

They don't see our children. They don't see us either.

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

Part 1 in a 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 are what this essay is about.

This is the first in a series of essays in which Inclusion Europe talks about the situation and experiences of parents and siblings of children with an intellectual disability.

We explain why we want you to know about parents and siblings and about the main issues they face. In the essays that follow we'll look deeper into:

- **Navigating complex care system to get the support and services they need,** and having to do it yourself when the system fails.
- **Financial hardships** in the family, and the difficulty of balancing work and care.
- **Fighting for a 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.

To help us write these essays, 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.

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.”

Coming up next in the series:

- **Navigating complex care system to get the support and services they need,** and having to do it yourself when the system fails.
- **Financial hardships** in the family, and the difficulty of balancing work and care.
- **Fighting for a 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.

“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



**Ambitions.
Rights.
Belonging.**

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

“They don’t see our children. They don’t see us either.”
What parents and siblings of children with intellectual disabilities face every day.

Author: Inge Volleberg

April 2026

Inclusion Europe

Avenue des arts 3, 1210 Brussels, Belgium
www.inclusion.eu



**Co-funded by
the European Union**

Inclusion Europe is co-funded by the European Union.
This publication reflects the views only of Inclusion Europe.