

FSAPH and the fight for social inclusion of people with disabilities

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For many years disability has, in theory, been a policy priority of the Senegalese government. Officially, people with disabilities (PWDs) represent 5.9% of the Senegalese population.¹ This data, however, is contested and many argue that it is closer to 15.5% of the total population. In 2010, the Social Orientation Act (SOA)² was adopted to protect the rights of PWDs and remove barriers to their empowerment and inclusion. The Equal Opportunity Card (EOC) program was introduced to provide PWDs free health care, transportation, employment and other assistance. However, officials were failing to provide the cards to eligible people, and even those who did receive a card were having trouble accessing benefits. Out of 50,000 people who had registered for a card, only 19 230 were enrolled in the Universal Health Coverage plan and even those who were enrolled experienced gaps in services as the state regularly failed to pay the insurer.

In just over a year, the Senegalese Federation of Associations of People with Disabilities (FSAPH), with our support, facilitated access to basic services and benefits for more than 100,000 of its members. FSAPH helped 15,000 people get access to EOC cards and helped increase the number of PWDs enrolled in the Universal Health Coverage program from 38.5% in 2019 to 42% in 2020. They also ensured that 100,000 of its members received COVID relief. Importantly, they influenced key Senegalese government ministries to commit to improving three programs focused on facilitating employment, vocational training, and social protection opportunities for PWDs. The process of fighting for and achieving these changes have transformed how government sees and listens to people with disabilities and have lasting impact on how PWDs see themselves and their place in Senegal.

Background

¹ According to the 2013 population census.

² The Social Orientation Act is a legal instrument that promotes the social inclusion of people with disabilities. It provides a legal harmonization framework that makes it possible to address issues pertaining to the social integration of people with disabilities on a national level. The primary purpose of the Act is to guarantee equal opportunities for people with disabilities and promote their rights against all forms of discrimination.

FSAPH was founded in 1997 to guide national and state governments in creating opportunities for PWDs. It is a nationwide, independent umbrella organization—with a secretariat and 29 branches and regional representations— that brings together PWD associations of all disability types.

Thanks to FSAPH's advocacy over more than two decades, the government first introduced the Equal Opportunity Card (EOC) program in 2017 and included card holders in social safety net programs, such as the Family Allowance Program³ and Universal Health Coverage plan. However, they were struggling to get the program properly implemented so that it could lead to tangible improvements in the lives of its members. It faces two key challenges. Firstly, there is an insufficient production of cards – with no cards at all being produced in 2018. Secondly, even with a card, accessing the benefits is difficult. Both challenges were related to budget execution (the budget had been cut by two-thirds for instance in 2018) and FSAPH lacked knowledge of the budget system or how to influence it. After discussions with FSAPH's leadership, we stepped in to build their ability to add effective budget advocacy as an additional tool to bring about the change they sought.

FSAPH's path to results

Joining of technical and political power

We and our technical partners— OSIDEA⁴ and ONG 3D⁵— helped FSAPH build budget analysis skills and navigate political institutions to identify and address the resource challenges that were keeping the EOC program from being properly implemented and to open the door for PWDs to have a say in policies that impact them.

FSAPH pursued a two-pronged strategy to navigate the ecosystem of actors, roles, institutions and contexts that influence budget decisions affecting their community. First, they worked hard to reinforce and improve already strong ties with members of parliament and local elected officials. Second, they leveraged those relationships to monitor how the relevant programs were being implemented and to gain insights on shortcomings. The nationwide membership structure of FSAPH has provided a distinct organizing advantage. They have a deep and wide enough base to mobilize members, engage officials and influence decisions that are being made at all levels of government. IBP, ONG 3D and OSIDEA have also lent our political know-how to help FSAPH navigate these channels and sometimes contradictory positions from officials at different levels.

³ The Family Allowance Program is part of the Senegal Safety Net Project. It supports 300,000 of the poorest Senegalese households with quarterly cash transfers to reduce extreme poverty.

⁴ OSIDEA is a Senegalese association that implements programs that focus on fiscal and economic accountability mechanisms to assess the conduct of public policies.

⁵ ONG 3D is a pioneering CSO organisation on budget work that has accumulated significant experience in budget advocacy, specifically the budgetary accountability of elected officials at national and local levels.

Strengthening FSAPH’s “collectiveness”

It quickly became apparent that a crucial first step to effective campaigning was improving FSAPH’s internal governance. FSAPH was struggling with inclusion and representation of women and different disability types in its governing structures. Regional branches felt isolated due to lack of communication from the leadership.

IBP facilitated a series of workshops with FSAPH’s members to help improve their governance, communication and cohesion. They agreed to a more robust downward and upward accountability chain for the program management committee; weekly email chains to regional structures to keep them informed of plans and progress; and a commitment to have at least one woman and different disability types represented in their regional COVID-monitoring and evaluation committees.

FSAPH also identified strong regional groups that could drive some of the work forward. The Pikine and Ziguinchor groups quickly stood out as active and competent. FSAPH leadership turned to these two groups for strategic planning of advocacy actions, which reinforced their sense of inclusion, ownership and purpose.

Building budget and political advocacy skills

While FSAPH had been at the forefront of disability inclusion advocacy for a number of years, they lacked the budget knowledge to address why services were not flowing to their members and were therefore not yet seen as a credible partner by government. To get there, we and our technical partners supported FSAPH through workshops and activities that built their budget understanding and empowered them to know what they were looking for, whom to address, what to expect and what to ask for. We trained 110 of their members from various regional groups to analyze budgets and advocate for better allocation of resources in the budget.

*“The budget training allowed us to better understand budget processes. Since then, we have **improved relations** between local officials and our regional FSAPH structure.”*

Pikine training participant

Generating and leveraging data to make demands

In 2019, FSAPH collected information from the EOC implementing agency to understand why so many people with disabilities had not been issued a card and why those who had were struggling to access benefits. The data showed that only about a third of EOC recipients were enrolled in the Universal Health Coverage plan. Those enrolled were struggling to get consistent care because the government was not paying the insurer. FSAPH brought this evidence— which government did not have and could not gather— to

meetings IBP and technical partners set up with key institutions and agencies.⁶ When they brought this issue to the attention of officials, they helped uncover the fact that the failure to deliver on the promise of the EOC program was not due to reluctance on the part of decisionmakers. Rather it was due to several impediments: 1) the government was not allocating sufficient funds for the EOC program; 2) the government was behind in paying the Universal Health Coverage plan premiums; 3) officials implementing the Universal Health Coverage plan were not adequately targeting PWDs; and 4) other key ministries were not incorporating and prioritizing PWDs in their budgets.

COVID-19 was particularly challenging for people with disabilities and threatened FSAPH's ability to organize and mobilize. Nevertheless, they took the data analysis skills and relationships we helped them forge to pivot quickly to get their members relief.

In March 2020, FSAPH set up a COVID-19 monitoring and evaluation initiative and used its regional structures to collect data from 820 PWDs. The data revealed that most respondents had not received COVID-19 assistance because PWDs were not included in the national registry of poor households that was used to target recipients. FSAPH wrote a letter to the Director of Community Development and Social Equity. As a result, the Ministry of Community Development and Social Equity decided to include FSAPH

members in formal national and local COVID technical committees. They also provided COVID-related food and utility assistance to 100,000 PWDs.



May 2020 press conference on the inclusion of PWDs in COVID-19 assistance programs

Shifting narratives on disability

To truly get buy in for the social and economic inclusion of PWDs, we and FSAPH realized that we also had to change people's perceptions of and misconceptions about disabilities. On the one hand, official PWD population data is contested. Furthermore, a person needs to obtain a medical certificate to certify that they have a disability and there are not enough medical specialists in Senegal to verify a disability. What qualifies as a disability is poorly understood and is too often defined as a "medical condition."

We helped FSAPH partner with the Cheikh Anta Diop University of Dakar who provided them technical support to undertake a participatory study on norms and discourse on

⁶ For instance, the Ministry of Health and Social Welfare, the National Assembly, the Universal Health Coverage Agency (ANCMU), and the Municipal Development Agency, as well as local authorities (such as Dakar municipality).

disabilities. FSAPH leaders invited 65 of its trained regional members to participate as peer-researchers in the study.

1,025 PWDs responded to the study's quantitative survey, which documented for the first time the stigmatizing practices PWDs face at the family, community and institutional levels.⁷ It also generated rich qualitative insights from life stories and testimonies respondents shared about the various ways they have felt marginalized.

*"My participation in this [norms and discourse on disability] study **has been life-changing...** Seeing my contribution is valued has helped me regain my confidence. I am now more determined to advocate for our rights."*

Study peer-researcher from the regional research team of Ziguinchor

*"PWDs around the country are facing barriers to unemployment and employability. **Government must put in place a global strategy for their recruitment in the public sector.**"*

Recommendation from the study

FSAPH used the study's insights, and the data on budget challenges that were keeping programs for PWDs underfunded (for instance arrears in government payments to the Universal Health Coverage plan and poor targeting of PWDs in that plan), to shift the narrative and raise public awareness about the need to better support PWDs. FSAPH spearheaded traditional and digital media campaigns to shed light on the lived experience of PWDs and urge the public and government to be more responsive to their needs. For the first time, PWDs occupied media spaces and broadcast their data on prime-time television, urging viewers to hold government accountable and officials to reach out to them for collaboration. The most popular television channel in Senegal, RTS, broadcast public service announcements highlighting the exclusion of PWDs in 7 official languages. FSAPH held a press conference that was well attended by news channels and high-profile journalists. Three of the most popular national radio stations (RFM, RSI and SUD FM) hosted shows with FSAPH members, which were retransmitted by local radio channels.



FSAPH broadcasts public service announcements highlighting the exclusion of PWDs.

⁷ The study was conducted by FSAPH with the support of a scientific committee composed of university researchers and academic experts. Using a robust mixed methodology (qualitative interviews, focus groups and a survey) and a participatory approach that included more than 100 FSAPH members throughout the national territory, evidence was collected on the perception of disability from the different stakeholders' points of view.

Formal and informal engagement and participation



Yatma Fall, FSAPH President, during a press briefing on the effective implementation of the Social Orientation Act

We helped FSAPH leverage informal and formal opportunities to engage government officials. FSAPH established regular contact with: the Director of Social Action in the Ministry of Health and Social Action; the Director of Social Equity in the Ministry of Community Development; the Director of Community Development in the Ministry of Community Development; the Director of Employment; and the Minister of Urban Planning, Housing and Public Hygiene.

Incrementally, they leveraged these contacts to get more formal commitments. The Ministry of Community Development, Social and Territorial

Equity invited them to help draft the Program for Economic and Social Inclusion (PAIES), which seeks to ensure the effective inclusion of PWDs.⁸ The Director of Employment⁹ invited FSAPH to discuss PWD access to employment and signed a Memorandum of Understanding with them for long-term collaboration. The Director of Development and Social Equity committed to collaborate with FSAPH to better integrate PWDs in its programs. The Minister of Community Development recognized that PWDs are a priority group and made assurances that they would be included in social programs implemented by the ministry.

*"We work to support community development. Our community targets are diverse and loose because community development takes into consideration all society groups, without distinction. **We are thrilled to be working with an organization [FSAPH] that can be propositional to us because of who it represents and the pertinence of its actions.**"*

Mr. Moussa Bar Faye, Director, Community Development, Ministry of Community Development, Social and Territorial Equity

⁸ The Ministry of Community Development, Social and Territorial Equity organized a workshop on the PAIES program, inviting FSAPH alongside other concerned ministries, including the Ministry of Health and Social Action; the Ministry of Women's Affairs, Family and Children's protection; the Ministry of Labour, Professional Organizations and Relations with Institutions; the Universal Health Coverage Agency; and the different directorates for social development programs that are part of the Ministry of Community Development, Social and Territorial Equity.

⁹ Ministry of Employment, Vocational Trainings and Crafts.

Working with oversight institutions



Parliamentarians receiving FSAPH's memorandum during a 2019 advocacy dinner

FSAPH has strengthened its watchdog role by leveraging the power of the National Assembly's "checks and balances" to bring government to account. Towards the end of 2019, we supported FSAPH in the organization of an advocacy dinner with members of the National Assembly Health and Social Affairs Commission. On that occasion, FSAPH gave a memorandum to parliamentarians to inform their interventions during the budget preparation debates. Several parliamentarians, mostly female, including the president of the Health Commission, went on to question the Ministry of Health on why his ministry had not issued

EOCs and called for an evaluation of the Social Orientation Law. FSAPH continued to engage with parliamentarians in 2020, who remained important allies to make sure government delivered on its various commitments, for instance putting pressure on the Ministry of Health to continue the production of EOCs and improve the enrollment of PWDs in the Universal Health Coverage Program.

*"We parliamentarians are meant to have a say in everything, without us necessarily having the expertise. [During FSAPH's advocacy dinner] we were given factual information [on PWD exclusion] and got to hear directly from PWDs. **The engagement with FSAPH was an eye-opener for us.**"*

Ms. Mariam Sodey Nyaye, National Assembly Parliamentarian

FSAPH's main successes to date

In this midst of a difficult organizing context, FSAPH nevertheless garnered significant wins for its members— such as their inclusion in COVID relief— and expanded access to EOC benefits and economic and employment opportunities.

Thanks to FSAPH's efforts, 100,000 PWD households who were initially excluded from the national resilience program have now received COVID relief kits. State institutions such as the Ministry of Health and Social Action, the Ministry of Women's Affairs and the Ministry of Culture have distributed relief kits to FSAPH or dedicated a quota of their sectoral resilience funds to PWDs.

Our collective advocacy helped 15,000 people access EOC cards in 2019 and 2020 and increased the number of PWDs enrolled in the Universal Health Coverage program from 38.5% in 2019 to 42% in 2020.

FSAPH also secured important commitments from government institutions to expand opportunities for PWDs. The Director of Employment signed an agreement with FSAPH to ensure a 5% quota for PWDs to receive internship placement through the State-Employers' Agreement (CNEE). FSAPH also secured an allocation for the Vocational and Technical Training Fund (3FPT) to include training for prosthetic specialists. Many national and regional orthopedic centers lacked trained specialists who could provide quality prosthetic care to PWDs, so this fund will help fill this gap. The Ministry of Community Development has reaffirmed its commitment to PWD inclusion as it finalizes the Support Program for the Social and Economic Inclusion of PWDs (PAIES) with contributions from FSAPH.

Conclusion

With our help, FSAPH has improved its governance and forged valuable relationships with government decisionmakers. By building their budget literacy and gathering data they are now able to support their demands with facts. They have also been empowered as individuals and as a force to be reckoned with in Senegal. They have built their credibility as a valuable source of information and partner for government and the media and have shifted public narratives and perceptions about PWDs and their needs.

Moving forward, FSAPH will focus on ensuring the commitments they obtained in 2020 are delivered. In particular, they will seek increases in budget allocations to the EOC program and access by PWDs, especially women with disabilities, to effective health services under the Universal Health Coverage plan. They will also continue to strengthen ties with government reformers that can influence budget outcomes to advance disability-sensitive policies and budgets.