

**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.

Part 2 in a series of essays
By Inge Volleberg



“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,

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 is the second essay in a series about parents and siblings of children with intellectual disabilities. The first essay introduced family members and their experiences. 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.

In this series:

- **Introduction:** [What parents and siblings of children with intellectual disabilities face every day.](#)
- **Navigating a complicated care system.**
- **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** and neglecting their own needs.

For these essays, we spoke with 9 parents and 6 siblings from 10 European countries. Parents told us about their current lives with a child with an intellectual disability and complex support needs, and siblings looked back on their childhood. We are very grateful they shared their time and experience.

The right to have support (just like everyone else)

In this series of essays, 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

Coming up next in the series:

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**Ambitions.
Rights.
Belonging.**

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

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

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