

## Networks make the dream work: the podcast

Clients and experienced staff testify about the importance of network strengthening

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### Episode 5: Romania - Tudor

*All narratives in this podcast shed light on the often unseen journey of parents raising a child with special needs. The love for their child as well as the support they receive are a lighthouse for the storms that often cloud their path.*

*Our European voyage of gathering stories guides us from Hungary to the neighbouring country of Romania. The dream of Maria is clear: a seamless, integrated approach to her son Tudor's care.*

I feel like I've entered a new world. I have to adjust to it. I never lose sight of the future I envision for my son, my Tudor. I give my all.

My life has been a bit of a whirlwind the last past years. I'm 42 years old, and though my journey began in the world of medicine as I graduated as a doctor with dreams of healing others, life has steered me in a different direction. Currently, I am not practicing medicine because I am taking care of Tudor, my eldest child, who was diagnosed 3 years ago with infantile autism and moderate intellectual disability. My calling for help has shifted from being a doctor to being a mother whose focus is solely on Tudor, who is seven, and my other child who is still under five. I'm also navigating life as a single mother, having been separated from their father for the last two years. This has been challenging.

When I heard the diagnosis, initially, it was a shock. However, I quickly mobilized myself. My motivation as a mother is at its highest level, both now and from the very beginning. I have approached this challenge from multiple angles. It is indeed a challenge for me and an experience. The daily hardships are significant, especially since separating from their father; I have to shoulder all the responsibilities and struggles by myself. It's continuous work without breaks. I only get a little rest during sleep; otherwise, it's a constant effort.

I am carrying this burden alone. Honestly, I rely on myself for the most part, without any false modesty. Family support is practically nonexistent at the moment. On the other hand, I do have support from therapists and people around me. I select those I trust, so I can stand strong, survive, gather my resources, and recharge my batteries. This human resource is essential... I'm not sure how to explain this. But especially since I am alone, having moments of respite is vitally necessary. It alleviates the constant pressure. Yes, even just five or ten minutes, or during his therapy sessions—an hour or so—provides a much-needed break, not just for me but also for him and my other little one. It's important for Tudor to have interactions not only with me and his little brother but also with others. Building connections with different people allows for mutual understanding and social interaction, which is really important.

Right now, the help we get is rather fragmented. This means that a day in the life of Tudor is also fragmented. For example, he goes to kindergarten in the morning for a short period,

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attends therapy and then goes back to kindergarten after therapy sessions. Some days of the week, he has private therapy as well. My concern is that we need to make sure the therapy continues at school too. I'd love to see the school activities integrated with his therapy—for example, that his homework should align with what he learns in therapy. This approach would be beneficial, and would really support us as a whole family.

So, when professionals would build a community or network around Tudor to ensure he receives the greatest possible benefits, for me it would all start with organisation. It is the foundation of any construction. Just like a house, you must begin with a solid base before reaching the roof. Therefore, a strong organization is essential. Better communication among organisations is crucial and the lack of communication between institutions is detrimental. If I don't know what you are doing and you don't know what I'm doing, then we miss out on opportunities to collaborate. We should basically stick to the same objectives. We need to work together as a team rather than operating separately. Of course I do recognize the value of individual institutions each having their own methods, but it's important to remember that these are special children. It's not effective to see everything in the same light. The same reasoning counts for me and the organisations. For example, I would like the therapist to follow similar patterns to mine, but not to be a copy of me. It's important that we differentiate ourselves. Maintaining open lines of communication and feedback is vital. Organization is a key strength.

Above all, I know, I set high standards. I have high expectations of the professionals. And it is essential that I express my expectations clearly. I feel the need for feedback every time. The kind of feedback really depends on the situation and various factors. There are times when I need more information, but I also understand things quickly with just a few words. Given my motivation and prior knowledge, I'm able to align with the therapist effectively. Sometimes, I might want to ask questions or explore ideas further, but other times, minimal explanation is sufficient for me.

There are professionals that really stand out to me. There is this teacher from the kindergarten who is a wonderful example. She is truly a special person. She and Tudor have their own relationship, with moments of hugging and playing. She includes him in a lot of activities. I feel that he is included now. She is very approachable. There is a strong connection between me and her, as well as with Tudor's therapists, both professionally and personally.

It is also sensible if a professional is genuinely putting in the work. It's essential that their support is tangible and sincere. The effort is felt. And when I feel the commitment from educators and therapists, it truly makes a difference. This effort, coupled with effective communication, has been invaluable for both me and Tudor.

Being able to trust the professional is extremely important. Trust is paramount. If a parent comes to therapy but doesn't trust the therapist working with their child, it definitely affects the process. The process must be rooted in trust, communication and honesty. Those are key! They are vital. I'm not sure if there is anything else, really. I don't want to hear only positive,

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reassuring words; I need to know how Tudor was throughout the day: “The child was like this today, he wasn’t like that, he did this, he didn’t do that.” I value continuous feedback because I’m always monitoring his condition to find ways to support him better and prepare for the next day. This vigilance is part of my strategy to stay alert and ultimately help him. It’s important to note that children with autism have varying moods and responses. For example, Tudor can be quite different from one day to the next. I can often feel his mood—through his body language, tension, and movements. When he gets up in the morning, I can already gauge what kind of day he’s going to have. Sometimes he may open up during the day, but usually, my instincts as a mother are right. So I adapt on how Tudor is feeling on any given day and it’s important that also the professionals have this flexibility and that they approach a situation from different angles. Being rigid, sticking strictly to a plan without deviating, is not effective at all, it makes the process harder. If it’s not a good day for the child we need to utilize alternative strategies. That’s why we consider intervention plans that include plan A, plan B, and plan C. Professionals need to try several methods. We must find a way to achieve something, even if it’s small, both for the children and for ourselves. Professionals too can feel frustrated sometimes when things don’t seem to be working out, and I’ve certainly felt the same before. It can be disheartening at the end of the day to feel like we haven’t accomplished anything. Personally, I find great value in the contributions and efforts of the people I work with; it keeps me engaged, alert, and motivated. And the opposite is true; my motivation diminishes when I feel stagnant or ineffective.

Bottom line is; we must team up. Every therapist, co-therapist, doctor, psychologist, and counselor does contribute to the development of the future adult. And it’s true, not only to children with special needs but also for typical children. It’s important for everyone to contribute their part, and let’s be honest; just one person; whether it’s the therapist, the doctor, or the parent at home—can’t do it alone. It requires collaborative effort for meaningful progress. So, each person contributes a bit of effort to raise the ideal future adult and, in our special case, to help them reach their maximum potential.

I believe that anything—how should I put it—anything is welcome; any small contribution and effort made for each special and different child, from any direction, is beneficial and contributes positively. There was this doctor who wanted to test a new procedure for Tudor, and of course I was willing to try it, as anything in terms of materials and devices can add value. We will continue to participate in these experiences, as in reality they benefit both the children and us the adults. For me, it helps my personal growth, I really enjoy challenges; they motivate me greatly. I treat every opportunity seriously, as well as any interaction; for example, something that might seem trivial, like gluing a piece of paper, might not mean much to us, but for Tudor, it is significant. I consider these experiences crucial.

To strengthen Tudor’s network, I believe there should be more social opportunities for children to interact with one another, to foster connection, perhaps through group activities and for example incorporating walking, singing, coloring—activities that should happen together. At a community level, different centers and organizations should organize collaborative activities, rather than keeping kids separate.

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I also went to a parent's school, both for exchanging ideas and for emotional release. I have learned many techniques that I felt obliged to learn, both for myself and for Tudor. It helps me a lot. But other than that and the professionals that are concerned, I don't consider that I have this primary need for support at the moment. I rely largely on myself, and I feel that if I had the option to depend too much on others, it might change how I function as a person. I worry that when the support I give is taken away, I might no longer feel useful or capable of making a meaningful contribution anymore...

But on the other hand, when a larger community would be formed, it would also absolutely help. We then know each other, I know about you, and you know about me. If we're always in this space where I don't know what you think of me, it leads to a lot of uncertainty. When a community is created with open communication, and feedback, I think it becomes a bit more relaxing. What can I say? It's important to avoid separation. Because yes, that feeling of being separated from others is definitely there. Having a child with special needs makes that clear. But I keep trying in every way to integrate him.

I'm putting in more than the maximum effort to help my son. I'm unsure what the outcome will be, but I still hope and firmly believe we will make progress. My personal drive gets me moving again each day. I wake up every day with the motivation that even five minutes are important for him. In the evening I reflect on what we've contributed to his day. This thought helps me, I do believe that. And... what can I say? I think that effort, practice, patience, and perseverance do lead to success. I do have my difficult moments, I admit. But then I think: if I were in an empty room with nothing, I would have to cope and survive. How would I approach that? I don't immediately think of the difficulties; instead, I find a solution and adapt. This mindset has helped me adapt and rediscover myself.

I feel like I've entered a new world. I have to adjust to it. I never lose sight of the future I envision for my son, my Tudor. I give my all.

*We don't want to summarize all the do's and don'ts. Instead, we invite you to reflect. Because this is what a professional has to do: to unravel every story, to understand in any possible way what is being said and what is not being said. This unraveling makes it possible to offer aligned help. And sometimes, all we can do, is just listen, unravel and understand.*

*We would especially like to thank Maria for sharing her journey with us.*

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