

Families should not have to carry everything alone.

Parents and siblings of children
with intellectual disabilities
on their every day

Full series of essays
By Inge Volleberg



Hundreds of children with an intellectual disability are born every day in Europe. There is a lot of love, joy and happiness – but also, the lives of their family members change. After learning your loved one has an intellectual disability, you gradually come to see the world differently – and you also realise that the world sees you and your loved one differently too. Sometimes this change is sudden, sometimes it takes years.

“As my sister is nine years older than me, it came slowly.

By primary school I realised there were things I understood that she didn't. **The older I got, the more I started to become aware of the lack of support and opportunities she got and I got frustrated with that.**” - sibling, France

However fast, that change is a reality for millions of parents and siblings of children with intellectual disabilities around Europe. Many were not familiar with intellectual disabilities until all of a sudden they were; they had to be.

Just like other families, they love and care for each other, joke around, and laugh together. But parents also have to navigate the complex system of medical diagnosis and healthcare, arrange support, fight for education... And deal with harsh comments from family members (and from complete strangers); with losing friends.

“Nobody cares. Our children are at home, and nobody sees them.

We go out with our children, we try to include them, but it is always us.

Society does not see them.

And because they don't see our children, they don't see us either.”

- parent, Germany

Siblings' lives change as well. They get less attention from their parents. They worry about the family and about their future. They have new, big responsibilities they did not have before.

“I was 13 when my sister was born. Because she was a newborn baby and my mom was working, my brother and I were already quite involved in the care. I think that if she had not had a disability, the high caring role would have lessened as she got older, but that's not what happened. Instead, it just stayed like that. I was there the day that she was diagnosed. My mom and I discussed getting her the assessment together. **And then I was at every appointment that I could be after that. I was really involved in her support, and the treatments that we would give her.**” - sibling, Ireland

This new reality of changed perceptions and new roles and responsibilities is what this report is about. We wanted to highlight the situation of parents and siblings of children with intellectual disabilities. That is why we wrote a series of essays that were published separately. This report combines these essays, so that you can find them all in one place. The essays cover how family members:

- **Navigate complex care systems to get the support and services they need,** and having to do it themselves when the system fails.
- **Financial hardships** in the family, and the difficulty of balancing work and care.
- **Fighting for good education** for their loved one with an intellectual disability, but also balancing school and care.
- **Struggling with mental health and wellbeing** and neglecting their own needs.

These were the main topics and issues that came up when talking with parents and siblings of children with an intellectual disability.

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.

Table of contents:

1	Introduction
4	Essay 1: “They don’t see our children. They don’t see us either.” What parents and siblings of children with intellectual disabilities face every day.
17	Essay 2: “If you don’t know how to navigate the system then you are lost and your child is too” Family members making sense of a complicated system to get the support they need.
29	Essay 3: “The financial situation of the whole family is affected.” Financial hardships: family members balancing work and care.
40	Essay 4: “If this school hadn’t worked, we would have had to move.” Family members fighting for good education for all.
55	Essay 5: “Nobody is really ok, even if they say they are.” Family members struggling with mental health and meeting their own needs.
71	Recommendations

Essay 1:

**“They don’t see our children.
They don’t see us either.”**

**What parents and siblings
of children with intellectual disabilities face every day.**

**Families should not have to carry
everything alone**

Most attention usually goes to the person with an intellectual disability – that is perfectly understandable and right. Often, it’s still not enough.

But their family members are overlooked while also struggling with inadequate support systems and society’s prejudice and discrimination. They too need support, and they deserve recognition for everything they do.

Family members of people with intellectual disabilities carry on the duties and responsibilities of a “typical” person. Parents go to work, care for their children and try to keep the household running. Siblings go to school, try to complete their homework and go out and play.

Then, there's the extra responsibilities coming from having a child with an intellectual disability in the family¹. A child they love. A child that needs more care and support. A child they worry about now and for the future. A child whose needs change the family dynamic, even if nobody wants that and even if they try to keep them the dynamic the same.

"We do everything ourselves:

the therapies, the coordination, the appointments, because we love our son. We want him to have the best life possible. But love should not be the only thing holding the system together.

Families should not have to carry everything alone."

- parent, Belgium

¹ Just to be clear: It's not the child with intellectual disabilities' fault! It's the result of inadequate support, of social stereotypes and discrimination against people with intellectual disabilities (and by association, their families).

Health risks and social exclusion according to research

- “58% of parents rated their life satisfaction as low.”¹
- “Parents of children with moderate to profound intellectual disabilities reported diminished quality of life for themselves and their families, experiencing increased physical and mental health issues associated with caregiving burdens.”¹
- “Parents of children with disabilities face intricate health challenges, including physical challenges like fatigue, musculoskeletal pain, and sleep issues. Additionally, they experience significant emotional strain, with symptoms of depression, anxiety, and hopelessness. Social isolation and stigma further compound these challenges.”¹
- “Being a family carer often results in isolation and exclusion. [...] Carers reported that they felt isolated with no time, or possibility to leave their house, or take part in social activities.”¹
- “Carers experience stress, exhaustion, financial insecurity and social isolation. [...] Employment and pension rights remain limited, and mental health risks are significantly higher than in the general population.”¹
- “Siblings of children with disabilities or childhood-onset chronic conditions (eg, autism, cerebral palsy or congenital heart disease) often face challenges in mental health, quality of life and psychosocial adjustment.”¹
- But also that “siblings scored higher on empathy, teaching and closeness, and scored lower on conflict and rivalry compared to those with typically developing siblings”.¹

² <https://www.aaem.pl/pdf-203276-124452?filename=124452.pdf>

³ <https://pmc.ncbi.nlm.nih.gov/articles/PMC11724350/>

⁴ <https://link.springer.com/article/10.1186/s12887-024-05104-3>

⁵ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf

⁶ https://easpd.eu/fileadmin/user_upload/Publications/Policy_Papers/2025-Oct16-Empowering_Families_and_Informal_Carers-Digital.pdf

⁷ <https://bmjpaedsopen.bmj.com/content/9/1/e003189>

⁸ https://english.tau.ac.il/news/sibling_study

Many family members feel alone, but as a group of people they are with many. How many people are we talking exactly? Sadly, that is hard to say for these 3 reasons:

1. There are many different diagnoses that can fall under the term ‘intellectual disability’, but there are also a lot of people with intellectual disabilities without any official diagnosis. This makes it difficult for them and their family to get access to support services, and to be included in statistics.
2. Most European countries do not keep track how many people with intellectual disabilities there are or how many family members are providing informal care.
3. There is research on informal carers (who are most often family members), but caring for a child (with a disability) under the age of 18 is often not included, and siblings are also often excluded from research.

We do not have exact figures for how many family members of people with intellectual disabilities live in Europe. But we know that between 1% and 3% of the population has an intellectual disability. With around 450 million people living in the European Union, that means between 4.5 and 13.5 million people have an intellectual disability. When we include family members, the number can be around 20 million people.

It is harder to say how many of these are children. Research from the United Kingdom shows that people with intellectual disabilities often have shorter lives, with many living to around 60 to 65 years.⁹ Taking this into account, we estimate that around one third of this group are children with intellectual disabilities and their families.

This means that around 6 to 7 million children with intellectual disabilities and their family members live in Europe.¹⁰ To put that in perspective, that is roughly the same as the population of Austria or Bulgaria.

⁹ [LeDeR Annual Report, Learning from Lives and Deaths: People with a Learning Disability and Autistic People, updated January 2026](#)

¹⁰ [MENCAP reports](#) that there are 349,000 children with intellectual disabilities in the United Kingdom. On average, this means that there would be around 698,000 parents, and 268,730 siblings in the United

You feel like you are completely alone.

Family should be just that – a family. That is what Inclusion Europe says in our advocacy.

And it is easily said when all family members are adults, but what does it look like when the child with an intellectual disability is still a child? When siblings are still children? You might think it is normal for parents to care for their children. That it is normal for siblings to help out around the house. We are not here to define what is or isn't "normal". "Normal" looks different for each family.

But we can clearly see that families with a child with an intellectual disability have more on their plate, and they have even more if the child has complex support needs. Parents are dealing with additional responsibilities and worries. Siblings have needs that are unmet. There is little support for any of them.

"There is no system at all for teenagers with an intellectual disability. Nothing new, no plan, no special services. **You feel like you are completely alone.**" – parent, Lithuania

Here are some of these issues and what parents and siblings told us about them:

Kingdom. Adjusting for population, we could estimate that there would be around 7.5 million parents and 3 million siblings in Europe.

Every day, a parent is teaching themselves a new skill to better support their child.

Children with intellectual disabilities require more support, but that support is often not available at school or anywhere else. Parents have to teach themselves a variety of different skills to give their child the support they need. They want to help their child learn how to speak, how to read, how to move. Milestones that would come naturally to other children of the same age now require more effort and specialised training.

When such support is not available at school or elsewhere, parents are left alone to help their child the best they can, often investing many hours to educate themselves and to teach and support their child.

Parents of children with complex support needs need to learn even more skills, often including medical skills, to be able to support their child in the way they need.

“I concentrated all the years, 17 years, on physical rehabilitation of my daughter. **I did everything:** physical therapy, different languages, piano. **I did it because I wanted her to have every chance.**”

- parent, the Netherlands

Every day, a parent is fighting administrative systems.

In many countries, support in different forms is available for children with disabilities and their families. But accessing this support is often not straightforward or easy. Many parents have an additional administrative job, on top of their real job and caring for their children. That extra job is to make sense of the system and make use of the different policies and options that exist.

Support is often fragmented. This means that parents need to navigate multiple systems to access the care and support their family needs.

This is especially difficult for parents of children with complex support needs, who have to navigate multiple systems and agencies.

Many systems are built on distrust of their citizens. They require proving over and over again that the child and their family is in need of support.

It consumes a lot of energy and time to do these administrative tasks and to fight for the support their child and their family need.

“For me as a legal advisor, I’m used to navigating bureaucratic systems, but when I started researching for my daughter, even for me it was difficult. I had a lot of discussions with all these experts and I asked them questions that they couldn’t answer. It took five years, five years, to prove to them what my daughter needs. I read all the laws myself, from bottom up, after work. **The system is so bureaucratic that you need to take your own case and write it down and say: this is what I read in the law and this is what my child is. Not every parent can do that.**” - parent, the Netherlands

Every day, a parent feels lonely, having to do everything by themselves.

Parents often feel lonely. Having to combine their job with caring for their child with an intellectual disability, they have little time, energy or opportunity to meet others. Friendships drift apart, and their world gets smaller. In addition, parents feel that they are not getting much support. This can make them feel even lonelier as they are the only ones fighting for a better life for their child.

“We do not have help from a social worker, I have to be the manager of everything because my son or his sibling are not receiving any support in this way. **We are pretty much on our own.**

- parent, Germany

Every day, a family struggles balancing the care and attention everyone needs.

The child with an intellectual disability requires more attention from the people around them, specifically from their parents. This is something families struggle with. Siblings struggle with getting less of their parents' time and attention, and because of this they have their own needs that are not being met. Siblings can experience feelings of jealousy or resentment. At the same time, parents struggle with guilt as they want to treat their children equally and want to give each child the attention they deserve.

“Because, you know we don't have a life. We focus on the child. We have also one other child and sometimes he said to us, ‘What can I do with this? **Because it's your problem, not my problem.**’ It's difficult.”

- parent, Albania

Every day, a sibling makes themselves smaller to not add to their parents' worries.

Siblings see their parents worry about their sister or brother with an intellectual disability. They see their parents doing their best, but that it is simply too much for them. Siblings want to help, but do not know how. They often cannot help with the administration, care, or finances. Instead, they try to help by making themselves smaller. By not adding their worries or needs to the pile. They try to take care of themselves even though they need support too, as every child does.

“I was also doing that role of trying to be a good daughter, so I don’t give more problems to my parents. [...] Really making sure when I was super little that my parents were alright and not suffering, **that’s not a behaviour that a child just does by itself.**”

- sibling, Spain

Every day, a sibling takes on responsibilities well beyond their age.

As siblings grow older, they want to do more. They see their parents struggling and start thinking about what they can do to help. Siblings take on responsibilities that can range from giving emotional support to their parents or their sibling with an intellectual disability, to helping with appointments, to taking over some of the physical care, and much more. Tasks that usually only adults are responsible for but that siblings take on from a young age.

“During my brother’s teenage years, he had a lot of issues regulating his emotions. My parents could become tense when this happened so **I would step in and tell them to leave the room and try to calm him down. I took a big responsibility there and I think I still do.**

– sibling, Sweden

Every day, a sibling feels invisible

Siblings can feel overlooked and invisible compared to their sister or brother with an intellectual disability who often gets more attention (either negative or positive). This can make them feel less worthy of time or attention, decrease their self-worth, and have negative effects on their development. Some call this ‘glass child’ or ‘shadow child’, meaning that the sibling is looked right through like glass or always standing in the shadow of their disabled sibling.

“Some old lady would come up to us and only seems to look at your sibling and talk to them and **you're just standing there like, oh, I exist too.**” - sibling, Ireland

Every day, a sibling is missing out on social interactions.

Often siblings can feel lonely. Lonely because their parents have less time or attention for them. Lonely because they do not feel understood by their peers. Lonely because it is more difficult to make friends when you cannot take them home or have less time because of responsibilities. They miss out on social interactions, they miss out on having a fun time, they miss out on an important part of their development.

“It was never time for me. I have never had a parent helping me with me with schoolwork or having time for activities. I was very lonely at school, because friends could never visit me and I could never visit them as my parents couldn’t pick me up. [...] Because of this, I was very lonely as a child, I also felt like I didn't have that social training as other kids had.

That made me feel like I was also different.”

- sibling, Sweden

Every day, a child with an intellectual disability is loved by their parents and siblings. And loves them back.

Parents and siblings face many challenges. But it doesn't mean everything about being a parent or sibling to a child with intellectual disabilities is negative.

There is laughter, joy and happiness. It can come from small things or big things. Small things like seeing their loved one react to their favourite song, or big things like celebrating a major milestone.

Whatever the struggles, there's always love. Love they feel for their loved one and love they feel in return. Knowing whatever challenge is coming their way, they face it together and for each other.

“The positive, I think, is the unconditional love. I always know that my brother will scream of joy every time he sees me and throw himself around my neck. As if Santa Claus is coming, you know. I always have someone to come home to or go to that gives me that kind of joy and love. **He has given me my life purpose and I am 100% who I am because of him** and I don't know who I am without him. So I owe him my whole life meaning of some sort.” – sibling, Sweden

After reading this essay, Jeanne Nicklas-Faust, President-Elect of Inclusion Europe, shared the following:

“When Eva was younger, everything was much harder for all of us as a family. But looking back I see that through all this our life around a child with a disability has become colourful, varied, and, in many ways, deeply joyful. When people ask what my life with Eva is like, my answer remains: It is more strenuous than life without Eva would be, but it is not less happy.”

“This sounds really bad, but...

I almost feel bad for people who don't have disability in their family, because they miss out on that whole education and that whole development. I really do think it greatly benefits the whole family, you learn to be more caring and empathetic, not just towards your sibling, but towards everyone. **It changes the way you view the world.**” – sibling, Ireland

Essay 2:

“If you don’t know how to navigate the system then you are lost and your child is too”

Family members making sense of a complicated system to get the support they need.

“I can’t say we did not have any guidance. That wouldn’t be true. We had some, but it isn’t systematic enough. It has to make sure everyone gets support. Because if you don’t speak the language, or if you don’t know how to navigate the system, then you are lost and your child is too. Nobody’s going to look out for you.” – parent, Germany

Every day, hundreds of parents of children with intellectual disabilities are scratching their heads over a new form they have to fill out, wrecking their brains trying to navigate multiple government websites, losing their minds trying to find the right service provider for the support their child needs.

Finding the right support can feel like searching for a needle in a haystack. If the needle was cut into multiple tiny pieces.

Navigating the bureaucratic system can feel like needing to find your way through an unknown jungle with only one out-dated map to help you. While at every cross-roads there’s a new guard with a new form to fill out before you can carry on.

Parents have to fight every day to get the support their child with an intellectual disability needs; not taking into account the support they themselves and their other children would need. To balance this, siblings often step up and try to help their parents where the system fails, even though they need support of their own.

This second essay focuses on the challenges of navigating a complex care system. Our main goal is to show how difficult it is for parents of children with intellectual disabilities to get the support their child needs, and how little support there is for them in this process. We also want to show the role siblings play.

The right to have support (just like everyone else)

In this report, we use the term ‘support’ quite broadly. It can mean any type of support that a child with an intellectual disability or their family members might need. For the child with an intellectual disability, this can include very specialised physical therapy, speech therapy, or support with specific health issues. It also includes daycare, something that most parents need for all their children. It’s one example of mainstream support that is generally available for parents but is suddenly more difficult to arrange when the child has a disability.

That mainstream support is not accessible to children with intellectual disabilities is less a problem of complex systems that needs to be navigated, but a problem of discrimination. Because support services are there, parents make use of them for their non-disabled children all the time. But when a parent of a child with an intellectual disability comes knocking, the doors stay closed.

We spoke with José Smits, former secretary-general of Inclusion Europe, and mother.

This is what she had to say:

“Parents need a lot of support for their children without a disability. Society provides for such support with daycare, medical advice and treatments, schools, financial allowances. The thing with having a child with a disability is that such general support is either not adequate or right out refused to them.

There is a lack of knowledge, but mostly there is a lot of discrimination. Children with disabilities are often deliberately excluded from general support. That is what’s making raising a child with a disability so difficult. It is doors slammed shut in your face, by daycare, by schools, by doctors.

For me this was a shock. I did not receive the support I got for my other children. Society refused to help my daughter because she is disabled. She was simply unwanted.

The main question is: why is it acceptable that all general facilities are made inaccessible? Why do teachers claim they cannot teach a child with a disability because they are not trained to do so? They are trained to teach, so why can they claim they cannot teach a child with an intellectual disability? It is the very essence of all our hardships.

People with disabilities are considered a separate category that can be discriminated against and excluded. So, asking for more ‘support’ is never the answer if this exclusion mechanism is not taken into account.”

More support is not always necessary or the right answer, especially not when it comes to mainstream support that is already there for other children. But mainstream support needs to be inclusive to all children, including children with intellectual disabilities and complex care needs.

“We had to do the research ourselves to get what we have a right to.
And it's the same thing in the school. I still have to go to the school and
say: ‘They have a right to this and this and this.’
‘Oh, we don’t have enough resources,’ is their answer.
It's like, come on, we're in Switzerland.
We're in the richest canton in Switzerland.
The children have a right to more.” – parent, Switzerland

Completely on your own

“If you have work all day, you don't have time to do research. To find out: What is possible for my child? You don't know, and that's it. **You don't get it.**” – parent, Germany

Every day, parent is buried in research trying to learn more about their child's disability and what support is available for them.

In many countries, the social or medical care system has become quite complex. There are different types of support available but knowing that they exist and accessing them is a different story altogether. All parents said that it requires a lot of research to discover what support is out there and how to get it. Because in general, there is a lack of information. From the moment their child with an intellectual disability is born or gets diagnosed, parents need to be given information on the different support services there are (financial, medical, social, etc.).

"Parents need to know what support they will receive from the moment their child is born." - parent, Lithuania

But because this does not happen, parents are required to do all this research by themselves. And that takes a lot of time. Time many parents do not have next to their job and taking care of their children,

**Every day, parent has to be the case manager
in a fragmented system,
because no one else is going to do it.**

Many parents are alone when it comes to research and support administration. There are many people who want to help, but only within their own area. Maybe there is someone in the hospital to help out with everything hospital-related, but they do not help, for example, with exploring financial support, or private therapies outside the hospital.

“The therapies you need are all private. They are not part of a hospital setup, so **there is no real communication between them.** Unless we, the parents, decide to put people in contact because they're working on something that complements the other, it doesn't happen.” – parent, Belgium

There is no general case manager who helps with all the different types of support and care. So, it is up to the parents to 1) do the research, 2) contact service providers, 3) prove that your child qualifies, 4) arrange appointments, 5) review what works - and take these steps again and again.

“We've never received any social support, someone to direct us where to look for therapies or how to find the right schools. We don't have a coordinator who assists us with appointments. You have so many appointments that need to be managed every single week and coordinated with the school schedule. We do that, the parents. **There is no one in the system who actually takes that into consideration.**” – parent, Belgium

Some days, a parent is grateful for that one person who goes the extra mile.

One parent we spoke to did have experience with a general case manager who helped them out a lot. Someone who took that role upon themselves and did more than officially was required of them.

“We had one person who helped us to manage, but it was only because she wanted to. The guidance you get depends too much on the individual will of the case manager you get assigned. If we had gotten someone else, I probably wouldn’t have learned half the things I learned.” – parent, Germany

The little help some parents get is too dependent on the individual.

"When you dig into the system, it looks good: there is infrastructure and money. But there are not enough qualified people to do the work." – parent, the Netherlands

Every day, parent or sibling are filling gaps left by the failing system without getting formal support or recognition.

No matter if there is a ‘good’ system in the country, if there is support available for children with intellectual disabilities, the parents are mostly on their own trying to find the support their child with an intellectual disability needs. They are spending time,

energy and money on research, contacting service providers and government services, and making and going to appointments.

“The only support we receive is informal — recommendations from friends who have children with similar issues, or WhatsApp groups.
Somebody told us to send our child to Italy, because the system here in Albania is so bad.” – parent, Albania

Siblings see their parents struggle and try to help wherever they can. They often provide support to both their parents and their brother or sister with an intellectual disability without any (formal) recognition.

"Our parents don't get support. They are in survival mode constantly.
We fill the gaps, but our role is not formally recognised, so we don't receive any formal support." – sibling, France

The consequences of a failing system

The system is failing in many countries. Yes, there might be some money and support available, but if parents do not know about it, are not able to navigate the system, cannot successfully apply for support, and have to do all of this by themselves, then the system is failing. And this is not without consequences.

Every day, parent worries they are not doing enough.

Parents are doing the best they can, but they often feel that they are not doing enough, that they should be doing more. This feeling is created by the failing system; they see the gaps and know if they do not fill them themselves it won't happen.

"There is a lot of stress around making medical decisions, therapy decisions and educating ourselves. **We always feel like we are not doing enough.**" – parent, the Netherlands

Every day, parent worries their child will be institutionalised.

In some countries, if parents cannot manage on their own there is a risk that their child will be put in an institution. This is especially true for children with complex support needs. One parent from the Netherlands shares the pressure they feel because of the threat of institutionalisation:

"The system in the Netherlands is good, but after you get the money, **you need to prove that you're able to arrange everything yourself as a parent, or they will institutionalise your child.** More than 80% of Dutch families choose institutionalisation for their children with intellectual disabilities. We did not want that. I tried to show them that I could take care of my child." - parent, the Netherlands

Every day, a parent is fighting to be part of decisions about their children.

The system is failing in other ways too. As we have seen, parents play a crucial role in organising the care and support for their child with an intellectual disability. Still in some countries, official decisions can be made without involving the parents, without even meeting the parents and the child about who the decision will be made. In cases like these, the system seems to disagree with itself. On the one hand, the parents are responsible for all and have to figure it out on their own. On the other hand, government employees can make decisions about a child's care and support without discussing it with the parents who organise and arrange all the care and support.

“Parents must be included in all decisions. Decisions cannot be made without meeting the parents or the child.” – parent, France

Every day, sibling asks how they can better support their brother or sister.

Siblings also feel the consequences of this failing system. They often fill in gaps left by the failing system to support their parents and brother or sister with an intellectual disability. This role is almost never recognised.

Often, the child with an intellectual disability needs support and therapy at home too. Siblings want to help and want to know what to do in certain situations. But service providers and therapists often do not include siblings in explanations and trainings. Siblings then have to ask if they could be trained as well so they can better support their brother or sister with a disability.

“When my sister started going to her therapies, we asked if we could also join so we would be trained on how we could best support her at home” – sibling, Ireland

Every day, sibling wonders if they could get support too.

At the same time, siblings are children themselves and often need extra support themselves because of the situation at home. None of the siblings we spoke to received any support during their childhood and often had to look for it themselves, or discover it by accident.

“While going to speech therapy with my brother, I found a book titled 'Having a Different Sibling'. That is all the support I got as a child. [...] **I wish I had been offered support without having to seek it myself.** My brother was offered therapies without having to seek them; I wish someone had offered counselling to me”. – sibling, Sweden

Conclusion

There is some kind of specialised disability support for children with intellectual disabilities available in many countries. But mainstream child-support mostly shuts them out.

And the segregated "care" services that are available are locked behind systems that are often so complicated that it takes a lot of research and effort to actually get the support the child needs. There is also a lack of information. Parents are alone in

organising and arranging the different types of support as there is no help in the form of a general case manager. Because of this, parents struggle to get everything done and feel that they are not doing enough. Siblings are often invisible to the system; they do not get recognised for the support they provide or for the support they need themselves.

But throughout all of this, parents are doing the best they can and juggling multiple 'jobs' at once. Where the system fails, family members work together to make it work. Even though the circumstances are bad and need improvement, it also makes family members resilient, flexible and creative.

"We are so experienced in facing issues that challenges are now just tasks. Regular families might see them as major challenges, but **I think we are winners, because we win every day,** even when we are struggling. We share this unbound commitment to our children. We are not victims." – parent, the Netherlands

Essay 3:

“The financial situation of the whole family is affected.”

**Financial hardships:
family members balancing work and care.**

“They don’t allow you to just live a ‘normal life’: working, benefiting from all those years of studying, building a career, living your life. Instead, they tell you ‘no, you don’t get to do that, but we will give you a bit of money.’ So, yes, they give you some benefits, but it doesn’t make any sense. **This is not how it’s supposed to be.**” –parent, Belgium

Every day, parents of children with intellectual disabilities are trying to make ends meet, deciding if they should stop working to care for their child(ren), and receiving another bill in their mailbox for therapies that are not covered by their insurance.

Parents have to put their own career and dreams on pause to provide the support their child(ren) need, while also making sure all the bills are paid.

Parents have to decide between losing income but being able to better support their child or keep working so that the money keeps coming in, but their child does not get the support it needs. Often it is not possible to do both; let alone to have the career they dreamed of and worked towards.

Siblings might notice the struggles their parents are having and see first-hand the sacrifices that they make.

There is no Europe-wide data that looks at the financial situation of families with children with intellectual disabilities specifically. The data that exists focuses on broader disability statistics. According to that European data¹¹¹², the average risk of poverty among people with disabilities in Europe is estimated at around 20%. The risk of poverty and social exclusion in 'households with dependent children' was at 22.1% in 2025¹³.

Research from a case study in Belgium showed that without financial support, children with disabilities are at higher risk of poverty. It also shows that 'around 10% of children with disabilities amongst the most financially vulnerable families do not receive any benefits'¹⁴.

A survey¹⁵ answered by French parents of children with intellectual disabilities showed that 43% of parents had difficulty in making ends meet, 37% of parents reported that the financial benefits were not enough to cover costs, 62% of parents reported that their employment had been significantly impacted because of their child's disability, and 41% of parents worked part-time compared to 17.3% in the general population.

This essay focuses on the financial hardships families might experience and the difficulty of balancing work and care. Our main goal is to show how families of children with intellectual disabilities struggle financially, the sacrifices they have to make and how difficult it is to balance work and care.

¹¹ [Living with disability in Europe: what open data shows, European data, EU](#)

¹² [Targeted measures for persons with disabilities to cope with the cost-of-living crisis, European Parliament's Committee on Petitions](#)

¹³ [People with dependent children face higher poverty, 6 May 2026, Eurostat](#)

¹⁴ [Vinck, J. \(2021\). Income poverty among children with a disability in Belgium: the interplay between parental employment, social background and targeted cash support. *Journal of Social Policy*, 51\(4\).](#)

¹⁵ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

Combining work and care

Every day, a parent is working overtime so that they can take time off tomorrow to take their child to therapy.

All parents struggle from time to time to combine their work with raising their children. A child gets sick; school has a 'teacher training-day'; parents are needed for a school trip; and so much more.

Parents of children with intellectual disabilities have all this and then some, think off: speech therapy, physical therapy or hospital visits, their child having to stay at home if the personal assistant is not available, and school is often further away which means parents also have longer commutes.

It is difficult to combine all of that while working full time, and because of this many parents have to frequently ask to take time off.

“It’s a lot of work at home, making all those appointments with doctors and therapists, but it is possible to combine with my job as a teacher. Officially, I am not allowed to take time off just because my child has an appointment. But in practice, **I have never had a problem**. As a public servant, I’m in a privileged situation. I can get three days off to take my son to the hospital and I don’t get any less pay. But that’s not the case for an employee in a private company. **My husband can’t ‘just’ take time off to take our child to the doctor.**” – parent, Germany

Parents are thus very dependent on their employer. Do they allow the time off? Are they flexible when it comes to working hours? Is it okay to work from home? Are they empathetic and understanding of the situation at home? Parents consider themselves incredibly lucky if their employer is flexible and understanding.

"When I told my employer I had a child with special needs and I needed to arrange my schedule accordingly, they were accommodating. **I have two additional weeks a year that I can take off for medical necessities.**" - parent, the Netherlands

But for many parents, it is not possible to keep working full time. They reduce their hours to work part time, or one parent has to stop working all together.

Having to stop working altogether

Every day, a parent is handing in their resignation letter because they can no longer combine work and care for their child.

For many parents, it is not possible to combine the care for their child(ren) with a job. And even though they love what they do, they have worked their way up to where they are, and they still have many dreams of what they want to do next, they stop working to be home full time. This is especially true for parents of children with complex support needs. The higher or more complex the needs of the child, the more difficult it is for parents to combine it with working.

“I’m originally a lawyer. I stopped working when my son was two years old because someone needed to take care of him. When we moved to Belgium, I was already unemployed, so I don’t receive any unemployment benefits. **Even though my son is now in school, looking for a part-time job is still not an option. It’s too uncertain.** Last year, there were two times he had to stay at home for a whole month.” – parent, Belgium

It is not only about being able to do the work. It is also about being able to do the work consistently and being a reliable colleague. This can be impossible, because of their child’s support needs and the little support parents receive.

Every day, a mother is sacrificing her career and dreams.

Many parents struggle with combining work and care for their child(ren). Many parents have to stop working to be able to provide the support their child needs.

But in the majority of cases, it is specifically mothers who take on the additional care tasks; mothers who reduce their working hours; mothers who quit their jobs to be at home.¹⁶¹⁷ Research shows that caring for children with disabilities severely impacts mothers' employment rates, forces them to part-time work or leave employment entirely and, consequently, affects their income¹⁸. Because of this, mothers are more likely to be financially dependent on their partners, have less career opportunities, and have lower benefits and retirement.

"I started thinking about the cost of my mom's additional care burden as a teenager. My parents did mostly well in sharing responsibilities, but my mom s worked part time and took more leave to care for my brother. Because of this, she earned a lot less than my dad. **It had a big impact on how I think about money and gender equality.**" – sibling, Sweden

¹⁶ "Caring responsibilities for children or for adults with disabilities were a main reason [why more employed women work part-time than employed men]. In 2024, 27.5% of women working part-time reported caring responsibilities as the main reason for doing so, compared with only 7.1% for men." Eurostat, April 2025, 'SDG 5 – Gender equality', [SDG 5 - Gender equality - Statistics Explained - Eurostat](#)

¹⁷ "Mostly women provide care for incapacitated relatives: 63.0% in contrast to 37.0% of men. [...] Women reduce working time or interrupt work more than men." Eurostat, September 2019, 'Reconciliation of work and family life – statistics', [Reconciliation of work and family life - statistics - Statistics Explained - Eurostat](#)

¹⁸ "The results showed that caring for children with disabilities has a negative effect on mothers' labour market participation, working hours and labour income. The more severe a child's condition is, the more likely the mother was to work and earn less, or to stop working entirely." [Yisfashewa Wondemu et al., 2022](#)

But what about if stopping with work is not an option...

Every day, a parent is worrying because they know their child needs more support, but they cannot afford to work less.

Not all parents who want to stop working are able to do so. In many countries, financial support or benefits for parents of children with disabilities are low. This can make it financially impossible for a parent to stop working; even though they want to; even though their child needs it.

"Because the government in Albania does not support us at all, we cannot leave our jobs. **Both my wife and I need to work.**" - parent, Albania

When financial benefits are not enough

Every day, a parent is struggling to make ends meet.

In some countries, parents can get an allowance when they stop working to take care of their child. However, in many countries this allowance is not enough to pay the bills for the basics, let alone, to replace the lost income. As a result, parents struggle to make ends meet.

"I only receive about €138 per month as a caregiver allowance for my child. **This amount is completely insufficient even for basic needs.**"
– parent, France

In other countries, parents can get a financial benefit because their child has a disability. But also in this case, the benefit is often not enough to cover all the disability-related costs. So, parents have to either find other sources of income or make decisions that affect the wellbeing of their children.

"It's impossible to manage with only 500 euros of financial benefit
— there is no money left for medical visits, and my son has epilepsy.
It's impossible to live on this budget with only one working parent,
while the other parent is forced out of the labour system." - parent,
Lithuania

"The government does not support us much — they only give us the equivalent of 250 euros per month. **It's not enough to pay for therapy.**" – parent, Albania

**Every day, parent is unsure
to try certain therapies or services
as they are not covered by insurance or benefits.**

Not all therapies or support services are covered by insurance or benefits. Parents have to look at private options where they have to pay out of their own pocket. Or they have to decide not to go through with the treatment or service that would help their child.

“We had to pay privately for most therapies and support outside the system.” – parent, France

"We wrote to the ministry and local governments about our needs. They just said they are sorry but that **there is no funding available for individual services.**" – parent, Lithuania

When policies forget family members

Every day, a sibling cannot join a sport or hobby because of financial struggles at home.

The reality is that many families of children with intellectual disabilities struggle financially. And all the different members of the family are affected by this. For example, a sibling is not able to join a sports team of their choice because the family cannot afford it.

In some countries, governments want to help families by creating policies that, for example, help the child with a disability access sports, museums or other activities, that would otherwise be too expensive. But they forget that many siblings do not have access to those things as well, as they have the same financial situation at home as their brother or sister with a disability.

“Society as a whole needs to know more about siblings. Siblings must be taken into account by the government, especially when it comes to benefits. There is a policy that makes activities cheaper for children with a disability. But **you also need to make activities cheaper for their siblings, because the financial situation of the whole family is usually affected.**” – sibling, Sweden

Conclusion

Many families of children with intellectual disabilities are struggling financially.

They struggle because it is difficult to combine work and care.

They struggle because one parent (often the mother) has to stop working.

They struggle because allowances or benefits are not enough to cover therapies or basic needs.

Or they struggle because therapies and services are not covered all together and have to be paid out of pocket.

Benefits and allowances are often not enough to cover the disability-related costs or to replace the lost income. And policies that should help make things more affordable are often only available for the child with a disability, and not other family members, like siblings, who are in the same financial situation.

The majority of the parents we spoke with shared that they have big financial worries, and that they are struggling.

Rare were the parents who said things are good. Few parents shared that the financial benefits they receive are quite high, that they feel well supported and that most therapies and services are covered. But we would like to end with their positive experiences.

"The financial benefits in the Netherlands are quite high, but so are taxes. They calculate what your child needs and cover costs accordingly." – parent, the Netherlands

"We get financial support from the government. It's very good." – parent, Germany

Essay 4:

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

Family members fighting for good education for all.

“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.¹⁹

Even if children go to mainstream schools, the quality of education is not guaranteed.²⁰

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.

¹⁹ [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

²⁰ [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

This essay focuses on how parents have to fight for good education for their child, and how siblings struggle at school because of the situation at home.

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.²¹

At Inclusion Europe, we always advocate for inclusive education²². 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.

²¹ 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](#)

²² [Why we care about education, Inclusion Europe, 2021](#)

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.

“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 24,000²³ 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.

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.

²³ [Inclusion Indicators 2025 report](#), 01/12/2025, Inclusion Europe

“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.

Essay 5:

“Nobody is really ok, even if they say they are.”

Family members struggling with mental health and meeting their own needs.

“You feel like you have failed, failed to have a child like this, failed to not be able to manage it, and then failed because there is nobody who cares about your mental health. By luck there was one person who stepped in and saw how I was struggling. It’s good they did, because otherwise, I don’t know if I would be living today. It’s really hard and nobody’s there. We need systematic help at the beginning, at the very beginning, from the diagnosis. It’s important to look after the parents or the carers and ask: ‘Are you okay?’ **And I think nobody is really ok, even if they say they are.**” –parent, Germany

Everyone cares for the people they love; in big or small ways, every day or just sometimes. Parents and siblings of children with intellectual disabilities are no different. They love each other; they care for each other.

But often there is little room to care for themselves.

Parents and siblings give everything they have to their loved one. Their own mental health and wellbeing gets neglected.

A survey by Unapei²⁴ asked parents of children with intellectual disabilities about their mental health:

- 85% of parents reported psychological distress,
- 46% of parents reported emotional distress,
- 46% of parents reported sleep problems,
- 57% of parents felt alone in their experiences.

Parents also reported that it was more difficult to do any sort of personal activities (66%), keep up with family life (53%), or enjoy romantic activities (49%)²⁵.

So, parents are not only under more stress, they also have a limited social life, which further increases the pressure.

On top of that, 44% of parents said they experience being treated differently by others; that being a parent of someone with a disability is seen as something negative²⁶.

Thus, society's stigma and discrimination towards people with disabilities and their family members increases the pressure even more.

Even with the best pressure cookers, the lid would fly off at some point.

No one is built to withstand that much.

Research on siblings tells a similar story:

- Siblings of children with disabilities or childhood-onset chronic conditions “often face challenges in mental health, quality of life and psychosocial adjustment,”.²⁷

²⁴ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

²⁵ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

²⁶ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

²⁷ [Daily life situations and participation of siblings of children with childhood-onset disabilities: a scoping review, Linimayr et al., 2025](#)

- The situation at home has consequences for the wellbeing and mental health of siblings, and care organisations need to look at the whole family, especially when a child has externalising behaviour problems.²⁸

This essay focuses on the mental health and wellbeing of parents and siblings, and how that often goes unnoticed. Our main goal is to show that struggling with mental health is not a personal failing, but a predictable result of carrying too much, for too long, with too little support.

Adding to the pressure

There are many things that add to the pressure that family members are under; that add to the mental health challenges family members face.

Every day, a parent or sibling disappears into invisibility.

There are 2 types of invisibility: you or your effort is invisible to others, or you make yourself invisible. Both are damaging to someone's feeling of belonging, visibility, and confidence. But they are different.

“When you have a job, and you do your project successfully, you receive a tap on the back, your salary, a bonus and recognition. **When you are a special needs parent, you are invisible to the outside world.**” – parent, Belgium

²⁸ [Well-being and mental health of siblings of children with intellectual disability: a longitudinal twin-family study, Honingh et al., 2025](#)

The first type of invisibility is about recognition. For example, parents often feel invisible, because the effort they put in at home to care for their child often goes completely unnoticed. There is no one to give you a pat on the back when you figured something out, or to celebrate a win.

“I feel like I ended up forgetting a little bit about myself... You’re an individual on your own, but you’re always compared to your sibling’s needs.” – sibling, France

For siblings, this type of invisibility comes from the comparison with their brother or sister.

“I had a lot of expectations of myself when I was younger, perhaps because I needed to have something for my parents to talk about. When they spoke about my brother with other people, they had a lot to say. For me, if nothing extraordinary happened, they wouldn't have that much to say.” – sibling, Sweden

In a way, the second type of invisibility is self-inflicted, mostly as a means to survive. Parents are so busy managing therapies, appointments, schools and paperwork that their own wellbeing comes last, if it comes at all. Siblings grow up learning to take up as little space as possible, so they do not add to their parents’ pressures. Both end up carrying the weight quietly, and alone.

“I had to grow very invisible at home, and I had to manage myself from a very young age. I've always been good in school and always trying to read the situation and do everything I could to keep everyone happy.” – sibling, Sweden

Parents and siblings alike describe a similar feeling: of shrinking themselves, of managing on their own, of becoming invisible so that nobody else has to worry. There is often no room to be seen as anything other than ‘fine’.

“I really tried to make people happy and not be a nuisance because my sister was so naughty. And **I tried to play that role of a good daughter, so I did not add to the problems of my parents.** I always tried to improve myself so my parents did not have to take care of me.” – sibling, Spain

Siblings of children with disabilities are often described as a ‘glass child’²⁹. The term comes from two characteristics of glass:

- See-through: they are often overlooked and attention is going to their brother or sister.
- Appearing resilient and strong: they seem to be very self-sufficient, independent and fine, but they are often struggling quietly not wanting to add to the stress.

“When I first heard the term glass child, I was thinking that my own experience wasn't in the definition. But I did feel sometimes I was treated like glass. Because my parents were so afraid that I would get hurt or something would happen to me. Because in my parents' view, I was a child who was going to succeed or make something of myself and thus nothing could happen to me. **I was put on a pedestal and treated like I was something that was so easily broken.** So for me, I recognised that in the term ‘glass child’.” – sibling, Sweden

Not all siblings we spoke with recognised themselves in the term, while some did. All of them, however, related to many of the signs of glass children: growing up fast(er), feeling older than their peers, stepping into parenting roles beyond their years, struggling to set boundaries, and wanting to be the ‘easy’ child³⁰.

²⁹ [On growing up as a glass child: emotional impacts & the path to healing, Kindman&co, 2026](#)

³⁰ [Always coping, rarely seen: explaining glass child syndrome, Cleveland Clinic, 2025](#)

“It feels selfish to think of myself as a glass child, **which is maybe the proof that the definition fits me.**” – sibling, Ireland

Every day, a family is judged.

Having a loved one with an intellectual disability often means having an audience: family, friends, strangers, all reacting, comparing, or commenting on things they do not fully understand. Family members carry that too.

It can be friends who come over and find it weird how things go in your house, even though it works for your family.

“I think I was 7 or something and I tried to start playing with this other girl. And one time I invited her home and my mom really put up an effort. She bought ice cream and when we ate that ice cream, my brother was sitting at the table as well. And he just took a spoon, ate and put it back into the container. My friend just had this look of disgust in her eyes. She said: ‘oh, I don't want ice cream anymore’. And then she left. **It was that moment where I realised: this is so different and I'm not like them.** It isn't worth it to have friends over. Not because I was ashamed, but it was just so hard for me to experience that.” – sibling, Sweden

It can be extended family commenting on how you treat your brother or sister with an intellectual disability, even though you treat them the same as your other siblings.

“If an aunt or an uncle or someone else told me: ‘oh, you shouldn't get annoyed with your sister, she has a disability and she doesn't understand’. That would just piss me off so much because in my mind I think: **‘that’s my sister and she is also a person and I should be able to treat her the same way as I do my other siblings’.**” – sibling, Ireland

It can be people making comments about your loved one which do not match your experience at all, and having to make sense of it.

“When my brother was a teenager, everybody around us would say: ‘oh, he's so happy and easy to be around.’ Then I saw his outbursts at home and would compare them with what people were saying, and that was so confusing. **It's hard when you're a teenager yourself to understand what the hormones are doing. Now it's easier to see that.**” – sibling, Sweden

Every day, family members become more isolated.

As the needs of the child with an intellectual disability grow, the world around the family often grows smaller. Friendships fade, extended family drifts away, and there is simply no time or energy left to maintain a social life.

“I don't really have much of a life other than supporting my children. I **rarely meet my friends because I hardly find the time.**” – parent, Albania

At the same time, the need for support and help grows. But regularly, people turn their backs to families with a child with a disability. People no longer come over. Friends no longer call. Neighbours no longer check in.

“The hardest part was the support we didn't get, and the isolation that came with it. We used to be close with people on our street and extended family, but that changed as our needs grew. **When we needed more help, everybody isolated us.** That was hard to see as a teenager who was trying to find their place in the world.” – sibling, Ireland

Every day, a sibling is struggling with their emotions, not knowing how to ‘switch off’ or set boundaries.

Siblings often witness moments that are frightening for a child to witness alone: crises, hospital visits, outbursts they do not know how to respond to. And they have to process it without much guidance.

“When I was in primary school, I could see that my sister was struggling to keep up. She got bullied and was eventually moved into a special school. When she had outbursts, I didn't know what to do; I would hide and wait for the crisis to pass. **Visiting her in psychiatric hospitals was hard, especially at 10 or 11 years old.**” –sibling, France

Siblings often describe having to regulate their own emotions constantly, supporting their brother or sister while feeling they cannot have needs, frustrations or boundaries of their own.

“If I think back on when I was a child, I think the thing that made me most angry was that I wasn't allowed to have boundaries to my brother. It was never his fault if he like trashed one of my toys or ate my candy. If he did something that any other child would have been told ‘no’, he would get excused because he couldn’t know any better. So it was always my fault because I got upset. **It was the constant feeling of having my boundaries pushed and I was always had to be so understanding.** But as a child you just want to scream at him. And for that to be OK, because every sibling does that.” – sibling, Sweden

If their brother or sister does something they do not like, siblings are often told not to get upset because their brother or sister does not know any better. But that leaves the sibling with unaddressed frustrations they cannot do anything about; expressing them is not an option.

Many siblings also expressed that they felt they were ‘on’ all the time. Constantly checking in with their loved ones. Constantly aware of their surroundings, checking if everything is safe. Constantly having an antenna out, ready to react immediately at any given notice.

Siblings explained that it was difficult to ‘switch off’ when they were younger, and they had to learn how to take care of themselves and regulate their emotions.

“I think that's also a process where you need to regulate yourself when you're still growing up and you see that you cannot be ‘on’ all the time. Like we say **‘the rope cannot be tight all the time’**, you need to let it go from time to time. You just cannot be there all the time supporting and helping them.” – sibling, Spain

The pressure rises and becomes too much

In the introduction, we already shared some research that shows the consequences of the pressure family members are under. The majority face mental health challenges of varying degrees. Many have trouble sleeping. Some face long term (mental) health problems. Here, we share what the parents and siblings we spoke with said.

Every day, a family member's mental health suffers, often unnoticed.

Because family members hold so much in, and because they are often the ones who seem to be doing fine, their own mental health struggles can go unseen for years.

“When I was a teenager, **I suddenly had a lot of problems with anxiety and I developed mental health issues.** I think it's had to do with the situation at home. For me it had been like years and years of just holding everything to myself and having no one to talk to and I was always adapting to others. I kind of lost myself. And when I came into my teenage years, it was too much. So I developed a lot of anxiety issues. **And even then, not even my parents or school could see that I needed a counsellor.** They thought there couldn't be problems because I had good grades.” – sibling, Sweden

It can be difficult to discuss these mental health challenges with your loved ones, for the same reason family members make themselves invisible in the first place. They do not want to add to the problems and worries of their loved ones.

“My parents saw me as a calm and regulated teenager, who did her schoolwork, hung out with friends, and didn't have mood swings. But I was undergoing a lot of mental struggles at the time, which my friends knew about. **It was hard for me to talk to my parents about my personal issues because I had to think about my brother.**” –sibling, Sweden

And the mental health struggles of loved ones can add to the pressure family members experience.

“Because of the situation at home, my dad became depressed and it was really hard to navigate that depression as a child. And I don't think it was his or my mom's intention to put pressure on me, but there was always this sense of: ‘you can do everything that your brother can't, so you should’.” – sibling, Sweden

Support is needed

Throughout this series of essays, we have highlighted the different challenges family members of children with intellectual disabilities face and the absolute lack of support. The absence of support could be added as one of the things that adds to the pressure.

(More) support for family members is absolutely essential, especially to limit the risk of longer term (mental) health issues.

Every day, a parent looks for understanding that never comes.

Parents told us that nobody checked in on their mental health, not even at the moment they needed it most: the diagnosis itself. One parent even shared that how they received the diagnosis was a traumatic experience in itself.

“I would have needed somebody to go to us, or not only to me, but to the whole family and offer some help or some assistance in terms of mental health, but that never happened. Nobody asked me if I needed counselling because of the diagnosis of my child. The doctors are not trained at all and it's a real disaster. They are not even trained on how to give you this diagnosis. **I would even go so far to say it's a trauma because of how they brought the news.** It's really horrible.” – parent, Germany

Parents shared that few people understood what they were going through, let alone were able to help.

“**Many doctors had no experience with trauma and could not understand what we had been through.**” – parent, France

Every day, a parent worries about their other child's unseen struggles.

Parents know they are not getting the support they need. But they also know that their other children are not getting the support they need either. Parents have to see their children struggle, unable to help them even though they desperately want to.

“The siblings need support too. I remember my son was two years old, and he behaved really strange, but I didn’t know how to help him. I could not even manage myself. How could I even do something with him? I don't know. It's like nobody cares.” – parent, Germany

Some days, a sibling finds support in peers who share their experience.

For a few siblings, the one form of support that reached them came not from professionals, but from other siblings who understood without needing an explanation. Sometimes by chance becoming friends with another sibling.

“There was a boy who lived across the street who had a brother with Down syndrome, and I definitely found that having him as a friend was helpful. Because **we would go off by ourselves and almost escape reality a little bit and have fun together.** And I think we didn't really talk about our brothers and sisters that much, but we both kind of understood each other in that way without even communicating it. So I think that was definitely helpful, a kind of peer support too, that friendship.” – sibling, Ireland

Sometimes it was more organised, going to activities organised for siblings to get together.

“When I was maybe around 10 years old, I went to a summer camp for children for 3 days. And you do fun activities with other siblings who have brothers and sisters with disabilities. It's not all about your brother or sister, but they also focus on how that affects you and that kind of stuff. So I found that really beneficial, but I definitely think it's something that should be more known and funded by the government to be available to all siblings. **That was the only kind of support I got being a sibling during my entire childhood.**” – sibling, Ireland

Siblings benefit a lot from spending time with peers and it is great when peer support is available, but it is not the same as professional support. More support, both peer and professional, should be available for all family members to help them navigate and handle all the different challenges they face.

“My other child doesn't receive any psychological or mental health support. And I would like that because **I don't know everything which goes on in his mind.** I don't see everything. I don't feel everything. The only place where I think he gets the support is in the meetings from our syndrome society here in Germany, Switzerland, and Austria. There are other siblings. It is peer-support, but it's not the same as professional support. If he got that, I would feel more comfortable because with our situations I think it would be like very, very helpful for him.” – parent, Germany

Every day, resilience and empathy grow alongside the struggle.

“I think as a sibling you also gained resilience and developed a lot of empathy and sensitivity to other things.” – sibling, Spain

Family members face a lot of challenges, including mental health struggles. But none of this means that struggle is all there is. Looking back, several siblings spoke about what they gained, even from the hardest parts of their childhood.

“Looking back on the isolation and vulnerability I experienced, the positive thing is allowing myself to be vulnerable. It's obviously hard when you're a teenager, but when you're an adult, you realise it's a strength.” – sibling, France

Conclusion

Struggling with mental health is not a personal failing of parents and siblings of children with intellectual disabilities. It is the predictable outcome of a life spent carrying too much, for too long, with almost nobody checking in.

Parents feel invisible, and feel like they have failed, even though they are doing everything they can. Nobody asks how they are doing, not at diagnosis, not years later.

Siblings grow up learning to take up as little space as possible. They become invisible too, and worry about their brother or sister while nobody worries about them. Their own mental health struggles often go unnoticed for years, mistaken for being ‘fine’ because they get good grades, or do not cause trouble.

And yet, alongside all of this, there is resilience. There is empathy. There is love.

But resilience should never be the reason support does not arrive.

Over five essays, parents and siblings across ten European countries shared what their daily lives actually look like: navigating a complicated system, facing financial hardship, fighting for a good education, and carrying a mental and emotional load that is rarely seen, let alone supported.

We end where the first essay in this series began.

“This sounds really bad, but... I almost feel bad for people who don’t have disability in their family, because they miss out on that whole education and that whole development. I really do think it greatly benefits the whole family, you learn to be more caring and empathetic, not just towards your sibling, but towards everyone. **It changes the way you view the world.**” – sibling, Ireland

Recommendations

This report is a collection of essays written to show the situation of parents and siblings of children with intellectual disabilities. It describes their lives and highlights some of the challenges they face. The essays did not focus on any specific policies, but here are some general recommendations:

- Early childhood interventions and pedagogical support that is available for the child with an intellectual disability should also offer support to the parents and siblings, and offer support to the family as a unit.
- A general case manager should be assigned to each family to help lift the bureaucratic and administrative burden.
- Policies on employment should better protect parents of children with intellectual disabilities and allow for more flexible work hours, work from home, and paid leave to attend (medical) appointments with their child.
- Financial benefits to parents who cannot work due to their child's disability should be enough to match minimum wage and any disability related costs.
- Financial policies that are specifically targeted to the child with an intellectual disability, for example discounts for sport clubs/museums, should also apply to siblings as they have the same financial situation at home.
- Schools should offer more support and flexibility to siblings of children with intellectual disabilities who have to balance school with the situation at home.
- Mental health support should be available to parents and siblings of children with intellectual disabilities. Peer support options are great but are not a substitute for professional counselling.
- Medical professionals should be trained in how to support parents and siblings from the moment of diagnosis of their loved one.



**Ambitions.
Rights.
Belonging.**

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

Families Should Not Have to Carry Everything Alone

Parents and siblings of children with intellectual disabilities on their every day.

Author: Inge Volleberg

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