

If this school hadn't worked, we would have had to move.

Family members fighting for good education for all

Part 4 in a series of essays
By Inge Volleberg



“We began with specialised schools. Throughout the entire process, we had no guidance from anyone. It was all trial and error, asking around, and often making decisions based on information that later turned out to be inaccurate. And of course, **it’s the children who pay the price for those mistakes**. You have to manage everything yourself.” – parent, Belgium

Parents are making the difficult decision of where to send their child to school, not knowing if their child will get the support they need.

Parents are trying to get a hold of their child’s teacher to know what is happening at school, because the child cannot tell them.

Siblings are rushing to get to school in time because they needed to help their brother or sister at home and it took longer than anticipated.

Every child goes to school, right? Education is compulsory in all European countries after all. And most children just go to the nearest school in the neighbourhood.

It is not so straightforward for children with intellectual disabilities.

Is the local school inclusive and does it offer the right support for them?

Are assistants available to provide support where needed?

Is the special school further away more reliable in some sense?

Our Inclusion Indicators show that around 900,000 children with intellectual disabilities go to mainstream schools, 640,000 children with intellectual disabilities go to special

schools, but also that 24,000 children with intellectual disabilities do not go to school at all.¹

Even if children go to mainstream schools, the quality of education is not guaranteed.²

Parents have a hard time figuring out what is best for their child: to go to a mainstream school with the kids from the neighbourhood but where they might not get the support they need? Or to go to a special school which seems to provide more support, but the school is far away and segregated from other children?

Even after choosing a school, parents are constantly fighting for more information about their child's progress and for better education for their child.

At the same time, siblings face other challenges. They struggle to combine school with the care at home for their brother or sister, similar to how parents struggle with balancing work and care (you can read more about that [here](#)). Siblings can also have a hard time at school because of the situation at home, and getting very little understanding from teachers.

This is the fourth essay in a series on the lived realities of parents and siblings of children with intellectual disabilities. It's focused on how parents have to fight for good education for their child, and how siblings struggle at school because of the situation at home.

¹ [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

² [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

In this series:

- **Introduction:** [What parents and siblings of children with intellectual disabilities face every day.](#)
- **Navigating a complicated care system:** [If you don't know how to navigate the system than you are lose and your child is too.](#)
- **Financial hardships:** [The financial situation of the whole family is affected.](#)
- **Fighting for a good education** for their loved one with an intellectual disability, and balancing school and care.
- **Struggling with mental health and wellbeing** and neglecting their own needs.

To help us tell these stories, we spoke with 9 parents and 6 siblings from 10 European countries. The parents told us about their lives with a child with an intellectual disability and complex support needs now, and the siblings looked back on their childhood. We are grateful they shared their time and experience.

Choosing the right school

In most European countries, when a child turns 4, 5, 6 or 7, they go to school. Parents enrol their child in their neighbourhood school. Before you know it, they run into the classroom with all their classmates.

For parents of children with intellectual disabilities, this is not so straightforward. The local school often does not (automatically) offer the personal support or adjusted curriculum their child needs. Personal assistance of some sort might be available after request, but it all depends very much on the school and national policies.

“In his current class, there are five or six children with autism and only one teacher. **It isn't the teacher's fault, but this is why we are considering a special school for next year.** We are scared about it, because he doesn't speak at all.” – parent, Albania

There is also another option: special education schools. Special schools, on paper, offer more support and an alternative curriculum. But special schools are segregating children with disabilities from all other children. They are also often farther away and children have to travel long distances to get to school.

“Germany's system separates every type of need, but you can't always separate special needs in real life. In theory, my son could attend a mainstream school with an assistant, but there are so few teachers that even the regular classrooms are overloaded. You can imagine what happens then: a teacher who is already overwhelmed cannot meaningfully include a child with complex needs. In the end, the special school he attends now was the only realistic option nearby. Families travel 70 kilometres or more to reach it. **If this school hadn't worked for him, we would have had to move.** For now, we are happy, but if things change, our only alternative might be relocating to a larger city.” – parent, Germany

Sometimes parents choose special education because of the costs. Sending their child to a special school can be cheaper because it includes therapies that parents would otherwise have to cover themselves.³

At Inclusion Europe, we always advocate for inclusive education⁴. Schools where all children can learn together with the support they need. In many countries mainstream schools are not inclusive, and parents make the difficult choice to send their child to a special school instead. All schools need to be inclusive, so that parents do not have to make that kind of decision again.

Every day a parent is comparing different special schools, because even that route is not straightforward.

When parents decide to leave mainstream education behind, a new set of questions pops up. There are often many differences between special education schools. Especially for parents of children with complex support needs, it can be difficult to find the school with the best fit. One school focuses more on intellectual disabilities and offers a different curriculum, another school focuses on sensory disabilities, yet another one also offers physical therapy.

³ As can be seen in: [Decision on the merits: International Federation for Human Rights \(FIDH\) and Inclusion Europe v. Belgium: Complaint No. 141/2017, para 101, 179](#)

⁴ [Why we care about education, Inclusion Europe, 2021](#)

“The decision to send my son to a mainstream school for children with visual impairments was based on our doctor’s advice, and the adapted materials there helped him enormously. **Without that guidance, navigating the school system would have been extremely difficult.**”

– parent, Lithuania

You would also hope that special schools offer the individualised support your child needs. This is not always the case; even though special schools claim to offer more support than mainstream schools, that does not mean that the support gets adjusted to each child. This is challenging specifically for children with complex support needs or who are non-verbal.

“In the francophone system, there is a strong expectation that the child must adapt to the school, not the other way around. There was no real effort to understand his situation. They didn’t ask how he eats, how he communicates, or what support he needs. My son is non-verbal and communicates by typing on a keyboard, with someone holding his hand to stabilise it. Yet no one took the time to learn how to assist him with that. **There was no preparation, no understanding, and no willingness to adapt.**” – parent, Belgium

Every day a parent can sleep a little easier knowing their child goes to a school that fits.

It can be a tiring search for parents to find a good school for their child with an intellectual disability.

Where does my child get the support they need? Which school fits best? What should we prioritise in making this decision?

Sometimes the answer is unexpected, for example when a parent finds the right fit for their child at a private international school with personal assistance:

“Given the options available in Belgium, this school works for us because it offers a healthy environment. These private schools are usually international, with children from all over the world rather than only Belgian students with one specific way of doing things. The diversity means the children all look different, speak different languages, and come with different backgrounds. **He was accepted by the other children, and that has made a real difference.**” – parent, Belgium

Finding the right school for your child can feel like an enormous weight is lifted from your shoulders. You know your child will go to school tomorrow, and hopefully for many more years to come, will get the support they need.

But this is not the case for all children with intellectual disabilities. At least 24,000⁵ of them are not going to school at all. Imagine there isn't a school, mainstream or special, that has a place for your child.

⁵ [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

What is going on at school?

Every day, a parent is writing another e-mail to their child's teacher asking for some information on what is going on at school.

When they get home, most children tell their parents what they did at school, what they have learned, with whom they played. If parents have a question, they quickly walk into the school at pick-up and ask if the teacher has a minute to discuss something.

But with children with intellectual disabilities, it can be more difficult to get information. The child might not be able to tell about what happened at school.

"A bus picks him up at our home and brings him back in the afternoon, so **I have no direct contact with his teachers**. That makes things complicated. The only communication tool is a notebook where I can write questions, sometimes the teacher responds, sometimes she doesn't. Because he speaks very little, I rely entirely on what the school tells me. **I often feel I have to fight just to get basic information, since he cannot come home and tell me what he did all day.**"–
parent, Germany

Having so little information on what is happening at school means that some parents have to trust that all is going well or the school will let them know. During our conversations, one parent said they realised very late that something was wrong at school.

“When I started looking more closely at the kind of education my daughter was actually receiving, I was shocked, depressed, and hopeless. They had always told me she was the best in the class, so I had no reason to question anything. For 17 years, I focused entirely on my daughter’s physical rehabilitation. **Looking back, I realise how much I missed, especially her schooling.** Now we are facing problems because they say she is not able to continue her studies.”- parent, the Netherlands

Schools not doing their job

Children go to school to learn, to develop their talents, to gain new skills. Sadly, some schools either forgot, or decided that children with intellectual disabilities are not worth the effort.

Every day, a parent learns that a teacher has given up on their child.

Some parents reported that they discovered their child was not doing much at school. They were not learning new things. They were simply not being taught.

“The reason we decided to leave was that there was no real education happening. They had assured us that academics were part of the programme, and they knew this was our priority, not therapy. But as we kept asking questions, we realised we had no idea what he was doing in class. They said they didn’t give homework because the children ‘did enough at home,’ which meant we saw nothing. **Eventually, it became clear that they were not teaching anything at all.**” – parent, Belgium

Every day a parent has to fight for bare minimum support for their child.

For example, one parent said that the school failed to make tests accessible to their child. As a result, the school could not know how the child was actually doing and support them accordingly.

“The school programme has held her back. The tests are difficult to understand, English is not explained, yet her IQ is measured through it, and the books use print that is too small for her to see. She has no real teacher and no interactions with her classmates, instead she sits isolated with her headphones in class. **They are testing these children’s IQ without even explaining the test to them.**”- parent, the Netherlands

Other examples show schools that refused to provide support in one way or another.

"For years, we didn't have an individual educational plan, although it is a legal obligation. The school kept pushing back, saying 'we need to know her first, it's difficult.'" – parent, Belgium

"My son never received a social worker at school because, they say, 'they must help people with difficult families who need it more than your son'." - parent, Lithuania

Every day a parent worries that bad education is taking away their child's future.

Many children with intellectual disabilities receive bad education. Either because they cannot find the right school for them, because the school does not share what is going on, or because the school is failing to teach in an accessible and effective way.

The lost potential for these children is enormous. And many parents are sad when they wonder what their child could have accomplished under better circumstances.

"Sometimes I think of what my daughter could have been like if she had been in a normal environment, with more stimulation and development." - parent, the Netherlands

Family members becoming teachers

Because many children with intellectual disabilities receive bad education, their family members step up and try to fill the gaps that the school leaves behind.

Every day a sibling gives it another shot to teach their brother or sister a new skill.

They can take on this role slowly over time. For example, siblings playing together, first as equal playmates. But as they grow older and differences increase, the dynamic can shift towards one teaches and the other learns.

“At first, when you are close in age to a sibling with an intellectual disability, you play together like any other children. They feel more like a friend than anything else. But as you grow older and your interests mature, something shifts. You keep playing with your sibling, but it becomes clear that you are doing it for their sake. **It starts to feel less like shared play and more like taking on the role of a teacher or a parent; supporting them rather than genuinely enjoying the same things.**” – sibling, Ireland

But taking on a teaching role can also happen suddenly. When a family member notices that school is failing and takes it upon themselves to help their loved one reach the next milestone.

“As we grew older, I began to realise how inadequate his schooling was; he would spend his time filling textbooks with words containing the letter M, even though he could read the newspaper at home. I **started giving him lessons after school.**” - sibling, Sweden

Parents and siblings often take on these teaching roles out of necessity, because others are not doing it. This is another big responsibility on the shoulders of family members who receive little support and recognition.

“We are not supposed to be the children’s teachers. We are supposed to be parents like all parents, and maybe we need a little more support than this”. – parent, Belgium

Support at school for the sibling

So far we described the situation of children with intellectual disabilities and their education. But, their siblings are going to school as well, often at the same time.

Siblings have a different situation at home compared to their peers. They often help out in the care and support for their brother or sister, they worry about them, and receive less time and attention from their parents.

All of this can affect them at school. School is where they spend a big part of their day. School is also the spot where they could get and need extra support.

Every day, a parent worries if their child is having a hard time at school because of the situation at home.

Many parents try to go to the school and explain to them the situation at home and to see if their child can get a little bit extra support. Support can look like: having a discussion about disability in the class and explain how some families are different than others.

“I have to manage everything myself because my son receives no support in this area. I even have to write to his teacher to remind her that he has a brother with a disability and to check whether this is ever discussed in his group. I’m not at the school, so I don’t know what happens, and **I don’t want him coming home one day saying that other children laughed at him because his brother cannot speak or looks different.**” – parent, Germany

Support can also look like giving the sibling more flexibility and time. This can help them balance the care and support they provide at home with what they have to do at and for school.

Every day, a sibling learns the hard way that there is no one to support them.

“I had no support from my school. When I was 16, my mum informed them about my sister’s diagnosis and the fact that my dad was not around, but they offered nothing. They even refused to let me do transition year, despite my mum advocating for me. **That experience taught me not to expect support at all.**” – sibling, Ireland

Siblings often receive little to no support at school. None of the siblings we spoke with had gotten any support. For some siblings, school refused outright even when support was requested, like the quote above shows. While other siblings simply slipped through the cracks, because they had good grades or because they were quiet.

“Looking back as an adult, I am amazed that no one in the school system, the municipality, or any of the other places who saw me regularly, ever approached me about my experience as a sibling. **No one asked how I felt or whether I needed support.** All they saw was an able child who did well academically and in sports, and that was enough for them.” – sibling, Sweden

Having trouble at school because of the situation at home

If there is little support or attention at school for the situation at home, siblings can start to struggle. They might not be able to keep up with their homework, pay attention in class, and receive lower grades as a result.

Every day, a sibling has to fight back tears on the playground.

But siblings can also struggle with their emotions, because they have difficulty processing what they are going through and what they feel. As a result, many siblings get bullied at school.

“When I was 12 or 13, during a period where my sister was going back and forth between home and psychiatric hospitals, **I was struggling to regulate my own emotions and became an easy target at school.** I was bullied.” – sibling, France

Conclusion

Every child has the right to good education.

Children with intellectual disabilities do too.

But their parents have to fight for them to actually get it.

Parents have to make difficult decisions on which school is the best fit for their child. Choosing between the local mainstream school which often does not offer the right support, or the farther away special school which has support but is also segregated from the other children.

Even after finding a school that fits, parents have to constantly fight to know what is going on at school, to make sure their child gets the support they need, and to guarantee that their child is being taught.

At the same time, siblings are struggling to balance school and the care at home. Many siblings do not receive any form of support from school, even though they need it.

Coming up next in the series:

- **Struggling with mental health and wellbeing** and neglecting their own needs.



**Ambitions.
Rights.
Belonging.**

**Working together to make Europe finally end segregation
of people with intellectual disabilities and isolation of their families.**

“If this school hadn’t worked, we would have had to move.”

Family members fighting for good education for all.

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