# How to Join Forces of Public Bureaucracy and External Stakeholders to Enhance the Current Legislation

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## Abstract

Once new legislation, whether federal or local, is passed, the next step for the responsible executive is to monitor how the law is applied and what shortcomings are in its use. Often, after the new law goes into effect, the local bureaucracy is swamped with tons of claims and complaints from affected citizens, leading to dissatisfaction and questioning of the state's capacity. Moreover, the authorities continue to incur costs, that is, waste taxpayers' money, due to ill-conceived legislation.

To investigate the downsides of law enforcement practices, the authors developed a research methodology and a three-component approach, both of which were successfully applied to address two issues related to the Russian social welfare system concerning socially vulnerable groups. The first issue concerned the accessibility of higher education for people with disabilities. The second issue was related to the features of socio-medical examinations for children with rare diseases to confirm disability status.

With the support of senior executive officials and the use of bureaucratic mechanisms, the authors not only conducted research to identify shortcomings in current legislation but also successfully attracted external stakeholders to amend and streamline relevant federal laws. As a result, from 2017 to 2020, both new laws and corresponding changes to existing legislation were adopted.

In the paper, the authors share data from both studies and detail the efforts that have helped bring together civil society, researchers, bureaucracy, journalists, and politicians to craft more effective legislation for socially vulnerable groups of citizens.

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## Introduction

One of the objectives of good governance is to monitor law enforcement practices, obtain meaningful feedback from stakeholders, and, if applicable, correct ill-conceived, outdated, or erroneous legislation. Many problems and difficult tasks may arise along this path. How to organize monitoring of law enforcement practice? How can we obtain detailed and balanced feedback that includes the perspectives of both service consumers and officials, the service providers? How to generalize the problem without losing details? This list of questions can be continued endlessly. Meanwhile, flaws in legislation or obsolete laws lead to a waste of budget funds, in other words, taxpayers' money. Likewise, defects in legislation can cause dissatisfaction and cast doubt on the state's capacity. There is no one-size-fits-all solution, and much depends on the context of law enforcement practice and affected groups of citizens.

The authors were challenged several times to find shortcomings in current legislation and explore possible ways to correct or overcome the identified flaws. In the paper, the researchers share their experience and the approach they developed and successfully applied twice. Strictly speaking, the authors applied the corresponding approach three times. The first research project involved monitoring housing reconstruction carried out in 2016–2017 throughout the Russian Federation. The researchers had a task similar to subsequent research projects: to analyze the application of existing relevant legislation and find ways to change it. Unfortunately, no legislative changes regarding housing renovation followed the presentation of the research results. For the second and third research projects, the authors, based on lessons learned, moved ahead and engaged external stakeholders, including active advocacy by civil society activists and journalists. This engagement helped overcome bureaucracy resistance and monitor law enforcement practices.

Both cases discussed by the authors in this paper were related to public social services provided by the federal authorities to vulnerable groups of the population. In the first case, it was about making higher education more accessible to young people with disabilities. The second case concerned people with rare (genetic) diseases and their obligation to undergo repeated socio-medical examinations to confirm their disability status. This practice was long considered meaningless and had not been changed for a long time.

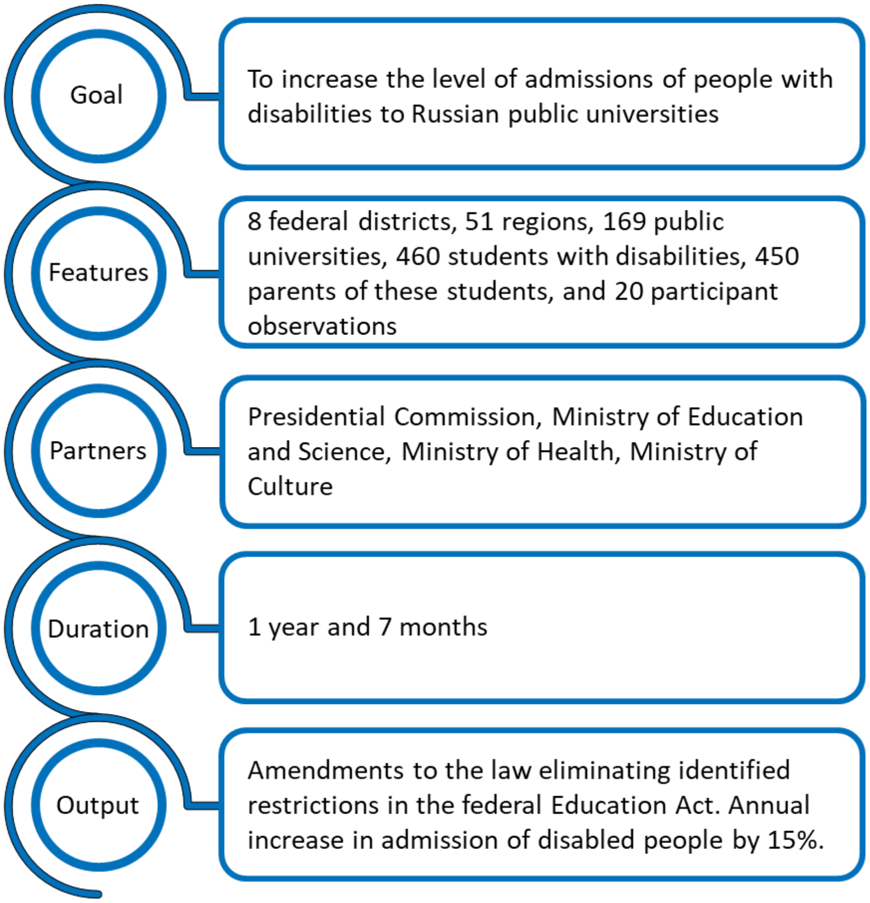
In both cases, the authors were tasked with conducting research and collecting evidence, enlisting the support of experts, engaging stakeholders such as patient organizations or organizations of people with disabilities, engaging journalists and civil activists for advocacy, and, finally, defending the findings and convincing officials and politicians change legislation.

In both cases, the relevant legislation was adapted either through changes to federal law or through the issuance of corresponding government regulations. Notably, in both cases, the researchers convinced statutory officials to go further and continue to monitor enforcement practices by creating a feedback loop and collecting data for a year after the new legislation was passed. The latter played an invaluable role in developing guidelines, adapting local governments to comply with these rules, and monitoring consumer service experience.

## Descriptions of cases

In the first case, the Research Center “Minority Report” was tasked with finding the reasons for the low level of admissions from people with disabilities to Russian public universities (ANO "NITs “Osoboe mnenie”, 2017a) (Fig. 1). In this regard, it would be worth recalling that higher education in Russian public universities is free. Russian federal legislation provides a 10% quota for people with disabilities along with other groups of underserved people. The Russian Ministry of Education and Science considers applications from all these categories separately. Researchers had to find out why people with disabilities did not seek to enroll in public universities and did not fill the quota and suggest ways to improve the situation.

The study found that the federal education law had two restrictions that public universities strictly adhered to. These restrictions prevented people with disabilities from submitting applications to multiple universities simultaneously. The researchers presented their findings at the All-Russian Forum of University Rectors. Then the results were discussed at interdepartmental meetings of the Ministry of Labor and Social Protection (Ministry of Labor) and the Ministry of Education and Science. This case was special because many stakeholders would have preferred to maintain the status quo. For example, some of the most powerful rectors of major public universities had gone out of their way to avoid making changes. The reason was that if the number of disabled students increased, universities would be required to provide an accessible environment and appropriate equipment, which, in turn, would require large expenditures from the university budget.



| | |
|---|---|
| Goal | To increase the level of admissions of people with disabilities to Russian public universities |
| Features | 8 federal districts, 51 regions, 169 public universities, 460 students with disabilities, 450 parents of these students, and 20 participant observations |
| Partners | Presidential Commission, Ministry of Education and Science, Ministry of Health, Ministry of Culture |
| Duration | 1 year and 7 months |
| Output | Amendments to the law eliminating identified restrictions in the federal Education Act. Annual increase in admission of disabled people by 15%. |

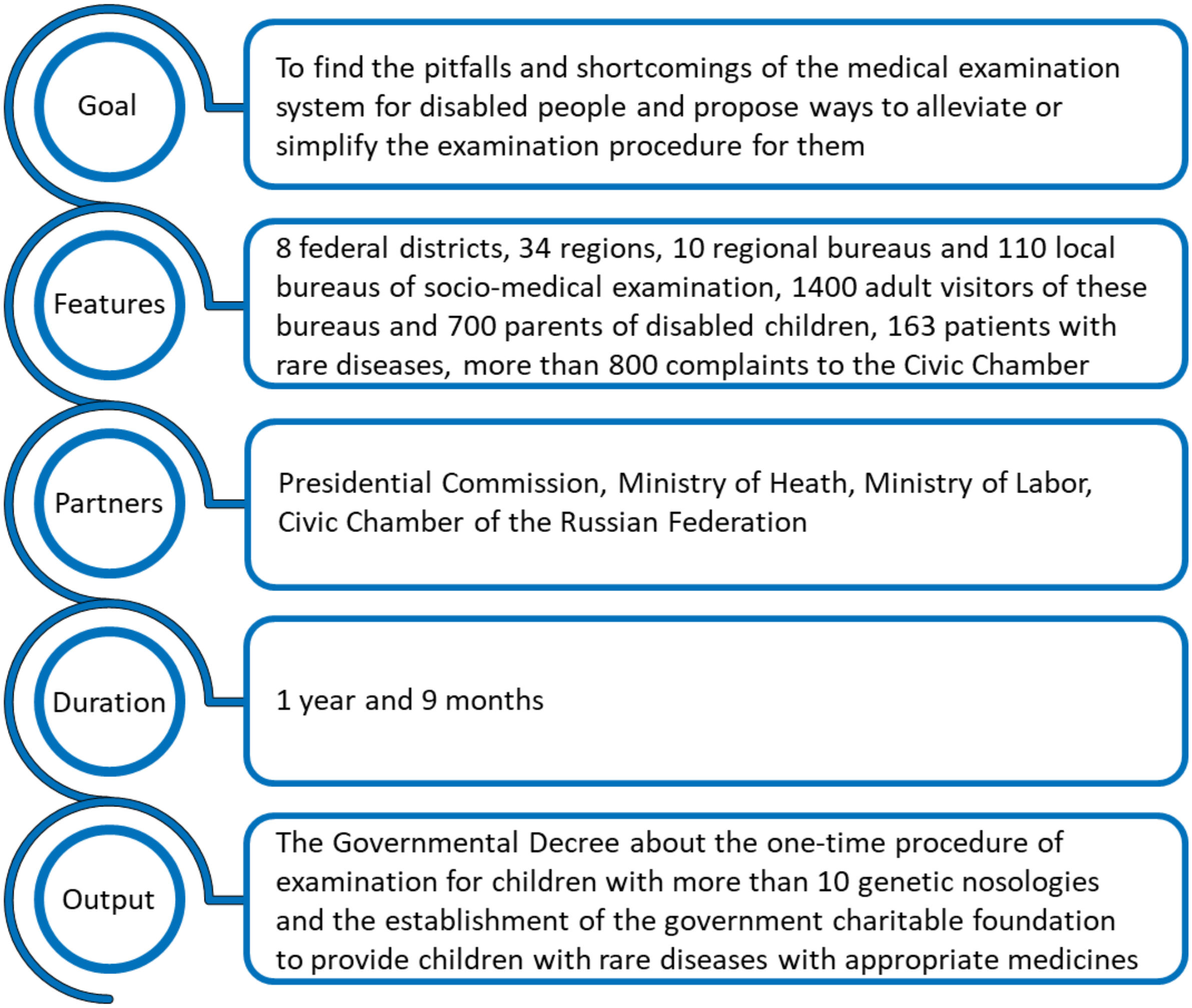
Fig. 1. Case 1 description.

Eventually, by adopting amendments to the relevant law through a vote in the Russian parliament (Ofitsial'nyy internet-portal pravovoy informatsii, 2018b), these restrictions were removed. Significantly, only 19 months passed from the presentation of our findings to the signing of the law. Subsequent monitoring of the admission of people with disabilities to universities revealed an increase in the number of applicants by 15% annually.

The second case was more complicated and involved people with rare (genetic) diseases (ANO "NITs “Osoboe mnenie”, 2017b, 2018). This requires a little more explanation. The fact is that most drugs for people with rare diseases are extremely expensive. They cannot afford to buy them themselves and are forced to rely on government supplies. However, to be eligible to receive appropriate medications, the patient must be officially recognized as a person with a disability.

Each person expected to receive such special status is supposed to be subject to certain procedures by designated federal authorities. The system of these federal authorities, which constitutes a multi-level network throughout the country, is extremely complex and cumbersome. To talk in detail about all the difficulties and pitfalls would be a long off-topic story. As an example of the confusion, it is enough to note the fact that the Ministry of Labor oversees the entire system. At the same time, referrals for socio-medical examinations are mainly carried out by hospitals and clinics, which are part of the healthcare system under the jurisdiction of the Ministry of Health. Another annoying problem was that people with rare (genetic) diseases and other obvious disorders that could not be cured were forced to get examined every year or every two years. It is worth adding that at the time of the implementation of our research project, national neonatal screening had been carried out throughout the country for more than 10 years, making it possible to identify major rare diseases.

The researchers were expected to find the pitfalls and shortcomings of the system and propose ways to alleviate or simplify the socio-medical examination for such a group of people (Fig. 2).



| | |
|---|---|
| Goal | To find the pitfalls and shortcomings of the medical examination system for disabled people and propose ways to alleviate or simplify the examination procedure for them |
| Features | 8 federal districts, 34 regions, 10 regional bureaus and 110 local bureaus of socio-medical examination, 1400 adult visitors of these bureaus and 700 parents of disabled children, 163 patients with rare diseases, more than 800 complaints to the Civic Chamber |
| Partners | Presidential Commission, Ministry of Heath, Ministry of Labor, Civic Chamber of the Russian Federation |
| Duration | 1 year and 9 months |
| Output | The Governmental Decree about the one-time procedure of examination for children with more than 10 genetic nosologies and the establishment of the government charitable foundation to provide children with rare diseases with appropriate medicines |

Fig. 2. Case 2 description.

Our findings were presented and generated lengthy heated discussions at several intergovernmental sessions. The issue drew the attention of plenty of stakeholders and got more complicated due to participants from various patient organizations with different issues regarding medicines, disease profiles, treatment protocol, and level of curability. This wide outreach and participation has led to several government initiatives as well as challenges, some of which remain to be resolved.

All in all, positive outcomes of this activity included the Governmental Decree of 2018 about a one-time socio-medical examination of children with more than 10 genetic nosological groups (Ofitsial'nyy internet-portal pravovoy informatsii, 2018a) and the creation of a state extra-budgetary fund to provide children with rare diseases with appropriate medicines (Prezident Rossii, 2021).

### Stakeholders and partners

As both research projects unfolded and included outreach activities, the project team was able to attract more and more participants (Fig. 3). The initial partners of the projects were civil activists and organizations of people with disabilities or patients with genetic diseases, in particular cystic fibrosis. These organizations played a role not only as key stakeholders but also as network respondents for our research.

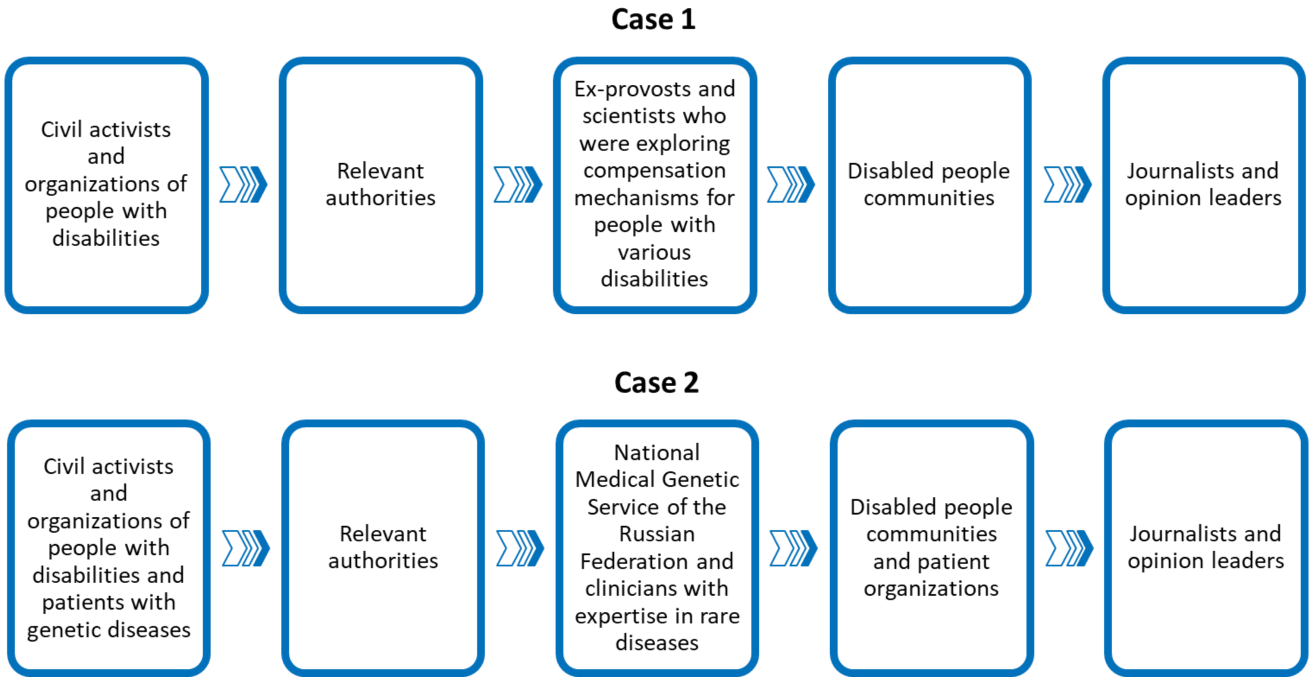


Fig. 3. Stakeholders and partners

In both cases, the authors managed to attract the participation of officials from the Presidential Commission, who were impressed by the scale of the problems and the possibilities of reducing projected budget expenditures and/or possible preferences for the federal budget.

Regarding the first case, we were unexpectedly supported by former rectors and scientists who studied compensation mechanisms for people with various types of disabilities. In the second case, we received strong support from the National Medical Genetic Service of the Russian Federation and doctors specializing in rare diseases. Later, several more disability communities and patient organizations joined us. The latter was extremely useful, since there were not many patients with rare diseases. They played a huge role in motivating officials to find a suitable solution. Finally, the project team managed to attract several federal journalists and initiate publications in federal newspapers (Allenova, 2017, 2018, Kretsul, 2017).

## Three-component project approach and special research methodology

Although these two cases varied greatly in terms of topics, problem context, key stakeholders, and possible solutions, both projects had two significant things in common. First and foremost, the projects relied on a three-component approach involving a strict sequence of actions: research, advocacy maintenance and outreach, and follow-up monitoring of law enforcement practice. Secondly, the research itself – the first component - was based on a specific methodology. This methodology allowed the researchers to fend off objections from officials, reconcile the warring positions of consumers and service providers, and delve deeply into the essence of the problem, capturing its context through personal experience.

### *Special research methodology. First component.*

To investigate such kinds of issues, the research center "Minority Report" has developed its own methodology, which boils down to three mandatory methods, performed in a certain sequence and including several suitable adjustments. The methodology includes, firstly, a survey of peer officials in different territories identified as service providers, and, secondly, a survey (questionnaire) of consumers. In this regard, researchers provide two or three common parts in both questionnaires to compare two perspectives—the service provider's and the consumer's—on the same issues. The third mandatory method is the most time-consuming but at the same time the most informative – so-called participant observation, but in an extended fashion. For example, in the first case, we found 20 people with disabilities who were ready to go through the entire process of entering a university: from choosing a university and checking for transportation difficulties along the way to submitting an application to the

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chosen university in person. At the same time, our researchers acted as guardians or proxies if they received appropriate permission. It is worth noting that, contrary to the generally accepted requirement in research not to interfere, the researchers were directly involved in discussions and meetings, often initiating them to understand the positions of both sides and focusing on the evidence they witnessed.

In the second case, our researchers accompanied 23 mothers and children through the socio-medical examination cycle, without, of course, going beyond the appropriate level of privacy and confidentiality that had been determined in advance. Most of the results were related to interactions between consumers and service providers along with customer usability. Undoubtedly, such extensive participant observation required lengthy and thorough preparation, careful prior interaction with participants, and immersion in the entire study.

It should be emphasized that although the surveys/questionnaires in both cases allowed us to assess various aspects of the interaction between clients (both patients and applicants) and service providers (university staff and authorized bodies), extended participant observation enabled us to better understand the discrepancies, monitor the way of communication and – what was especially valuable – to gain personal experience. This third method, which aimed to test each of the two perspectives has helped provide the study with a third, objective perspective from independent researchers. In addition, it should also be noted that one of the main requirements was to visit the same places (universities or socio-medical examination centers) where official representatives had previously participated in the surveys.

### ***Advocacy maintenance. Second component.***

All meetings, at which the results of the study were presented, were devoted to finding optimal solutions that meet both administrative requirements and the expectations of patients and disabled communities within the relevant legal framework. Thus, both parties - service providers and consumers - were involved in finding solutions. We also tried to cover the most significant cases in the media and social networks, using different genres: from interviews to analytical articles.

### *Following-up monitoring. Third component.*

From our perspective, in no case should monitoring of law enforcement practices be considered excessive. The authors faced a common problem: any bureaucratic system requires time and detailed guidance to adjust changes. We have agreed with patient organizations to alert their members to keep us informed. To do this, we simultaneously opened two hotlines: one in the Ministry of Labor and the other in the Civic Chamber of the Russian Federation (Civic Chamber). On top of that, since we did not have the right to officially consider complaints and claims due to limited access to personal data, we agreed with the Ministry of Labor to collect all evidence related to the complaints and send them to a specially created working group within the Ministry. Each complaint was to be verified and a formal response was to be provided within 30 business days. Notably, the responses were duplicated: they were sent to an applicant/a claimer, the Civic Chamber, and the appropriate appointed officials. Every three months meetings were held with the participation of the Ministry of Labor, the representatives of the Presidential Commission, patient organizations, the Civic Chamber, and the researchers. The overseeing procedure carried out during the year made it possible to satisfy 20% of complaints and ensure that local officials complied with new changes in federal legislation.

## Conclusion

The projects described cannot be called lobbying; rather, they were supported by the state. For starters, the relevant government agencies joined the projects but did not initiate them. In addition, government agencies had different, sometimes conflicting, positions regarding possible changes to the appropriate legislation. Moreover, from their bureaucracy's point of view, it would be better not to make changes at all.

It is safe to say that the projects ultimately led not only to the adoption or improvement of relevant legislation but also to the elimination of most frictions, including interdepartmental ones, in the subsequent application of this legislation. Overall, both projects included three sequential objectives and three interrelated components (Fig. 4), as outlined in the previous section, namely:

- To find, identify, and escalate the issue. To do this, the research is supposed to be done. In addition, the results must be presented and discussed publicly.
- To develop acceptable solutions and adopt effective legislation. To achieve this, it is supposed to gain strong support from inner and external stakeholders, which will help reduce bureaucracy resistance.
- To implement new/updated legislation smoothly and seamlessly. This can be achieved by monitoring over an appropriate period by analyzing feedback and resolving relevant complaints on a case-by-case basis to eliminate inconsistencies and demonstrate possible ways forward to local officials.

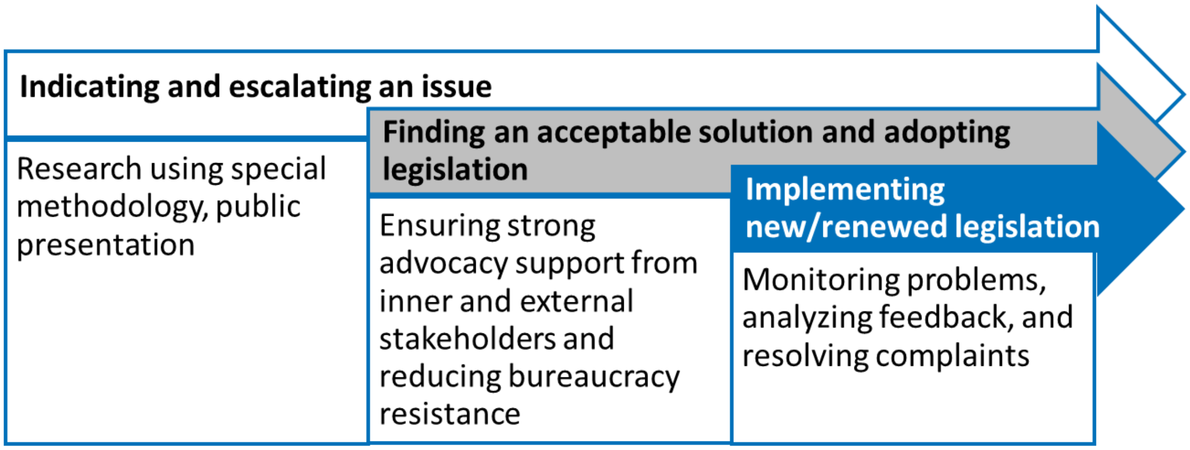

Fig. 4. Three-component project approach.

To sum up, the authors argue that such a three-component approach with special methodology inside the first “research” component allowed us to work out more thought-out legislation and then by focusing on its enforcement practices eliminate shortcomings and make it more mature and well-developed.

Undoubtedly, it would be immature and ridiculous to suggest that this approach might be applied to the entire scope of legislation, and the authors by no means insist on a one-size-fits-all application of the approach. From the authors’ perspective, it can be applied primarily in cases of social significance, if the legislation is too controversial, affects several government agencies, and concerns minors, vulnerable, or low-income groups of the population who cannot effectively protect or advocate their interests on their own. However, the direction and extent of applicability of the three-component approach as well as the special research methodology presented in this paper, remain to be determined.

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