Episode 1: Head-hands-heart

Dear you,

Yes! You!

Thank you for already being part of the community that wants to inspire care professionals to think and act out-of-the-box in supporting families with a child with a disability.

Huh, say again? Why should I continue listening?

So, you, me, everybody encounters at some point or multiple points in our lives a twist of fate that makes life challenging, and we'd then all would like someone to stand up for us and think and act out of the box, right? Okay, that is exactly what we want to do: to encourage this standing up for those in need and having this creative confidence in looking for persontailored support. Though the audience we aim is the European care professional working with children with a disability and their families, the idea actually applies to all of us, to every single one of us. So who-ever you are, keep on listening!

Being creative, means pioneering. Somehow you have to dive in the unknown. This is exactly what we hear that parents with a child with a disability have to do *all* the time. So if we ask these parents to be courageous, let's be courageous ourselves! As one of the parents we met during the making-off this podcast said: “people should want to jump out of their own safe professional role”.

We've been gathering insights from families and professionals across Hungary, Belgium, Italy, Romania and Finland. This navigating through Europe made clear that –oops, spoiler alert!- it's all about working IN a network rather than WITH a network, heartfelt communication and experimenting thoughtfully together. Creative care integrates the wisdom of both the professionals and the families. Yes, it is indeed a co-creative journey! After all, the families are the experts by experience, or, as a parent put it: “the real field professionals”.

This first episode clarifies ‘the big why’: why did we prioritize the support networks within a family? The need for support is hopefully clear when you hear the next, written by Jet Isarin:

"*Becoming a mother of a child with special needs means handling something you can't handle. It means loving a child who is not what you had hoped for, and being furious about the 'being' of a child who is closer to you than anyone else. It means longing for support, help, and compassion from others, and at the same time cursing it. It means being dependent on experts who can both create and solve problems. Living with a special needs child is living with contradictions: contradictions within yourself, in the child, and in the environment. Can you handle it? Yes, of course you can't. No, of course, you can.*”

In the making of this podcast, we've interviewed over 70 people: parents, professionals and loved ones. In this chapter, you'll hear their voices. And yes, we're reassured: all professionals are eager to make a difference and are searching for the best ways to do so! As

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one of the professionals sang: '*I have a dream, a song to sing, to help them cope, with everything.*'

The five episodes that follow this introduction take us on a journey across Europe. We've heard many stories of mostly parents, and each one deserves its own podcast episode. These are all stories that need to be told and that need to be heard. Five parents wanted to send their story out into the world. You'll hear each of them in a separate episode.

The closing episode is short and engaging. Don't forget to listen to this one!

Let's get started!

So, what led us to prioritize the support networks within a family having a child with a disability?

The need for support for these families is immense. Or, to put it more strongly: *vital*. It allows parents to get a good night's sleep, to educate *all* their children the way they dream to, to be able to take care of themselves and to breathe a little easier. Two main types of support are identified. The first comes from what we, as professionals, call the natural network. This network includes family, friends, parents, siblings—both the young and older ones, the partner, and neighbors. It even extends to inclusive initiatives that can reach far beyond the immediate circle: for example, one of the participants' son is an honorary member of his grandfather's volunteer firefighter group for youth. In these times of social media, we must not forget how important and supportive those platforms can also be. (A dad said): "*For us, the most concrete and understanding network is simply a WhatsApp group with parents of children with Angelman syndrome. It's very specific, as there are only about 50 to 60 people with that syndrome in Belgium, and they're all in this group. Once a year, we have a meeting in a European country. This is the most tangible support we have. These are the people who truly understand the impact of the syndrome. It's not practical support, but it provides moral support. And when we meet these people, you don't need to explain much. There's recognition, and the feeling , 'I'm not alone."*

What stood out during the interviews with the parents was how small or nearly nonexistent the natural network was for many of these children and families—and thus a reliable professional network becomes crucial.

Most parents had to adjust their social lives to accommodate their child's needs. Some had to give up their jobs. For those in their natural network, it can sometimes be difficult to accept the differences or to overcome their fears, leading them to pull away. In some cases, parents distance themselves from people in their network, particularly if they feel their child isn't welcome, or when they feel misunderstood, hesitant to ask for help, or caught in a grieving process. And often, there simply isn't time. (A parent expressed:) "*I don't see my friends anymore, nor do I do the things that other people in their fifties are doing. I've now calculated how many more years it might take before I can go shopping or have coffee with a friend after work*."

There’s a saying, 'It takes a village to raise a child.' In every family we’ve encountered, professionals are either an integral part of that village or, in some cases, make up the entire village. The scarcity of resources and the limited options when it comes to choosing professionals to shape this village, forces the professionals to make thoughtful, deliberate decisions. This means that there is a big responsibility for the professional network, the organizations and individuals who specialize in disability-related expertise or have an inclusive mindset. After all, these children—and their parents, siblings, and extended families—are part of today’s world and tomorrow’s future.

When professionals are an integral part of the village, it means they must create a holding environment. This involves professionals adopting a core attitude of being supportive, affective, predictable, sensitive-responsive, and attuned.

All the input we’ve received while interviewing professionals, parents and other people from the network fitted in the conceptual model of head – hands – heart, in which head refers to knowledge and theoretical understanding, hands to skills and behavioral effort and heart to emotional investment and passion. This holistic approach in which head-hands-heart are in balance is foundational. It was also remarkable that both professionals and the parents share the same desires and struggles.

Let’s dive a bit deeper in the head-hands-heart model!

"Head" stands for knowledge and the sharing of information. Families often describe entering a world they know nothing about, where they have to learn everything from scratch. (a father)*“Before my daughter was born, I knew nothing about people with disabilities. I didn’t know how to deal with it either. As a parent, you have to learn that, and in the process, you naturally become very tolerant. It's something you have to learn along the way. You don't start out knowing it, but over time, you adapt and become more understanding”.* (A brother said:)*"My brother has a disability, and I studied psychology. My studies help me learn how to interact with my brother better. When you have knowledge about what a disability is, it becomes easier to 'let go.' But, well, I don’t need to become his psychologist! And then my mom says... David, now let's just do it my way after all, the Polish way"* (laughs)

Being well-informed and having clear communication are crucial in fragile moments. Parents emphasize the importance of society, government, organizations, and individuals meeting them at the level of the care receiver/parent, and working together to create policies, actions, and communication at that level. (One parent adds:) "*We should build a culture of cooperation—professionals and everyone involved in care should work towards win-win situations, rather than hierarchical competition*." *(A therapist continues:) “Teamwork is one of the foundations of my work as a therapist, as often several actors are involved in the life of the family regarding the therapy and care. Teamwork can overcome formal, rigid, systematic barriers through informal solutions. I do acknowledge that a professional support network, is often difficult to activate and maintain. We've created what we call Operational Working Groups. These groups involve educators, families, and external specialists, who work together* *to create and regularly update individualized educational plans tailored to the child's strengths."*

" (another professional:) Continue learning. Attend professional conferences and events and visit other organisations. A network is so necessary both for the beneficiary and his family, but also for us, the professionals."

Parents emphasize the importance of avoiding sector-specific terminology and keeping communication systems accessible (professional:) "*We use photos and videos because images tell more than words do. When we go for a walk in the woods or when a child achieves to go on the potty, we send a photo. And I always remember what is important for families, even if what they shared doesn't seem relevant*".

Parents also stress the need for more efficient ways to share information between organisations about their child so that parents don't always have to serve as a communication bridge. A professional agrees, highlighting a related challenge: *"Communication between us, educators, and neuropsychiatrists is often indirect, leading to a loss of crucial information. This is primarily due to information being relayed through families rather than direct professional dialogue."*

Additionally, parent's knowledge and ideas about their child's care should be fully integrated into the action plans. *(professional:) "A lot of children residing in our group home have, due to a complex family situation, a juvenile judge who takes decisions about the care traject of the child and the family. This decision making process evolved over the last 15 years. There is no longer a deciding FOR the client because "we know what is best for you, we're not going to do that because it won't work". Now, there is a focus on HOW to try together a certain track. We say: okay, you know, let's try that, let's see what happens and let's talk together about how that gives us the best chance that something will succeed, or what are we going to do if something doesn't succeed."* Collaboration among professionals is also valued. *(other professional:) "I really like to work with many people around a child. It gives you different perspectives and I see this diversity as a resource. Kids can be their different selves in different places. "*

Often, parents receive information from other parents, for example, through Facebook groups. Parents have their own expertise, their own sources of information, their own experiences and above all: their intuition. These need to be acknowledged and validated, also by the doctors. "*In our Centre, we ask about the network in the application procedure and the first interview. This helps to see the overall picture of the child and the network from the beginning."*

In addition to knowledge about diagnoses, the treatment, the child and the family, parents face significant administrative burdens. The sector is highly bureaucratic, with many rules, procedures, and terribly long processes, as well as the constant need to justify and explain what is wrong with your child. The care landscape is fragmented. As several parents pointed out: the way care is structured and the fluctuating subsidies, create a lot of uncertainty.

(professional) “*I often sense feelings of shame or guilt when a parent isn’t able to take care of the administration. I try to be as clear as I can when I provide information*”.

This leads us to a clear call for action. This is what we mean by ‘hands’—it’s about the professional taking an active role. The Kafkaesque bureaucracy drains time and energy, resources that most parents simply don’t have. As a parent put it: “*we often have to deal with a system that is not always ready to support families*”. Tackling these challenges together, side-by-side, makes an enormous difference. Professionals can help lighten both the emotional and practical burdens these families face in complex situations. And it’s not just about professional support; the same goes for the natural network. We’ve heard inspiring examples of supporters stepping up—whether it's playing the role of a taxi driver, caring for a child with a disability, or helping look after siblings.

(let's hear from an aunt.)*"My niece always went to daycare, which is normally until the age of 12. Eventually, they became flexible and allowed her to continue attending for many more years. This made a world of difference for her and her parents for a long time."*

(A mom told us:) *“Recently, a friend of ours, who owns a café, said, 'Your daughter should come to the café on Saturday, and I’ll have her help with the dishes.' Now you can see that it's important to our daughter. She feels like, 'I can work here.' This type of inclusivity shows that there's still a lot of room for creativity in this area.”*

Professionals can take clear actions to support connection between people. *“We provide spaces or opportunities for families or beneficiaries to meet. The rest will go by itself, as they can relate to each other easily.” “I’d like to highlight the importance of encouraging families and beneficiaries to engage in everyday networks as well, where the main link is a common interest or activity. These can support the inclusion as a whole.”*

Lastly, we come to the heart. This represents connecting on a deep, emotional level—listening and seeing with your heart. Such a connection is often felt between parents raising a child with a disability. They share an unspoken understanding, offering each other the comfort of knowing they are not alone. Sometimes, just one word is enough to convey understanding. There is often a longing for both inclusive and disability related connections. However, negative interactions and communication can hurt, deepening feelings of isolation, being misunderstood, and undervalued. Parents shared several painful examples:
(1) “*My mother blames me when I let my daughter stay at a group home*.”
(2) “*People say, ‘Don’t worry about that yet.’ I get so frustrated, because as a parent of a child with special needs, you* always *have to anticipate. You* always *must*.”
(3) “*There are those who constantly criticize and can’t accept children for who they are, or even pressure them to be someone else.” This parent added: “You don’t have to keep such a network alive if it’s doing more harm than good to your family. It genuinely breaks children when they sense they’re not accepted as they are*.”
(4) *“My godchild has a disability, he and I, we have a good connection. There were sometimes really challenging situations and there were those multidisciplinary teams where*

there were a lot of professionals. Then my sister, his mom, said that she always feels like there is a whole football team on the other side and she is all alone, where is her team, that she also needs a team if there is a whole team of professionals."

We've already emphasized how important it is for professionals to inform families, but just as crucial is the manner in which you inform and connect with them. (Parents urge:) "*Communicate in a human way—we are still social beings, still people. We are not just a number. We are not just a diagnosis*."

This concerns both the formal and informal meetings. (professional:) *The most beautiful or the most connective moments that I've had with parents, were when we took the tram or the bus together when we had to meet another professional at the hospital for example. You talk differently then."*

(another professional:) *"I really like real contact. I want to understand their story and their history. I actively seek connection and welcome every person of the network."*

Sadly, we've heard devastating stories of poor and painful communication. (A parent recalls) "One doctor simply said: *"Here are the diagnoses. Oh yes, he also said: good weekend." I'll never forget when we left the hospital, all I had were the diagnoses—autism and intellectual disabilities—some paperwork, and a few notes*."

(a parent told,) "*Once a professional said to me; "Your child is too disabled. No one wants him. No parent should ever hear such words about their child."*

These three pillars – head**,** hands**,** and heart – are interconnected and influence one another. A mother suggested the following: "*Make sure professionals receive proper training and have opportunities for continuous learning. The more they know their job, the more creative they can be. They become freer, more open. Knowledge leads to more freedom and openness*." In fact, this is exactly what parents desire: being well-informed has a therapeutic effect! When you feel informed, you gain confidence as a parent, which in turn makes you freer and more open in your approach to raising your child.

Every family needs hope, and so do professionals. There are possibilities to go beyond the financial, procedural and time limitations that stress us; we just have to create these possibilities! This is essential for both families and professionals, offering them new perspectives, instilling confidence and renewed motivation. Let's change the following sentence a parent put forward: "It's a life of its own kind of survival"; into "It's a life with its own kind of thriving."

This thriving does not only concern the child with a disability, but every loved one. Children are doing well when parents are doing well. (A parent describes:) "*At times, I feel like I'm trapped in a bubble from which I can't escape. I find myself repeating the same actions daily and yearn for change, yet it's challenging to prioritize my own needs over my child's. I want* *him to reach the milestones I hope for, so I can also move forward in my life. While he is evolving, I often feel like I am taking two or three steps back each year. Even raising a typical child can pose challenges, but imagine the impact of caring for one with special needs.”* (voice of father) “*As parents, we sometimes forget that we also have our own needs to attend to. We need to remember ourselves too…*”

Not only do the parents need to remember themselves, we as supporters need to do the same. (a mom said:) “*One of our son’s therapists asked us: how are you parents? Then I stared at her for a moment wondering if I heard it correctly, because we had never been asked over the years how us parents were doing. So, it's been so arresting that she was really interested to hear how I'm doing right now, not as a parent, but as a person. This was such a positive experience. How am I doing?*”. (Another parent adds:) “*I’ve learned that moments of respite are not just a luxury; they’re essential.*”

Going through all the interviews with the families makes you humble as a professional. We are not all-knowing, and this podcast does not claim that you will become so after listening to it. One of the parents described it very beautiful. *“'Knowledge and care is fragmented, everywhere there’s a piece of the truth and something good, everywhere there’s a part of the puzzle and a piece of the answers. It’s also a search for professionals. Which puzzle piece is still needed?”* We hope that this podcast can provide a new puzzle piece, or even better: that it gives you the eagerness to unfold the bigger picture and the development of a blueprint where all the puzzle pieces can fit together.

In the following episodes, you can listen to the stories the way they have been told by the mothers. It was not our intention to only give mothers a voice, but that’s how it turned out. Maybe this has to do something with that “lion mother madness and instinct and search for knowledge” as a parent explained how this helped her boy get to be in the condition he is now. But what about the dads? We met several of them, all sharing the same intricate dance between struggle and hope, isolation and connection, challenge and triumph.

The stories haven’t been dramatized or made prettier. They are simply more coherently organized and narrated by a voice actor for better listenability. Other than that, they are what they are: life as it is for these five families.

outro: This podcast was made possible thanks to the time and effort of more than 70 people from the natural and professional networks of children and young people with intellectual disabilities. The input and stories were collected by the following organizations: MPC St. Franciscus from Belgium, CADIAI from Italy, Tukena from Finland, Hand in Hand from Hungary, and UCOS from Romania. Epos and Erasmus+ made this podcast series financially possible. We would like to thank the Podcastaar for the editing, as well as express our special gratitude to those who generously shared their stories and to those who offered their voices for this project.