Advocacy in Health Care in Albania: Actors, Achievements and Challenges

Assessment Report September 2022







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ABBREVIATIONS

ACA	Albania Community Assist
ADRF	Albanian Disability Rights Foundation
ALL	Albanian Lek
BIRN	Balkan Investigative Regional Network
CDT	Center for Development and Transparency
CSOs	Civil Society Organizations
EWMI	East West Management Institute
DSA	Down Syndrome Albania
GDP	Gross Domestic Product
GOA	Government of Albania
IANS	Institute for Activism and Social Change
MHSP	Ministry of Health and Social Protection
NPO	Not for Profit Organizations
OOP	Out of Pocket
PHC	Primary Health Care
TFL	Together for Life
WFD	Westminster Foundation for Democracy

1. EXECUTIVE SUMMARY

Introduction

Health care advocacy is important to ensure equal access to qualitative care for vulnerable population, increasing use of the referral system, addressing health inequities, influencing decision makers, and creating systematic change for a healthier population.

In Albania many interventions have been implemented to advance advocacy actions in health care. However, regardless of the success of isolated interventions, there is still much to do to create the culture of the bottom-up influencing approaches.

Health advocacy is a longer process and takes into consideration different actors and factors among which social determinants of health and health inequities.

Main Stakeholders

In the last 10 years the role of the Civil Society Organizations (CSOs) in Albania has increased in general, and in health care in particular. The CSOs that work particularly in advocacy have an important role to advocate for health equity, given the challenges that exist among civil society organizations, the research/academia (which is almost inexistent in advocacy), and the policy makers. The media organizations are not involved in advocacy per se, they still are considered an important ally in the advocacy efforts, due to the evidence their generate through their journalistic investigations and reporting.

The independent institutions are not directly involved in advocacy in health care but are a pivotal instrument in policy influencing like the Ombudsperson (Peoples Advocate), the Antidiscrimination Commissioner and at some extend the High State Audit.

The policy makers which make decisions and act on the recommendations given by the civil society organizations and not only, are the players that need to increase the efforts toward the consultation processes with the CSOs and take ownership of the ideas and proposal and act upon them.

Main Findings

CSOs in Albania have limited resources to lead strong and long-term advocacy efforts. Most of the reviewed organizations do not have a separate advocacy document that guides their advocacy efforts, or a dedicated staff for supporting advocacy actions.

Most of the organizations discussed in this report are categorized as representative organizations, and so they aggregate the voices of their target groups; the advocacy efforts as well are limited to such representation, and do not represent a united front of CSOs working in the sector. Advocacy efforts in this regard are mostly focused on increasing awareness among patients and their families about health determinants and their rights to health care services.

The partnerships in health advocacy can generate greater synergy and resources. New organizations partnering can benefit from the experience of the older ones, or small organizations can benefit from the profile and the capacities of the larger ones. The organizations reviewed in the report understand and promote the importance of the partnerships, but such examples need to be showcased and replicated when successful.

The main challenges are mostly related to lack of sufficient resources to support long-term advocacy efforts in communities and to push for policy change at the national level. For many grassroot organizations at the local level the advocacy efforts and impact measurement are limited.

One of the main elements to increase the sustainability of the advocacy efforts is long term planning, engagement of all partners and communities, and design activities that encourage people, politicians, and local partnerships to make choices that support future generations.

2. OBJECTIVES OF THE ASSESSMENT

The aim of this assessment is to strengthen the understanding on the efforts of the civil society for advocacy in the health sector in Albania, and if those efforts have impacted at any stage the quality of care, have increased the representation of the most vulnerable voices, have influenced policies or decisions and if have influenced budgetary revisions and solutions at local and national level. It also will help to understand what the main challenges are faced during the implementation of any advocacy activity, and how all the main stakeholders can work together to address some of these challenges.

The assessment sets out to answer the following research questions:

- How effective are the advocacy efforts in the health sector in Albania?
- What is the profile of the CSOs that work in advocacy and what organizational challenges they face?
- What are the key challenges for CSOs to ensure that the most vulnerable voices are represented to the higher levels of the decision makers, and how these voices influence decision making?
- How the advocacy efforts can be more sustainable in the future?

A more detailed methodology is presented in Appendix 1 of this report.

3. MAIN BURDENS OF THE HEALTH CARE IN ALBANIA

The population of Albania registered on 1 January 2021 was 2.829.741¹ with a 2,7% decrease in the last 10 years. Albania is an ageing society, with a declining population due to low fertility rates² and increased migration³. The data shows that migration has affected mostly young

The right to health care is sanctioned in the Constitution of Albania (quoting article 55 "the citizens equally enjoy the right to health care provided by the state").

adults, directly reducing the active population in the country, and impacting negatively on the

¹ <u>http://www.instat.gov.al/al/statistikat-n%C3%AB-shkolla/popullsia-e-shqip%C3%ABris%C3%AB/</u>

² According to the Albania Demographic and Health Survey 2017-2018 the total fertility rate (TFR) in Albania is 1.8 children per woman, which is below the 2.1 replacement-level fertility rate.

³ During 2011-2020 an estimate of 42 thousand persons migrated every year <u>http://www.instat.gov.al/al/statistikat-n%C3%AB-shkolla/popullsia-e-shqip%C3%ABris%C3%AB/</u>

number of children born. There has been a steady increase in life expectancy for both sexes in Albania and in 2020 was estimated 75,2 years for men and 79,6 for women⁴.

Non-communicable and chronic diseases (NCDs) constitute much of the burden of disease in the country, with an estimation of 96% of all deaths in 2018⁵. During the 2020 -2021 the reported number of total deaths in Albania were 26% higher than the yearly average⁶, suggesting that undiagnosed Covid-19 has caused such increase, although the official reported Covid deaths numbers were much low⁷.

Another persistent problem in Albania, is the corruption⁸ with an increased incidence in the health sector, leading to reduced community access to appropriate and high-quality healthcare and high levels of out-of-pocket expenses. The Government of Albania is working to address corruption and has developed a new Anticorruption Strategy 2023 – 2030,⁹ making the fight against corruption a priority, with specific actions to increase governance and transparency of the health system. Still, the corruption perception index ranks Albania at 110, out of 180 countries¹⁰ in 2021 dropping in scoring from 2020. The "Trust in Government report 2020" shows that compared to 2019, trust in the healthcare institutions has decreased¹¹.

The government of Albania in its program for 2021-2025 proposed a challenging plan: increase public investments in health care system especially of the rural areas and increase the provision of new packages of services as oral and ocular care. As a result, the budget of 2022 for the health care system was praised as a historical one, with an increase of 12.6% and continues the efforts of the universal care¹². The Health and Social Protection budget for 2022 is expected to be 91 billion and 365 million ALL (around 78 million Euro) that is 4.89% of GDP¹³.

Following the Government Program, in 2022 the 10-year Health Strategy¹⁴ (and Action Plan) was launched, that beyond the provision of care and the consolidation of the reform of the sector, includes some new important objectives that relate to digital health and the response to emergency and preparedness. The total cost of the 10-year strategy is 3.9 billion Euro: 35% are planned in the budget 2021-2024, 60% will be planned in the budget of the 2025-2030 government program, and the remaining 5% is the financial gap of the strategy.

The out-of-pocket payment (OOP, which are costs related to medical care that are paid by patients but are not reimbursed by the state), as part of the general expenses are affected directly by the public expenses in the health care system, and the coverage policies developed in the sector. The latest data on OOP are from 2016, that showed that 48% of the

¹³ ANHS 2030 pg. 16.

⁴ <u>http://www.instat.gov.al/al/statistikat-n%C3%AB-shkolla/popullsia-e-shqip%C3%ABris%C3%AB/</u>

⁵ http://www.ishp.gov.al/wp-content/uploads/2021/06/NCD-Albania-summary-2020.pdf

⁶ <u>https://www.reporter.al/2022/02/11/82691/</u>

⁷ As of 28 August 2022, the official reports number of COVID 19 deaths is 3,581.

https://www.ishp.gov.al/komunikimi-i-perditshem-per-koronavirusin-28-gusht-2022/

⁸ <u>https://www.usaid.gov/albania/news-information/fact-sheets/fact-sheet-transparency-health-engagement</u>

⁹ Strategic Concept Document

¹⁰ <u>https://www.transparency.org/en/cpi/2021/index/alb</u>

¹¹ https://idmalbania.org/wp-content/uploads/2021/11/IDM-OpinionPolI-2020-EN.pdf

¹² The world health organisation defines the Universal health coverage "that all people have access to the health services they need, when and where they need them, without financial hardship".

¹⁴ Albanian National Health Strategy 2030, pg. 93-94.

expenses in the health care in Albania are paid by the household budget. Data from the World Bank show that in 2018 the OOP reached 44.6%¹⁵, a slight decrease but still high. The financial protection in Albania remains very low, in comparison with the neighboring countries, and the main expenditures of households are done for the purchase of drugs and medicaments¹⁶.

The legal framework in health is quite complete and rich, but the challenge remains its implementation. The same remains for many advocacy efforts that focus in introducing new legislation, which is the challenge of creation of regulations and bylaws that improve the service and enforce legislation. Appendix 2 shows a reference list for the legal framework of the health care system in Albania.

This assessment report is not aiming to address and analyze the main burdens of the health care system but tries to provide the information on how advocacy efforts can help in addressing some of these issues.

The assessment aims to analyze the key players of advocacy, their roles and the impact of some efforts implemented in the last 10 years in Albania. It is important to understand how the work of CSOs as the main actor can be integrated into the policy processes so they can have a greater influence if they turn their practical knowledge and expertise into evidence.

4. DESK REVIEW

This assessment reviewed the limited literature on the health advocacy in Albania. (Donor reports, CSOs project reports and others) and tried to analyze the main factor and actors that contribute to setting the premises for successful advocacy efforts.

Why Advocacy is important?

In the health care system, the outcomes that ensure equal access to qualitative care, understanding and navigating through the referral system, addressing health inequities, influencing decision makers, and creating systematic change are all possible through advocacy interventions.

For better results in advocacy for health equity and access to quality services is important to understand the social determinants of health. Health advocacy is a longer process than community outreach and takes into consideration different factors among which the social determinants of health and health inequities. The social determinants of health (i.e., the conditions in which people live and work) account for a significant proportion of an individual's and a population's health outcomes. Health inequities are disparities in health among people, perpetuated by economic, social, and political forces.

Although there are many organizations in the country (the total number of non-for-profit organizations-NPOs-registered in Albania is 12,240), but there is no clear number of those working only in health care¹⁷. There is a lack of clarity in the sector, around how health advocacy is delineated, how policy is influenced, how the main actors in health advocacy are enacted.

¹⁵ <u>Albania - Out of pocket expenditure as a share of current health expenditure</u>

¹⁶ Can people afford to pay for health care?

¹⁷ Partners Albania, Monitoring Matrix on Enabling Environment for Civil Society Development, 2021.

Numerous short-term and sometimes long-term interventions have been implemented and are described in literature; however, regardless of the success of isolated interventions, understanding health advocacy instruction, assessment and evaluation will require a broader examination of processes, practices and values throughout the health care system and its main stakeholders.

In this assessment report, we aim to identify the main challenges that CSOs engaging in advocacy efforts face and propose some potential recommendations for all stakeholders. As well as we will try to discuss about the main stakeholders that are grouped below.

The Main Actors in Advocacy in Health

International donor agencies

Health sector has been a priority for many donor agencies after the nineties. The donor agencies have worked to reform the system, build capacities of workers in primary and secondary care, have developed training curricula and clinical guidelines and protocols, have provided infrastructure development, and provided equipment to increase quality of care. We can mention the US Agency for International Development, Swiss Agency for Development and Cooperation, UN Agencies, and other foreign development agencies. For a more detailed list of donors in health care please see Appendix 3.

The most important interventions in health care have been those large-scale investments in the form of multivear and multimillion dollar projects/contracts, that aimed reforming the system. These large-scale projects have worked with the aim to strengthen governance and introduce more bottom-up approaches to decision makers in relation to reform objectives. These projects are implemented from international agencies, companies, or organizations and are part of the respective agency or international organization strategic

documents/objectives and follow the Government of Albania and Ministry of Health and Social Protection priorities to strengthen the health care system. These projects last 4-5 years and cost an average of 5-12 million Euro.

Long term health system strengthening projects support Albanian health system to strengthen policy frameworks through technical assistance and advocacy. The advocacy work mostly is focused in pushing policymakers to define and improve the rules that govern the health sector more clearly, work with civil society to hold policymakers accountable for these rules, generate and use health system data, including financing and service data, to

Some important large-scale projects in Health Care in Albania in the last 10 years

Enabling Equitable Health Reforms in Albania 2010-2014 funded by USAID

Health for All 2015-ongoing funded by the Swiss Agency for Development and Cooperation

The Transparency in Health Engagement 2017 - 2019 funded by USAID

Schools for Health 2020 – ongoing funded by the Swiss Agency for Development and Cooperation

better understand and address health system needs.

The donor agencies fund also small-scale intervention like small project and grants, that are focused on specific interventions (advocacy efforts as well), and where short-term achievements are showcased as discussed under the civil society section. These interventions are supporting national CSOs to address the right to health care as a human

right; support litigations to courts on cases of misconduct or mistreatments in the system; provide information and education messages on health and wellbeing; work to increase capacities of health care staff; and provide recommendations for policy change that improve access to services for vulnerable communities, etc.

Civil Society Organizations

Civil society is defined as the wide array of non-governmental and not-for-profit organizations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious, or philanthropic considerations. CSOs therefore refer to a wide of array of organizations: community groups, non-governmental organizations (NGOs), labor unions, indigenous groups, charitable organizations, faith-based organizations, professional associations, and foundations¹⁸.

In the last 10 years the role of CSOs in Albania has increased in general, and in health care. It has gathered huge momentum in international development, becoming a focal point for a wealth of literature, conferences, funding, and policy initiatives. One of the leading factors of such increased role, is due to increased centralized authority in health care, dissatisfaction with the health care quality, infrastructure and services and increased corruption in the sector. CSOs that work particularly in advocacy have an important role to advocate for health equity, given the challenges that exist among civil society organizations, the research/academia (which is almost inexistent in advocacy), and the policy makers. Numerous studies suggests that an effective advocacy strategy and action plan should include persistent efforts to raise awareness and understanding of the social determinants of health.

The efforts of the CSOs that work in health advocacy in Albania can be grouped:

- Increase access to services these activities include efforts to assure direct assistance for vulnerable communities (patients and their families) to access health care services based to their needs and work with local and national authorities to include the needs of these groups in long term planning and policies. (*e.g., "Together for Life" works to increase access of cancer patients to quality health care services*).
- Influence Policy setting these activities include the efforts to increase public awareness over the right to participate in policies and processes that affect people's health and demand for improved accountability and transparency. It also includes lobbing for specific issues relating to the target groups they serve. (*e.g., Palliative Care has influenced the development of palliative care law in 2014*).
- Generate evidence of policy implementation these activities include frequent monitoring of how services are provided, how health care administration works at national and local level, procurements in health care etc. Such evidence presented to policy makers or to the public is a form of direct lobbying to influence changes that address accountability. (e.g., Albanian Institute of Science, through the Open Data Platform monitors the procurements in the health sector, providing red flags for the ones that do not comply with procurement standards).

Despite the cases of advocacy efforts discussed in this document, there is still little evidence available on their impact in improving quality of services, strengthening the health system, or influencing policy changes. Large scale evaluation studies are needed to understand and

¹⁸ Defining Civil Society, World Bank, web.worldbank.org

document the long-term impact of advocacy efforts and identify current knowledge structure and the trends for the future development of this field.

The role of the CSOs during the pandemic changed as well. The pandemic exposed the inequalities in health care and other basic services, the state response to emergency settings in protecting the most vulnerable, as well as the lack of transparency and accountability in decision making and finances. The civil society and media organizations working in health care in Albania were at the front line, either providing essential services or documenting and advocating for policy change.

Advocating for access to services during the pandemic

During the lock down, many patients in need for services where lacking access due to centralization of some services. TFL petitioned the MHSP to address these needs, and immediately the Health Insurance Fund issued an order that allowed these patients to receive the services at their regions. Mostly benefited the patients with hemophilia and HIV/AIDS that received treatments only in Tirana.

The media organizations are considered an important ally in the advocacy efforts, due to the evidence their generate through their journalistic investigations in health care.

The CSOs assessed in this report fall under several categories based on their functions (as differentiated by the World Bank):

- **Representation** that means they aggregate their constituencies voices. These organizations such as *the Down Syndrome Foundation (DSA), the Albanian Disability Rights Foundation (ADRF), and Palliative Care* represent different patients' groups, especially from the most vulnerable, and bring their voices to policy makers.
- Advocacy and technical inputs that are the organizations that provide information, advice, and lobby on specific issues. [e.g., Together for Life association through most of its interventions in health care is focused to provision of technical inputs for policy change. Another organization to mentions is the Institute for Activism and Social Change (IANS) that has also provided technical inputs related to the development of the new mental health strategy (underway).]
- **Capacity building** are the organizations that provide support to health care system, or other CSOs with funding and capacity building. There are times when all the assessed organizations take this function, depending on the program/project they are implementing and the donor they are collaborating with. (*e.g., ACA provides trainings for PHC service providers on reproductive health protocols.*)
- Service delivery are the organizations that implement development projects that provide services when not available. (e.g., palliative care organizations that provide direct services for the patients or facilitate receiving services, Aksion Plus provides methadone treatments for drug users. etc).
- **Social functions** are the organizations which foster the activities with a focus on health education and awareness raising. This function is an important component in the activities implemented by the assessed organizations when it comes to information and education (*all CSOs discussed in the report have expertise in health education and promotion*).

A more detailed profile of the assessed organizations is listed in Appendix 4.

Independent institutions

The independent institutions are not directly involved in advocacy in health care but are a pivotal instrument in policy influencing like the Ombudsperson (Peoples Advocate), the Commissioner on Antidiscrimination and at some extend the Albanian State Audit Institution (ALSAI).

The Ombudsperson in collaboration with the CSOs conducts joint inspections and produces special reports for the Parliament on topics brough to their attention by the Civil Society and media¹⁹.

All the mentioned independent institutions have their own legal framework of operating and functioning and all report to the Parliament of Albania with concrete actions for system strengthening and policy influencing. In the health care system, they contribute by safeguarding the rights and freedoms of patients, and combat corruption and misuse of public property. All the independent institutions foresee in their regulatory frameworks the collaboration with civil society and media organizations in conducting their administrative investigations, audits and or special reports. Such collaboration must be improved and strengthened.

There is no evidence of the discussed CSOs for any collaboration with the ALSAI, during the planning for audits, or using the Audit reports as evidence CSOs consultative board for the Ombudsperson

The USAID funded-project Transparency in Health Sector, created in 2018 the Consultative Board of CSOs in Health with the objective to strengthen collaboration of the Ombudsperson with the CSOs in health, increase the quality of recommendations for the Parliament, and as well increase collaboration on joint inspections.

Albanian State Audit Institution

ALSAI aims to be a reliable professional institution that contributes to increasing and saving the value of public money, providing security on the financial accounts of its users, and helping to improve the management of the Government and other public entities through auditing, thus gaining full confidence in the Albanian citizens and the auditees.

During the audits conducted in 2021 to the MHSP (<u>Annual Report 2021</u>) it shows that the evidence of economic damage and lack of effectiveness amounts to 25,307,000 ALL, and in total are 5 disciplinary and administrative measures given, and 6 recommendations for legislative amendments.

In United States and other European countries, the courts have a profound effect on the public's health. Courts interpret the law and determine the constitutional limits of legislative and regulatory policies that impact the public's health. Courts also decide cases brought against people or organizations accused of damaging the public's health and consider the appropriate balance among prevention, rehabilitation, and punishment in imposing criminal sanctions. In Albania there are few examples that demonstrate the role of the courts into regulatory policies (the cochlear implant case), and most cases brought to court are for individual damaging, without clear impact on the system itself.

¹⁹ Peoples Advocate

A successful advocacy effort that results in health care service improvement

Through an investigative article, published on April 20, 2016, entitled "Hundreds of children are at risk of becoming deaf, the state has abandoned them when they need specialized health" Together for Life association denounced for the first time the lack of service provision for the cochlear implant, for children with severe hearing problems. The case included testimonies of family members, claims of institutions and the opinions of experts in the field. Long waiting years for an intervention that should be provided and covered by the responsible state health institution (as foreseen by the law) never happened.

After the investigation, the case was brough to court, with the indictment for discrimination of the child G.L in the form of denial of a reasonable compliance, damage repair by establishing administrative actions to provide the cochlear implant and damage compensation, which was solved in the favor of the patient. After the case was won, the intervention at the Mother Theresa hospital was successfully done for 3 patients. The health structures promised that after the court decision, this was going to be a routine procedure for all the children with hear impairments. But the reality is that after that success little was done by the ORL department at the Mother Theresa hospital. TFL continued with the media articles and writing letters with recommendations to the MHSP with no results.

In 2019, the case was brought again in front of the Parliamentary commission for labor, social issues, and health, where recommendation for service improvement were presented. In October 2020, there have been 5 more interventions done at the ORL department, with the final confirmation that another 20 interventions were planned. Again, the promise was to make the intervention a routine process with an average 25 interventions per year. TFL continues to monitor the service provision for children with hearing impairment.

Policy makers

And finally, are the government institutions that make decisions and act on the recommendations given by the civil society organizations and not only. The MHSP and the Parliament of Albania, through the Commission of Labor, Social Issues and Health are the players that need to increase the efforts toward the consultation processes with the CSOs and take ownership of the ideas and proposals and act upon them. The Commission has the role to examine within its areas of responsibility the drafting of laws, draft decisions and other issues that are presented to the Parliament, conducts studies on the effectiveness of laws in force, follows the implementation of laws and controls the activity of MHSP and the independent institutions. The assessed CSOs have presented many recommendations for policy improvement to the Commission, but there is no evidence of any policy influencing.

5. MAIN FINDINGS FROM THE CSO ASSESSMENT

Beside the desk review of the existing literature, semi structured interviews with the civil society organization (that work in health care and have planned advocacy actions) were conducted to understand more the roles they have in the health advocacy domain and what are the main challenges they face.

Advocacy strategies, plans and adequate resources

CSOs in Albania have limited resources to lead strong and long-term advocacy efforts. Most of all the reviewed organizations do not have a separate advocacy document that guides their advocacy efforts, or a dedicated staff. Even when the advocacy objectives of the

organization exist, they are incorporated to the main origination strategy. (Together for Life - TFL has its advocacy strategy part of the strategic plan of the organizations).

The organizations discussed in this report have had their staff participate in the training organized by WFD, titled "How to be a successful advocate: strategizing, planning and measuring impact", and describe the experience as very useful. Although the staff of the organizations has participated in advocacy capacity building activities, their efforts Advocacy at local level

The Family Health Care association every year presents at the municipal council of Korça the need for support in provision of palliative care for patients in the region.

The municipality covers the operational cost of the center, but that requires for the center to advocate every year for the service, present data on the community they serve, be transparent on fund spending and results.

depend on donor support. Further support in capacity building is needed, especially in the pandemic context where access to health care services, especially for the most vulnerable is low.

There is a need to support CSOs in developing specific advocacy strategies in the health sector (specific to their objective and functions in the health care system), or an umbrella strategy that most of the organizations can jointly use.

Experience in Advocacy activities

Since most of the organizations discussed in this report are categorized as representative organizations, and so they aggregate the voices of their target groups, the advocacy efforts as well are limited to such representation, and do not represent a united front of CSOs working in the sector. For example, ADFR advocates for access to quality services for people with disability, while the Family Health Care, besides providing services, also monitors, and advocates for the full implementation of palliative care law, etc. Advocacy efforts in this regard are focused on increasing awareness among patients and their families about health determinants and their rights to health care services.

Together for Life, on the other hand, is an organization that is positioned in evidence generation for policy change, through studies and research of rights violation in health care, malpractice, and corruption, and orients its advocacy strategy for system change.

The Transparency in Health engagement project, financed by USAID and implemented during 2017 -2019, worked with the civil society organizations to increase their advocacy skills, and develop advocacy action plans for their target groups. Some advocacy plans were focused on: Increasing transparency of health budgets in primary health care (PHC) centers; implementation of HC standards related to publishing of patient's right chart and the fees of services.

Litigation in national courts, as literature suggests, is an important advocacy strategy to use for patients' associations. Litigation and legal

PRO Pacientit Network

The Network of Patient Associations is a union of patient associations that aims to protect and promote patients' rights, educate the population on health issues, advocate, and lobby for patients' rights.

The network is an initiative of the "Together for Life" association, which aimed to further strengthen patient organizations in Albania and increase their impact on the health system.

advocacy may be used to clarify and fill the gaps in legislation and promote health as a human right. This process is also being adopted by several human rights CSOs, that includes cases of health care, but there is no evidence how the decision of courts has impacted the modification of any law, bylaw, or regulation.

In general, there is a lack of clarity around how the health advocacy is delineated, how policy is influenced, how the main actors in health advocacy are enacted. Although there are many efforts, there is little documentation on the real impact that small – or large-scale interventions have had in the past 10 years.

Partnerships

The partnerships in health advocacy can generate greater synergy and resources. New organizations partnering can benefit from the experience of the older ones, or small organizations can benefit from the profile and the capacities of the larger ones.

The organizations reviewed in the report understand and promote the importance of the partnerships, e.g., ADRF and DSA work together to strengthen advocacy toward the access to health care of people with disabilities., or the palliative care organizations partner to monitor the implementation of Palliative Care law.

TFL and BIRN Albania collaborate in generating evidence and investigations in health care that can instigate further administrative audits and investigations with the aim to propose policy change.

Another important initiative that can be classified as partnership, is the creation of patients' associations networks. There are some models developed through different initiatives. One is "Pro Pacientit²⁰" as an initiative of TFL as part of their organization strategy to increase capacities of patients' associations, and the second one is "Zeri i Pacientit²¹", an initiative supported by the Health for All (HAP) project.

²⁰ <u>https://propacientit.al/</u>

²¹ <u>https://www.facebook.com/PATIENTINONEVOICE/</u>

These networks although being very good initiatives since they provide a platform for patients' associations to group and build capacities in advocacy, they still lack sufficient resources for a long-term impact.

Main Challenges

The main challenges are mostly related to lack of sufficient resources to support long-term advocacy efforts in communities and to push for policy change at the national level. The health system in Albania is very centralized, so little policy is made at local level, and mostly the advocacy efforts are focused to increase access to services for the most vulnerable, which again is faced with lack of resources of local health authorities, and lack of capacities to respond to advocacy recommendations. For many grassroot organizations at the local level the capacities to advance advocacy efforts are limited and impact is not measured.

Donor organizations as well lack coordination and partnership efforts in important areas of development, especially health, which means lack of synergy in advocacy efforts, lessons learned and documentation of success stories that can be replicated or used to further strengthen. E.g., during the pandemic, many donors developed communication and advocacy actions on disinformation on vaccinations. Stronger collaboration is needed at the donor level, for better synergy.

Regarding the policy makers, MHSP respectively, uses the CSOs contributions during the public consultations of reforms, legal amendments, or national strategies. The law on Public Consultation²² provides a platform for interested stakeholders to provide evidence and negotiate the proposes legislation. What organizations highlights as an area that should be improved, is the lack of feedback on recommendations provided by the civil society organizations during technical or public consultation processes.

Advocacy Sustainability

Depending on the available resource, context, and size of the organization, we may say that the CSOs in Albania that work in health advocacy, design and implement different types and levels of advocacy, and the approaches used must be tailored to each community or activity context. Some organizations have developed evidence-based advocacy, based on monitoring the system and finding areas of improvement (e.g., TFL has monitored the budget of the MHSP during the pandemic²³), others have emphasized advocacy focused on community mobilization and civil society partnership, often as part of an explicit rights-based strategy to achieve change. In some cases, organizations have invested in public policy advocacy, focused on national level budgetary, policy and legislative change – sometimes reinforced by global level advocacy by adapting the best international practices. In all the cases, the advocacy efforts finish when resources finish, or are oriented by the donor agenda.

The various approaches used by organizations have different impact and timeline, but all have one common ground for success that is: advocacy is a long process that needs a lot of political will by state to work with CSOs and negotiate the level of policy influence, improve access and quality of services.

²² <u>https://www.adisa.gov.al/wp-content/uploads/2021/03/Ligj_146_2014_30.10.2014.pdf</u>

²³ <u>https://www.wfd.org/what-we-do/resources/monitoring-state-health-budget-albania</u>

One of the main elements to increase the sustainability of the advocacy efforts is the longterm planning, engagement of all partners and communities, and design activities that encourage people, politicians, and local partnerships to make choices that support future generations.

There is not a clear evaluation framework adopted by any donor agency or organization that can set up objectives and measure the achievements of any advocacy related activity and communicate results. To assure more sustainable advocacy efforts in health care in Albania, long term interventions are required, but also measured and used as working models.

6. RECOMMENDATIONS

- Increased coordination and collaboration among CSOs that work in health care. It
 is important that the civil society organizations that work in health advocacy and are the
 main players, increase partnership and coordination efforts and generate a common
 "roadmap" of possible advocacy activities, establishing shared language and meanings
 to support communication and collaboration across target groups, communities,
 partners, and donors.
- Provide continuous support for capacity development in health care advocacy. The assistance provided for the CSOs through donors with the objective to have some level of control over health issues that affect the communities they represent, requires also to ensure that dependence on funding resources is limited. That puts an extra effort on strengthening the organizations capacities, which in turn is not a fast process and takes years. Capacity building assistance should aim that communities, and the individuals and organizations which are a constituent part of them, can increase their capacity to tackle health problems by the 'nurturing of and building upon the strengths, resources and problem-solving abilities already present'.
- Develop long term advocacy programs to influence change. Influencing public health policy change is a difficult and sometimes complex process, because it requires a lot of interactions and negotiations amongst a range of stakeholders that are politicians, CSOs, autocrats and communities. Gaining the support of the public is an important factor, so donor agencies should continue and/or design long-term advocacy efforts to educate and empower communities to ask for change.
- Strengthen the role of the CSOs in educating and informing the public on the main health determinants. CSOs have played a critical role in fostering expertise and knowledge, which can lead to increase in policy changes or create policy windows for change. In the long term, the role that many CSOs play in education may develop a well-informed community, with the capacity to pinpoint and articulate development issues in the health care in the future. Whether they initiate opportunities directly or respond to them, the CSOs must be able at understanding the contexts in which they work and want to influence.
- Develop what works in health care advocacy in Albania. All the main actors in Health Advocacy would benefit from a research agenda focused on "what works". As discussed in the report there is gap in the research literature as to what works for sustainable advocacy efforts. Such a research agenda would also support reporting on qualitative indicators, best practices, lessons learned and replicable models. A research agenda on what works would require in-depth assessments with each intervention beneficiaries, and actors.
- Strengthen existing mechanisms (patients' networks) and tools and use consolidated expertise. Donor agencies and CSOs, should continue to strengthen existing mechanisms, like the patients' networks instead of developing new approaches to represent communities.

APPENDIX 1 – METHODOLOGY AND DATA ANALYSIS

Desk review

CDT Albania conducted a review of all the literature produced in the last 10 years in Albania in relation to advocacy in the health sector. It included all national reports, studies, analyses produced between 2012-2022. The findings from the desk review will serve to draft the first section of the report and the situation of the advocacy efforts in the health sector in Albania.

Mapping of donors and CSO

The main information for the study was collected from the interviews through semi structured questionnaires with key informants that included: CSOs that work in health sector advocacy, donor organization that finance advocacy efforts and decision makers at national level.

The proposed set of recommendations was based of the finding of the desk review and the main analyses.

Questionnaire

The semi structured questionnaire was finalised after the finalisation of the desk review. The following are the main sections where interviews were focused:

Section 1 – General information of the key informant

- (For NGOs) Name, status, years of experience (if NGO)
- (For individuals) Organisation, position and for how many years
- Has your organisation developed in the past, recently or working on any advocacy strategy? If yes, has that been your initiative or requested as part of any project?

Section 2 – Effectiveness of advocacy strategies

- Have you/your organisation been working in advocacy in the health sector?
- What are the main donors you have worked with in the health advocacy sector?
- What has been the role of the donor in advancing advocacy issues raised/aimed through the project/grant/contract?
- What program have you implemented that focused on advocacy in health sector?
- What are the main results?
- On your opinion how has this program influenced any decision making at national level?

Section 3 – Main Challenges

- What are some main challenges faced during implementation?
- What mitigation plans have you proposed to overcome the challenges?
- How are challenges impacted results?

Section 4 – Sustainability

Is there any partnership created to advance the advocacy efforts?

- Are there risks identified by your organisation that affect the success of the planned activities?
- What is the role of the donor in helping your organisation to increase sustainability of the efforts?
- Is there any exit strategy planed/required when implementing advocacy activities/projects?
- What recommendations would you give to strengthen the sustainability of the advocacy in health sector?

APPENDIX 2 – LEGAL FRAMEWORK THAT REGULATES THE HEALTH SECTOR REFERENCES

- Law no. 7643 dated 2.12.1992 "On the State Sanitary Inspectorate" amended.
- Law no. 7703, dated 11.5.1993 "On social security in the Republic of Albania" as amended.
- Law no. 8025, dated 9.11.1995 "On protection from ionizing radiation" as amended.
- Law no. 8045, dated 7.12.1995 "On Termination of Pregnancy" as amended.
- Law no. 7975, dated 26.7.1995 "On narcotic drugs and psychotropic substances" as amended.
- Law no. 8528, dated 23.9.1999 "On the promotion and protection of breastfeeding" as amended.
- Law no. 8615, dated 1.6.2000 "On the order of doctors in the Republic of Albania" as amended.
- Law no. 8626, dated 22.6.2000 "On the status of paraplegic and tetraplegic invalids" as amended.
- Law no. 8876, dated 04.04.2002 "On reproductive health" as amended.
- Law no. 9106, dated 17.7.2003 "On hospital service in the Republic of Albania" as amended.
- Law no. 9150, dated 30.10.2003 "On the order of pharmacists in the Republic of Albania" as amended.
- Law no. 9474, dated 9.2.2006 For the ratification of the convention within the framework of the WHO "On tobacco control".
- Law no. 9579, dated 11.7.2006 "On the ratification of the financing agreement between Albania and the International Development Association (IDA) for the project "Modernization of the health system".
- Law no. 9636, dated 6.11.2006 "On the protection of health from tobacco products" as amended.
- Law no. 9518, dated 18.4.2006 "On the protection of minors from the use of alcohol, energy drinks and carbonated drinks containing added sugar" as amended.
- Law no. 9493, dated 13.3.2006 "The financial agreement between the Council of Ministers of the Republic of Albania and Artigiancassa S.P.A. for financing the program "For five polyclinics in the cities of Tirana, Gjirokastra, Korça and Peshkopia".
- Law no. 9718, dated 19.4.2007 "On the order of nurses in the Republic of Albania" as amended.
- Law no. 9739, dated 21.5.2007 "On blood transfusion service in the Republic of Albania" as amended.
- Law no. 9928, dated 9.6.2008 "On the dental health service in RSH" as amended.
- Law no. 9942, dated 26.6.2008 "On the prevention of disorders caused by iodine deficiency in the human body" as amended.

- Law no. 9952, dated 14.7.2008 "On the prevention and control of HIV/AIDS" as amended.
- Law no. 10138, dated 11.5.2009, "On public health" as amended.
- Law no. 121/2016 "On social care services in the Republic of Albania".
- Law no. 10107, dated 30.3.2009 "On health care in the Republic of Albania" as amended.
- Law no. 10383 dated 24.2.2011 "On mandatory health care insurance in the Republic of Albania" as amended.
- Law no. 10 469, dated 13.10.2011 "On protection from non-ionizing radiation" as amended.
- Law no. 44/2012 "On mental health" as amended.
- Law no. 105/2014 "On drugs and pharmaceutical service" as amended.
- Law no. 138/2014 "On Palliative Care in the Republic of Albania".
- Law no. 89/2014 "On Medical Devices" as amended.
- Law no. 147/2014 "On the Medical Emergency Service".
- Law no. 119/2014 "On the right to information".
- Law no. 163/2014 "On the Order of Social Workers in the Republic of Albania". amended.
- Law no. 127/2014 "On the order of the dentist in the Republic of Albania".
- Law no. 15/2016 "On the prevention and fight against Infections and Infectious Diseases" as amended.
- Law no. 27/2016 "On the management of chemicals".
- Law no. 18/2017 "On the rights and protection of the child".
- Law no. 37/2017 "Code of criminal justice for minors".
- Law no. 17/ 2018 "On official statistics".
- Law no. 23/2021 "On the ratification of the agreement between the Council of Ministers of the Republic of Albania and the Government of the Republic of Albania and the Government of the Republic of Turkey, on the donation in the field of health".
- VKM no. 327, dated 28.5.2014 "On determining the format and manner of data collection and reporting by public or private health care service providers" as amended.
- VKM no. 788, dated 22.9.2015 "On determining the criteria, standards and procedures of the process of accreditation of continuing education activities for health professionals" as amended.
- VKM no. 419, dated 04.07.2018 "On the creation, organization and operation of the Health Care Services Operator".
- VKM no. 418 dated 4.07.2018 "For some changes and additions to VKM NR. 788, Date 22.09.2015, for determining the criteria, standards and procedures of the process of accreditation of continuing education activities for health professionals".

- VKM no. 418 dated 4.07.2018 "For some changes and additions to VKM NO. 788, Date 22.09.2015, for determining the criteria, standards and procedures of the process of accreditation of continuing education activities for health professionals.
- VKM no. 47, dated 30.01.2019 "For the approval of the national cervical cancer screening program package in RSH".
- VKM no. 380, dated 05.06.2019 "On the approval of the political document "Disability assessment reform in the social protection system and the 2019-2024 action plan for its implementation".
- VKM no. 722, dated 11.11.2019 "On the determination of the measure, criteria, procedures and documentation for the evaluation and benefit of the disability and the personal assistant, and of the responsible structures and their duties".
- VKM no. 405 dated 20.5.2020 "On the approval of the strategy for the development of primary health care services in Albania 2020-2025".
- VKM no. 182, dated 26.2.2020 "On determining the measure, criteria, procedures and documentation for the evaluation and benefit of payment for persons with disabilities, as well as for personal assistants" as amended.
- VKM no. 503, dated 24.6.2020 "On the method of administering electronic health information".
- VKM no. 175, dated 17.03.2021 "On the establishment, organization and operation of the Regional Hospital "Memorial" in Fier, as a pilot project".

APPENDIX 3 – THE MAIN DONORS IN HEALTH CARE

Swiss Agency for Cooperation and Development

The Switzerland is now the biggest donor in the health sector, especially in primary health care. The projects financed by the Agency focus on improving access to PHC services and early identification and monitoring of non-communicable diseases (NCDs).

Its main program objectives are to improve the efficiency, coverage, and inclusiveness of healthcare services (including for emergencies and particularly for the most vulnerable people), and to promote healthy behavior amongst children and adolescents. The efforts include working with patients and independent institutions to strengthen their voices and keep health services accountable. Albania's first national PHC strategy, developed with Swiss support, was approved in 2020, thus paving the way for improved services. However, the twin crises strongly affected the priorities of the GoA, directly impacting the path and pace of reforms.

USAID Albania

USAID has started to work in Albania since 1992, and since the beginnings has invested in reforming the health care system, by improving its governance, reforming primary and secondary health care and the financing of the system, investing in management information systems, and increasing transparency and accountability in health.

The USAID investments in health in Albania in 30 years have impacted the achievements of the entire agency in the country, particularly in democracy and economic growth. The Mission office in Tirana had a dedicated health portfolio and dedicated staff to manage the projects, until the scale down of programs, with the last contract in health care ending in July 2019²⁴. As part of these large-scale projects, advocacy at different levels has been a part/component of the intervention: as advocacy for policy improvements to support the health care reform underway.

UNFPA

The United Nation fund for Population has assisted Albania to improve reproductive and sexual health, alongside population and development strategies and policies. Key programs of the agency have contributed to public sector reform for accession to the European Union (EU), one of Albania's main priorities. UNFPA also assists government counterparts in updating policy frameworks, developing higher quality services, enhancing standardized oversight mechanisms, and fostering a more effective use of data in planning and policymaking. The UNFA works with local CSOS to increase awareness, education and information on reproductive and sexual health, an important component of advocacy.

UNICEF

The United Nations Children's Fund speaks on behalf of and with children to support their rights, ensure safe and healthy childhoods in safe and inclusive communities, and build strong futures with opportunity and hope. Through its advocacy and communication for

²⁴ <u>https://www.usaid.gov/albania/news-information/fact-sheets/fact-sheet-transparency-health-engagement</u>

social change approach, UNICEF seeks to understand people, their beliefs and values, the social and cultural norms that shape their lives. It means engaging communities and listening to adults and children as they identify problems, propose solutions and act upon them. UNICEF sees the communication for behavior and social change as a two-way process for sharing ideas and knowledge using a range of communication tools and approaches that empower individuals and communities to take actions to improve their lives.

In Albania the organization is working closely with the MHSP on breastfeeding and nutrition issues, contributing to nutrition guidelines for health providers and communities, child health status monitoring and awareness raising on healthy behaviors for children and their mothers.

During the pandemic, UNICEF in collaboration with USAID, have led a national wide campaign on covid 19 risks, healthy behaviors, and vaccines.

Open Society Foundation for Albania

The Open Society Foundation for Albania is a non-profit organization, part of the Open Society Foundations network, created and financed by investor and philanthropist George Soros.

The Public Health Program of the Open Society Foundation for Albania has been active in the last 10 years, also reflected in the Foundation's strategy in 2010. With a human rightsbased approach, the program has supported and collaborated with civil society organizations to influence and advance issues related to the health of vulnerable groups in the country. People suffering from life-threatening illnesses and those affected by mental health problems are considered two of the population groups that face the most violations of their rights. The main achievements of the program in the health domain have been mainly related to supporting the fields of Palliative Care and Mental Health in the country. The palliative care law was approved in 2014 because of a strong technical and advocacy efforts of the organization and its partners.

The Democracy Commission Small Grants Program

The Democracy Commission Small Grants Program, of the US Embassy in Albania is designed to support initiatives that contribute to open and competitive political systems and to the protection of human rights. It provides biannually opportunities for CSOs to apply for grants that focus among other anticorruption, good investigative journalism, governance and human rights/minority rights, all potential cross cutting areas for intervention in health or designing advocacy efforts in health sector.

Other donor agencies

There are other donor agencies that have worked in health sector, but from a cross cutting sectorial approach.

The UK Embassy have worked in the health sector through the media perspective, working to strengthen disinformation, building media professionals reporting capacities and improving reporting in health care.

The embassy of Netherlands has had some interventions in health, and more specifically to generate evidence to push for policy change: a study in 2018 on selective abortion, presented a series of recommendation for the Parliament to enforce legislation on gender selective abortion practices.

APPENDIX 4 – MAPPING OF THE CSOS WORKING IN HEALTH CARE ADVOCACY

The following are a list of organizations that have established experiences in health care in the last 10 years and have the advocacy work as part of their strategies and action plans. Also, as part of the organizational analyses their capacities, skills and resources in advocacy are discussed.

Together for Life Association – TFL

TFL has been working from 10 years now in health care system, advocating for patients' rights at local, national, and international level. The association has partnered with local, national, and international partners, and implemented projects from a range of donors such as: USAID, UNFPA, Swiss Embassy, GIZ, Embassy of Netherland, Embassy of USA, British Embassy, WDF, NED. etc.

The organization has a dedicated staff on development and implementation of projects in the advocacy area. The organization has developed in 2021 its 5-year strategy which also includes the objectives of the organization regarding advocacy for equity and access to services for chronic patients in health care, as well as continuous education and information of communities on health issues and determinants. TFL has a strong and very well recognized media component and several social/online platforms, which are important in implementing any advocacy activity. The organization has developed many assessments, studies and reports concerning health care, with clear objectives and evidence-based recommendations. Much of these recommendations have presented also to the parliament's Commission of Labor, Social Welfare and Health.

The organization has actively participated in the development of the Health Strategy, where the specific contribution can be mentioned the adding of a chapter on the management of services in emergency settings with clear objectives on chronic patients. Also, through TFLs advocacy efforts, the children with hearing impairments can get the cochlear implant as part of the service package. And finally, through TFL continuous efforts a working group was established to work on the budget for the invitro fertilization service.

Institute for Activism and Social Change - IANS

IANS was stablished in 2019 and in few years was established as an important player in the advocacy in health care, and more specifically advocacy for equity and access to quality mental health. IANS has partnered with many national governmental and international donors such as: Ministry of Health and Social Protection, Peoples advocate, Commissioner for antidiscrimination, Swiss Embassy in Albania, UNCIEF, Global Fund for HIV, Embassy of United states, Embassy of Netherland, OSFA and WHO.

IANS works in improving quality of care through increasing the capacities and skills of health care professionals of primary health care on protocols and guidelines related to HIV patients, emergency care, psychosocial support, and referral services. IANS has conducted a situation assessment of the mental health and access to services for children and adolescents, assessment of the National Strategy on Mental health and provision of recommendations for the new strategy and has actively contributed to integrate personal care as part of the primary health care strategy.

Although IANS has not developed a dedicated strategy for advocacy in mental health, its staff has participated actively in advocacy activities related to legal framework improvements in mental health. Further capacity building activities are needed to strengthen more the organization domain in advocacy for equity in mental health.

Down Syndrome Albania Foundation – DSA

DSA is a not-for-profit organization founded in Tirana, Albania on the 9th of September 2013. Its activities aim to improve the lives of children and individuals with disabilities and support their parents. DSA is an organization founded by parents of children with Down syndrome to advocate for the rights and needs of people with disabilities in Albania and provides services to people with disabilities (children and youth). DSA works closely with parents to empower and support them in raising a child with disabilities. Through different projects DSA has trained: teachers, psychologists, speech and language therapists, social workers, medical care staff and parents.

Down syndrome is a health conditions, as such the need for specialized care for children with the down syndrome in Albania remains a priority and a topic of continuous advocacy. The children and adults with down syndrome in Albania need early detection and follow up treatments, which are not provided though separate protocols. The children with the down syndrome in Albania are followed by the same pediatricians of primary health care, without referrals to more specialized care. The main advocacy work of the DSA is to have clinical guidelines specific for the down syndrome in Albania, for children and adults. The organization does not have a specific strategy document on advocacy and dedicated staff. It implements small scale funded project that aim to increase awareness and educate parents and people with disabilities on their rights to health care.

Family Health Care

The association founded in 2003, has almost 20 years working to improve the physical, psychosocial, and spiritual wellbeing of patients with terminal diseases, and alleviation of care for family members. With its limited resources the organization offers care for an average 300 patients annually, mostly cancer patients in the southeast region. The service is provided at their home, or at the hospice care build for this patient's category.

Palliative care should be offered to all terminal patients, not only cancer patients. As foreseen also in the Palliative care law, an important achievement in the area, approved in 2014. Unfortunately, in Albania palliative care is offered only to terminal cancer patients, leaving a large group of terminal patients without this care. Palliative care is offered only by civil society organizations, and its funding is covered by donors or secondary income generated by the organizations themselves.

The organization does not have a separate advocacy strategy and dedicated staff. They work to empower communities, families, and patients to understand their rights to palliative care and increase pressure to decision makers. It also works in partnership with other organizations and donors to monitor the palliative care law implementation and inclusion of services at basic package of services.

Save the Children

Save the Children has been working to improve the lives of children and families in Albania, both since 1999. The organization focuses on reaching the most deprived and marginalized

children, who are too often excluded due to poverty, disability, where they live, their gender or ethnicity. The Programs and advocacy approaches empower and support children to meaningfully increase their participation in school and community life and influence decisions that affect their rights and their lives. Save the Children programs cover Basic Education and Early Childhood Care and Development, Child Protection, Child Rights Governance, Health and Nutrition and Humanitarian.

Save the Children is implementing a large-scale project funded by the Swiss Agency for Development and Cooperation (2021-2025) with the objective to promote positive behavioral changes among all primary schoolchildren (aged 6-16 years) in Albania for them, their families, and communities at large to engage in healthy lifestyle practices including healthy nutritional practices, physical activity, no use of tobacco, alcohol, or drugs, as well as promotion of other healthy behaviors. Among the many activities of the project, a strong focus is given to the advocacy at the national and local level of the main actors (education, local and central government, health) to collaborate in promoting health in an inter-sectoral approach based on evidence, new standards, and guidelines.

Albania Community Assist - ACA

ACA has been established in 1999 as a branch of International Community Assist-UK, its principal founder and donor. ACA works in health domain with objectives to increase health education, quality of health care, increase access to health care services for people in need, including minorities, women, and youth in rural and urban areas. ACA puts a special focus on continuous support of Roma and Egyptian minorities, people with disabilities and health workers.

Main programs implemented are focused on health education and promotion; access in health services, health rights; empowering of youth and people in need, capacity building, awareness, and lobbying. ACA has a strong local network with community, regional health authorities, health centers and other civil society organizations.

Albanian Disability Rights Foundation - ADRF

ADRF is a non-profit Albanian organization that was founded by OXFAM in 1996. ADRF programs aim at increasing the chances of persons with disabilities to integrate into the social, economic, political, and cultural life of the country, through respecting and protection of their rights.

The main and most important achievement of ADRF is the ratification of the international convention on People with Disabilities by the Albanian government, in 2012. From that moment ADRF has worked with the main national partners on monitoring the implementation on the convention, develop capacities to produce research-based advocacy reports, and follow up the with findings and recommendations.

When it comes to health, is not the main domain of ADRF, but health is a basic right for any citizen, PWD includes, which represents the most vulnerable groups in facing barriers to access, physical and emotional.

ADRF has strong capacities in advocacy in human rights, capacities in mobilizing communities and partnering with local and national actors to push for policy change. Their models are easily replicable in every area, health included and due to their strong positioning in advocacy settings they can share their experiences with other organizations as well.

MED PAK

MED PAK is a parent association for people with disability. Its mission is to protect the rights of persons with disabilities through recognition of the implementation of legal and by-law acts, capacitating its members on the disability, increase community awareness to increase accountability and law implementation and increase access to services.

Regarding health care sector the organization works to capacitate the parents by training them in the efficient use of medication and knowledge of health protocols, especially that of disability assessment (bio-psycho-social model) and monitoring the status of the disease, advancement or not. The organization has developed a strategy (2021-2025), that includes also objectives related to awareness raising on the disability, and their rights to access quality services. They have strong capacities in advocating for people with disability.

AKSION PLUS

The Aksion Plus Association was founded in 1992 by a group of volunteers, students with the aim of preventing the spread of HIV/AIDS in Albania, among youth groups and other vulnerable groups.

The purpose of the association is to sensitize the population and youth on social issues by promoting HIV/AIDS, STI and drug prevention including methadone therapy for drug users and other social services. The main activities of the association are related to the prevention of HIV AIDS, risk of drug use, treatment for drug use, capacity building and advocacy.

BIRN Albania

The Balkan Investigative Reporting Network (BIRN) Albania is a media non-governmental organization based in Tirana, and launched in March 2014, which specializes in investigative reporting, publishing, and media development. BIRN Albania aims to strengthen democracy and freedom of expression and promote respect for human rights through capacity building of Albanian journalists, increasing awareness of the rights of vulnerable groups, such as minority groups, Roma and Egyptian communities, LGBT, etc., promotion of transparency and accountability principles in public institutions, and fostering public debate on important political, economic, social, and cultural issues.

BIRN Albania supports the development of high-quality journalism and civil society and thereby contributes to the development of democracy by keeping public institutions and the government accountable to its citizens. In the last decade BIRN Albania has conducted several high-profile investigations in health care in the last decade, from corruption to pharmaceutical sector to procurements and the government response to covid 19.

BIRN Albania is not the typical grass roots organization discussed above that works in communities to increase awareness and implement advocacy activities but is a crucial partner in building strategies to improve health advocacy based on evidence and increase the public dialogue around main issues pertaining in the health sector.

Faktoje

Faktoje is a fact-checking organization that promotes accountability based on the right to information and transparency, was launched in Albania in May 2018 with full technical support from the USAID-funded Justice for All project and was implemented by EWMI. The overarching goal of "Faktoje" is to improve public performance standards in Albania and, in

less than two years, the platform has transformed into a reliable source of information and set an example of responsible and ethical journalism.

During the Covid-19 lock down and after, Faktoje²⁵ became an important player in the health sector, especially with the disinformation part which plagued even more the health care. The fake information circulating on the Covid risk factors and myths about the vaccine, contributed to a public confusion on many topics. Transparency and accountability in health care, that directly affects the services for patients and vulnerable communities, were also a target of their fact checking reports.

Again, both BIRN and Faktoje are important partners in evidence generation for advocacy, inform and educate the public to create the needed public pressure to keep policy makers accountable.

²⁵ <u>https://faktoje.al/category/aktualitet/covid-19/</u>

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Westminister Foundation for Democracy <u>https://www.wfd.org/what-we-</u> do/resources/monitoring-state-health-budget-albania Westminster Foundation for Democracy (WFD) is the UK public body dedicated to supporting democracy around the world. Operating internationally, WFD works with parliaments, political parties, and civil society groups as well as on elections to help make countries' political systems fairer, more inclusive and accountable.



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