

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

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

Part 5 in a series of essays
By Inge Volleberg



“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 Unapei¹ 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%)².

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

¹ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

² [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

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 negative³.

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,”.⁴
- 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.⁵

This is the fifth and final essay in a series on the lived realities of parents and siblings of children with intellectual disabilities. It 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.

³ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

⁴ [Daily life situations and participation of siblings of children with childhood-onset disabilities: a scoping review, Linimayr et al., 2025](#)

⁵ [Well-being and mental health of siblings of children with intellectual disability: a longitudinal twin-family study, Honingh et al., 2025](#)

In this series:

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

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

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

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'⁶. 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.

⁶ [On growing up as a glass child: emotional impacts & the path to healing, Kindman&co, 2026](#)

“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’ child⁷.

“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.

⁷ [Always coping, rarely seen: explaining glass child syndrome, Cleveland Clinic, 2025](#)

“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.

This is the last essay in this series. 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



**Ambitions.
Rights.
Belonging.**

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

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

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

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