectoral policies are being implemented effectively or not. The indicators also enable monitoring and comparisons over time in different regions, highlighting areas of improvement or regression. This comparative analysis can inform policymakers and citizens about best practices and areas that need

attention. Therefore, it is recommended to publish at least the regional strategies of public health and pre-university education; licensing standards; clear standards on school performance; health care results and medical procedures; the annual performance reports of regional directorate dependency units.

- In health care, transparency regarding patient rights means clearly informing patients of their rights to privacy, informed consent, access to medical records, and the right to choose health care providers. Similarly, in education, transparency regarding students' rights includes clearly defining their rights to equal access to education, non-discrimination, data confidentiality and the right to a safe learning environment. It is recommended that the bill of rights for patients and students be published proactively.
- Information on the services provided by the regional health service directorates and regional pre-university education directorates contributes to a more responsive service delivery system, where citizens can receive the most accurate information. At a time where disinformation or excessive information can lead to a lack of accuracy, reliable and updated information from the competent authority is essential. It is recommended that the information contains: a list of services that are offered, including application forms, the duration of the application; the complaint procedures; recruitment criteria for doctors, nurses and teachers; list of doctors providing service in health care units and their CVs/list of teachers and their CVs; opening hours to the public; hours of providing various services and relevant shifts, etc.
- Public participation in decision-making processes is essential for ensuring democratic governance, accountability and responsiveness to citizens' needs. Transparency plays a key role in facilitating and encouraging this participation. For these reasons, it is recommended to publish information about the mechanisms of public participation in decision-making processes related to education and health; the meetings calendar with patient associations, school senate and parents' meetings; clear procedures for receiving complaints from patients and students as well as clear procedures for addressing them, etc. To be as accessible as possible, these mechanisms should include clear, public and easy-to-understand processes, as well as support for those who need help using them.
- In addition to guaranteeing transparency and accessibility in health and educational institutions it is essential to ensure that all patients receive the care they need and equal treatment, and that students are guaranteed equal opportunities for education and inclusive school environments. This should include ensuring physical accessibility and the necessary infrastructure to enable it, such as wheelchair ramps, elevators, adapted

toilets and other facilities that serve people with disabilities. Braille signs, tactile guide strips, auditory signals or sign language interpreters for hearing impaired people are also essential for orientation and the independent movement within institutions.

- Accessibility to information and communication is also important to ensure that patients and students can understand and interact with service providers. This includes, among other things, designing the website and information to be usable and accessible by all and for it to be adapted for people with disabilities, e.g. devices with necessary features such as screen reader compatibility, alt texts to images, voice-to-text translation, or navigation aids.
- Psycho-social and support programs and services dedicated to responding to the needs of vulnerable groups, such as LGBTI+, Roma and Egyptian minorities and those with disabilities are also essential for creating safe and equal environments in health and education institutions.



MONITORING REPORT

TRANSPARENCY AND ACCESSIBILITY IN THE HEALTH AND EDUCATION SYSTEM

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