

The financial situation of the whole family is affected

Financial hardships: family members balancing work and care.

Part 3 in a series of essays
By Inge Volleberg



“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 data¹², 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 2025³.

¹ [Living with disability in Europe: what open data shows, European data, EU](#)

² [Targeted measures for persons with disabilities to cope with the cost-of-living crisis, European Parliament’s Committee on Petitions](#)

³ [People with dependent children face higher poverty, 6 May 2026, Eurostat](#)

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’⁴.

A survey⁵ 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 is the third essay in a series on the lived realities of parents and siblings of children with intellectual disabilities. It 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.

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** in the family, and the difficulty of balancing work and care.
- **Fighting for a good education** for their loved one with an intellectual disability, and balancing school and care.
- **Struggling with mental health and wellbeing**

⁴ 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).

⁵ [Enquête Handicaps et vie quotidienne : la voix des parents, Unapei](#)

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.

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.⁶⁷ 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 income⁸. 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

⁶ "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](#)

⁷ "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](#)

⁸ "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

Coming up next in the series:

- **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.



**Ambitions.
Rights.
Belonging.**

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

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

Financial hardships: family members balancing work and care.

Author: Inge Volleberg

Inge Volleberg is a researcher at Inclusion Europe. Her main responsibility is the [Inclusion Indicators](#) report about the situation of people with intellectual disabilities in 30+ countries. Inge also leads our work on the Young Families Project. Inge is a sibling to her sister with an intellectual disability. She uses her personal and professional experience to raise awareness and advocate for the situation of siblings of people with intellectual disabilities.

July 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.