

Challenging institutional stigma

Many of the problems faced by people with epilepsy are resolved by accepting and learning to deal with the condition, and by educating families, neighbors, and friends about the realities of epilepsy. However, overcoming self-stigma and interpersonal stigma is often not enough to break through the barriers preventing people with epilepsy from getting the medical care they need, accessing education, finding fulfilling employment, and participating in many aspects of community life. For society to recognize that people with epilepsy have the same rights as people without epilepsy, we all have to challenge the harms caused by institutional stigma and discrimination.

Schools should not teach stigma

Engaging educational and community leaders in epilepsy education projects is a good way to ensure programs and policies that benefit children with epilepsy will continue. When school teachers, principals, administrators, and local politicians have some direct exposure to projects, they can speak up within school or government bodies about the importance of making schools work for children with epilepsy (see “Build trust and allies,” page 154). Invite them to visit or participate in your efforts so they will support and make permanent programs that challenge stigma and discrimination in the education system.

From stigma to science: Teachers learn about epilepsy

For many years, schoolchildren with epilepsy in the Indian city of Mumbai did not have their teachers’ support. Many teachers believed that a child with epilepsy was cursed or controlled by an evil spirit, or that seizures were a sign of laziness or lack of focus.

The epilepsy advocacy group Samman Association decided it was time to change these harmful ideas, fight stigma in the classroom, and bring epilepsy education to classrooms in their city. They launched a pilot epilepsy education program with middle school and high school teachers. It included a talk about epilepsy from a neurology (brain health and medicine) specialist, followed by a person with epilepsy sharing their experiences, and ending with a question-and-answer session.

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From stigma to science: Teachers learn about epilepsy *(continued)*



Encouraged by the positive response, Samman expanded the program to reach 250 teachers in 12 schools within a few months. Then they approached the city leaders with a proposal to train teachers at every public school to recognize, support, and advocate for children with epilepsy.

Their project was approved just as the global COVID-19 pandemic forced schools to close. So Samman adapted their program to an online format with Zoom talks and WhatsApp groups where epilepsy information was shared, questions were answered, and harmful ideas were challenged.

The program reached 7,000 teachers in a year and a half, helping them to identify seizures (including an understanding that absence seizures are not the same as daydreaming), provide safe first aid (no spoons in mouths during a seizure!), and speak out against bullying of children with epilepsy. Through follow-up surveys, Samman found the program had succeeded in reducing stigma and improving education for children with epilepsy.

Advocacy to improve laws and policies

When people get their governments and health institutions to make laws and policies that recognize epilepsy as a disability, provide access to affordable medicines, and recognize everyone's right to housing and employment, people with epilepsy are more likely to be treated with dignity, equality, and respect. If enforced, laws protecting people with epilepsy can hold people and institutions accountable for discrimination and prevent further mistreatment.



When you compare these goals to current conditions, they may seem like wishful thinking, but taking steps to get there over time is very realistic. By speaking up, organizing, and working together as a community, you can begin to advocate for changes in laws and policies, so they better support human rights.

HOW TO**Start a policy advocacy campaign**

Identify a problem to work on. Talk to people with epilepsy, their families, health workers, parents of children with epilepsy, teachers, and others in the community to understand how institutional stigma and discrimination affect people.

Work together to clearly identify the issue you want to change. For example:

- Are people with epilepsy denied the right to marry?
- Do mothers with epilepsy lose custody of their children after divorce?
- Are children with epilepsy kept out of school?
- Is epilepsy left out of disability rights laws?
- Are antiseizure medicines not covered by national health insurance?
- Are people with epilepsy not allowed to work?

Then, find out exactly what the laws say about these issues in your country. This information may be found on government websites, in libraries and public databases, or with help from lawyers, government officials, or advocacy organizations. Look for specific laws related to epilepsy, disabilities, education, employment, and discrimination.

Discuss what you find with the people you have spoken with already. As you narrow your focus to the issues that interest most people, organize them to take the next steps in the campaign you are getting off the ground!

Decide exactly what you want to change. Write down your goal. Be clear and specific. For example:

- Change existing marriage laws so epilepsy cannot be used as a reason for preventing or ending a marriage.
- Ban housing and employment discrimination against people with epilepsy.
- Enact a policy that requires training teachers to safely respond to seizures and support children with epilepsy in schools.
- Get the health ministry to include antiseizure medications in a list of essential medicines that should be included on the national health insurance list.
- Change disability laws to recognize epilepsy as a disability.

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