STRONGER ROOTS

PLATFORM OF FAMILIES OF CHILDREN WITH DISABILITIES:
WHEN STORIES CHANGE THE SYSTEM

How an organisation for families of children with disabilities used the power of personal encounters to build alliances

Nadace OSF · Nadácia otvorenej spoločnosti · NIOK · glopolis · Batory Foundation

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Photo: Antoni Shkraba

Platform of Families of Children with Disabilities

The Platform of Families provides expert support to families of children with disabilities, drawing on the lived experiences of its members. It also connects them with professionals and other supporting civil society organisations. At the same time, it advocates for the rights of these families at both national and regional levels and strives to raise public awareness of disability-related issues and the inclusion of people with disabilities in everyday life.

The organisation employs a total of 16 people (approximately 10 full-time positions) and works with 45 volunteers who act as peer counsellors – parents supporting other parents of children with health disadvantages.


Photo: Antoni Shkraba

The challenge of invisibility

Although the Platform of Families is a strong initiative, its regional reach was insufficient, and too few families of children with disabilities or relevant professionals were aware of its activities. It was during the implementation of the Stronger Roots project that the organisation also launched four regional centres. These centres began organising community and leisure activities as well as support groups for families of children with disabilities. However, regional teams needed to strengthen their position and visibility.

Therefore, a key goal of the Stronger Roots project was to raise awareness about the organisation and its services among families of children with disabilities as well as the professional public, while also improving coordination of support services provided. Another important aim was to diversify funding sources by engaging corporate and individual donors.

After the initial preparation of the communication strategy – defining the target groups, the communication channels, and key messages – the Platform of Families expanded its presence on social networks. It created a profile on LinkedIn to reach potential donors and provide a clear overview of its work. Regional centres created their own Facebook pages, which the local teams gradually learned to manage independently. These pages focused on local content, leading to increased engagement among community audiences and a broader diversity of topics.

Another important step was to process the existing contact database, making it usable for regular newsletter distribution. This had not been possible for a long time, mainly due to technical and personnel limitations, which meant that an important communication channel remained unused. The newsletter has gradually been diversified and is now delivered according to topics, recipients or regions, so that each group can receive content tailored to its specific preferences.

Stakeholder mapping as a foundation

The next step was to deepen and expand personal relationships in the regions through community meetings. These events brought together families of children with disabilities, schools, local authorities, and other key partners. Guests were selected based on the Platform‘s existing contact database, built from years of experience and outreach.

From among numerous stakeholders, those with the greatest influence on the lives of families and who also demonstrated openness to inclusion were invited. Representatives of potential corporate donors were also included.

Photo: Platforma rodín – Campaign visual

The Living Book: A method that works

The meetings were called Talks on Inclusion and used the Living Book methodology – authentic and personal sharing of the story of a specific family with a child with a disability. Participants were able to ask questions they might not dare to ask in a formal setting.

“The Living Book isn’t just anyone telling their story,” explains Monika Fričová. “It needs to be a parent who can share their experience without becoming overwhelmed emotionally, or who is able to manage strong emotions if they arise. The storytelling part lasts around 15 minutes and is followed by 20–30 minutes of open questions.”

Knowing the audience allowed storytellers to incorporate moments into the story that the listeners could relate to and that could strengthen their empathy and experience, thus motivating them to become more involved in helping families with children with disabilities.

This method helped bridge the gap between families and influential stakeholders, creating a space for joint planning of future initiatives. As a direct result of these events, several follow-up meetings were held.

‘One of our events was attended by the director of the education department at the city council, who is responsible for dozens of schools. As a result, we organised five more meetings between school principals and families with children with disabilities who wanted to place their children in mainstream classes,’ says Monika Fričová. Feedback from participants showed that the meetings left a strong impression on them and gave them a greater sense of personal responsibility.

„We often saw that people had been doing this work for years, but without any direct contact with families with children with disabilities. They only have brief formal meetings with them and perceive them as numbers in statistics and reports. Suddenly, these numbers turned into real stories, and that brought a lot of new awareness.“

Monika Fričová

Photo: Yan Krukau

Specific Team Challenges

The Platform faced fluctuations in team capacity – up to 95% of its employees and volunteers are parents of children with disabilities. This means limited availability, more complex coordination, and varied skill levels. When the project entered its implementation phase, it was difficult to maintain the quality of work without disrupting team relationships.

What helped was intensive support, guidance on new tasks, and intentional capacity-building efforts – especially the connection between the central office and regional teams, and the transfer of know-how.
After a challenging start, employees gained greater professional confidence and took over most of the activities. Today, the regional centres operate much more confidently and independently.

"When we finish a job, team members now actively ask for feedback and a debrief. They no longer wait for evaluations with fear – they've become more independent and have a more realistic view of themselves. They know that what they're doing has value – and that's the most important thing," says Jana Lučeničová.

KEY FINDINGS

- **Personal contact breaks down barriers**
  Working with potential supporters in person brings much better results than remote communication.
- **Emotions and lived experiences are more powerful than facts**
  When sharing information, it is crucial to convey it through experience and emotions, not just data.
- **Simplicity and intensity in communication**
  Communicate simply but frequently – regularity and consistency are important.
- **Specialisation brings better results than diversification**
  It is better to do one thing well than seven things poorly.

PRACTICAL RECOMMENDATIONS

01

Team capacity must be carefully planned, adjusted and continuously monitored

It is equally important to create space for the team to not only fulfil the tasks assigned to them, but also to grow professionally.

02

Create a stakeholder map

Systematically mapping key players in your region will help you target your activities more effectively. Focus on those who are already ‘on board’ - you will use your energy more effectively than by trying to awaken the disinterested.

03

Use the Living Book method

Personal stories are more powerful than presentations – but make sure the storytellers are prepared for the experience.

04

Learn from other organisations

There is a lot you can learn from others – it is always good to share and learn from those who are more advanced, but also from the mistakes of others. When focusing on performance, we often miss the potential of sharing experiences with other non-profit organisations.

STRONGER ROOTS

This case study was developed within the Stronger Roots program.

The aim of the Stronger Roots program is to increase the resilience of civil society organisations and their networks, strengthen their social capital, and integrate them into the communities and societies in which they operate. The program is implemented by the Open Society Fund Prague, the NIOK Foundation, the Open Society Foundation Bratislava, and Glopolis.