

Autism

Let's not forget the parents!

Peggy-Ann Clarck

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(under the auspices of Raeger autism center)

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“That’s really heartbreaking. Sometimes I see that, too, he’s looking for words, you see the frustration that he can’t manage to express himself. Then I talk very calmly and I notice that it calms him down as well.”





Christiana Arzbach

1. Introduction

When I joined Raeger Autism Center over a decade ago, I noticed that parents were left with many questions. In searching for the right care for their child, they felt like they had entered a maze. There was so much they had to figure out on their own. Furthermore, I noticed that parents didn't always understand what the diagnosis of "autism spectrum disorder" (ASD) meant. Often, they disagreed with that diagnosis. After reading the book *Mijn Kind Heeft Autisme (My Child Has autism)* by Peter Vermeulen and Steven Degrieck, I decided to set up and give basic autism training. That training aims to mentally support parents in their search.

During the training, I take parents back to when they first heard that their child had (possible) autism and understood that their child needed more care. This training triggered many stories in parents. For example, that they were constantly being sent from pillar to post or that they didn't know what to do with their child with autism. The partner or environment can also deny that anything is wrong. The beauty of the training is that parents learn that they are not alone. From that, the idea of this book was born. A book that brings parents together and from which they can draw strength. They could use that, because often the training showed that parents felt misunderstood or criticized, that they became isolated and didn't receive support.

In this book, parents share honest, candid, and moving stories of how they live with their child with autism. Many parents report that the diagnosis of "autism spectrum disorder" touched them deeply. Emotions of sadness, loss, and in some cases also shame and guilt surface. Parents often struggle with the questions that arise, such as am I going to tell my family or acquaintances? How will they react? Should I just keep my child at home to avoid unpleasant questions and situations? Parents sometimes need psychosocial help to deal with such feelings. So there is every reason not to forget about the parents, if only to

give them a heart to heart and show through the stories of other parents – who may also be struggling – that they are not the alone in dealing with these kinds of emotions. The stories also show how others find strength within themselves to deal with it.

When caring for their children with autism, it is often not easy for parents to find their way in the Dutch healthcare landscape. Rules, different types of expense reimbursement, bureaucracy, agencies, forms, not to mention plenty of ignorance and misunderstanding, sometimes form insurmountable obstacles. If you have a child with autism and are confronted with the multitude of issues surrounding it, you cannot help but have a deep respect and admiration for parents who know how to move through the challenging landscape. This sometimes involves trial and error, as you can also read in this book, but most parents manage with admirable determination and grace.

The client, the child, always comes first. This is firmly embedded in our corporate culture and is in the genes of everyone who works at Raeger. Because these children are the future, our motto is: every child can develop. Since 2012, I have traveled all over the world and talked to pioneers in the field of centers for autism, asking how are they doing it? What is important? In the United States, they are much further advanced in Applied Behavioral Analysis (ABA) than in the Netherlands. I visited the institutes that were set up and developed for the needs of parents and came in contact with ABA. The successes were amazing. I returned with forty-five areas for improvement. These mainly had to do with the setting of the treatment location, among other things, having asked questions such as what do you need, what is related, what products do you use, are they safe and sturdy? In this field you also need well-trained people with the right schooling, including Board Certified Behavior Analyst®. And I always ask: is what is being employed efficient and effective? I want to know if the children are progressing and if that can be proven. So, we also do regular measurements and tests on the children. Each measurement shows

that they are making significant progress compared to the previous measurement. In this way, in the ten years that Raeger has existed, we have moved away from the model of primarily counseling and toward counseling and treatment. It is a much more solid form that bears fruit, with parent training for eating, sleeping, toilet training, and picto training, all in-house. In consultation with parents, we draw up individual care plans with concrete, far-reaching goals, developing a customized program for each child.

For the children (and their parents) it is important that they receive the best quality care from qualified staff and that it stays that way. That is why Raeger continuously thinks about how to realize a quality assurance system for ABA within the Netherlands. When I joined Raeger Autism Center, I was gripped by the need to provide quality care for children with autism. In addition to providing the highest quality, innovation remains a top priority. We continue to develop, and we have been able to build a wonderful team. There is a vulnerable target group that needs help and is entitled to good care. We can provide that care in a way that is accessible and affordable for them. Now we want to expand that social involvement and the knowledge base that Raeger has for society. This can be done, for example, through an Autism Helpdesk where organizations (daycare centers, municipal agencies, medical centers, etc.) can go with questions. We are also looking at other steps we can take in the future in the treatment of children and young adults with autism, for example, setting up a bakery or other business where people with autism can generate a salary under supervision, or new forms of recreation (a Raeger farm) and possibly a residential facility for people with autism. It's still future music, but it's already starting to sound gentle.

Hotoeper Kapar

If you have a child with autism, emotions and feelings of shame or guilt can cause you to lead a reclusive existence, afraid to go among people and avoid confrontations. Even if you know that shame and guilt are unnecessary,

feelings are usually not easy to dismiss. In our treatment program, we offer children and their parents what we call 'Hotoeper Kapar.' This stands for hope, future, perspective, opportunities, and participation. We offer hope, and we don't give up. With us, clients have a future, perspective, and opportunities, and we work on social participation. We want to reflect that in this book. Parents may read this as a helping hand, as a comfort that they are not alone in this struggle, that there are many parents who struggle with this. The book is also meant to give parents hope, inspire pride and perseverance, and, above all, encourage them to not give up. Autism is something beautiful and requires a different approach. Indeed, the world cannot exist without autism.

A number of companies are happy to hire people with autism, finding that groundbreaking successes mainly come from this corner. So there is every reason to be proud of your child with autism. In this book, that pride is also certainly echoed in the stories of brave and wonderful parents.

We see clients as pearls. We are proud to mean something in their lives.
Happy reading.

*Peggy-Ann Clarck,
Director-Treasurer Raeger*



Angelique Groeneweg-van Eijk



"I think it is not only a burden but also an enrichment. It's not only your child's journey, it's also yours as a parent."

2. The First Ten Years of Parenting Pretty Well

It all began with the start of Open Autism. Its initiative was in the hands of Naomi Veerman, who envisioned a center in which a proper place would be realized for her daughter Sienna. Later, Sienna's father Tony Illis became involved in this initiative. For compelling reasons, this collaboration came to an end and Tony established a new foundation under the name Raeger.

Tony came up with the name Raeger, which stands for the heron. In the present context, it is compared to the ibis that turns red after eating shrimp. This refers to our clients who change because of our treatment. We are grateful to both parents for this initiative.

Tony Illis and Sienna's story:

“Actually, the first ten years both raising and ‘managing’ Sienna went pretty well and easily despite her autism. Of course, we had to watch her constantly because she didn't understand that she could burn herself on hot things or drown in water, something that most young children *without* disabilities understand at some point, but with children with autism it just takes longer. And that takes a lot of energy and requires adaptability from your other children, because they never get full attention; you always have to keep an oblique eye on your autistic child. But looking back on it now, that was actually a super relaxing time.

“In 2015, Sienna was ten at the time, she developed a compulsive disorder that evolved into an extremely severe disorder in a year. It started with wanting to give a few more taps with her teeth against a glass before giving it back after drinking from it, but a few months later it was to the point where she could no

longer get from A to B without either having to touch everything along the way first or having to walk back to “tap” numerous times. That tapping consisted of touching something she had touched shortly before.

“That tapping became more and more severe; so much so that at one point she could no longer get out of the bath because she had to keep tapping the bottom with her back (even if you let the bath water run out and so she got cold, she would not come loose from her tapping). It also happened that she would sit or lie on the floor somewhere in the house and not come loose from it or that she would spit out swallowed food again because she had to chew several more times from her tap. Life then came to a complete standstill for her. All the things she enjoyed no longer worked out. Walking into town, going to the store, or taking a walk, going to her street dance and ballet, or even playing at parks like Ballorig, she could no longer do these things anymore. She became completely isolated and her only outlet to the world became YouTube, on which she spent entire days.

“Sienna also became increasingly depressed, desperate, and, consequently, aggressive, which is completely understandable when you become trapped in your own body. This resulted in some violent escalations. One took place when Sienna was taken by van to her then counseling center in Diemen. The person who was supposed to pick up another child from the van did not show up, so the driver brought this child inside and left Sienna alone in the locked van. She had a panic attack and people alerted an attendant. When the latter opened the door, Sienna made a wild move that hit the attendant in the face. The supervisor was upset, Sienna was upset, and her mother Naomi had to rush her to De Bascule (academic center for child and adolescent psychiatry). This affected Sienna for a long time.

“Another escalation was during a vacation in Rhodes. Sienna was supposed to go to Kos with me and my current wife Tamina in the summer of 2017, but the

day before departure there was an earthquake. The trip was cancelled by the travel agency, which was already a big disappointment for Sienna. As an alternative, we could go to Rhodes three weeks later. There, we already noticed that Sienna was less enthusiastic than she normally is on vacation. She had been looking at pictures of the Kos resort for weeks in advance and she had been looking forward to it and setting herself up for it. On day three, Sienna had a *meltdown* during lunch. The resort had three large pools arranged around a central island with an uncovered pizza restaurant on top. While eating, she became overexcited. We saw this happening, so we wanted to take the pizza and take her to the room where it was quiet. But Sienna wouldn't let us do this. She had to tap and wanted to stay put as she became increasingly overexcited. My wife asked me to go to our room ahead of time and she would come that way with Sienna, at her own pace. But a few minutes after I left, things went completely wrong. Sienna had a complete *meltdown*, overturned the table, screamed her lungs out, started beating around herself and also hit my wife. Two security guards approached the commotion and wanted to grab her. At that point she started screaming even louder; so at one point everyone was standing around her.

“Three hundred people, spread over three pools, were watching what was going on. My wife was shivering and crying, and a waitress ran to our room to get me. When I got downstairs, I heard Sienna screaming before I even got off the elevator. Once there, I grabbed her hard-handed and removed her from that situation. For the rest of the vacation, we still had eight days to go, Tamina did almost nothing but cry. Everyone in the resort avoided us like the plague, no one wanted to ride in an elevator with us, parents kept their children away from the buffet. It was really awful. Especially for Sienna, who was just happy the next day. I got pressure in my chest and throat that night. It only got worse over the following months and eventually resulted in burnout and sessions with a stress psychologist. For a time, my wife felt unsafe as soon as Sienna exhibited pent up behavior.

“Eventually, in the years that followed, with medication, we got the situation better under control. Sienna takes sertraline to stabilize her mood, so we haven’t seen aggressive outbursts in the last two years. She was given haldol against tapping, but that has since been phased out to zero, mainly because the tapping didn’t really decrease and it’s quite a violent drug. All in all, Sienna is now happy, cheerful, and joyful. She can somewhat control the tapping and sometimes even delay it (i.e. finish something first and then tap), but we still have a long way to go. We hold out hope that as she gets older – she is now seventeen – she will manage the tapping better and she will learn to do the things she used to be able to do again. The strange thing is that it is mainly the combination of compulsive disorder and autism that makes life so difficult. If it were only autism, I think we would all be tremendously carefree in life.”