נשמהלה
Neshamale
magazine

Sharing Our Special Experiences: Chizuk & Inspiration

THE EARLY YEARS /14

INCLUDING:
EARLY INTERVENTION TIPS
EI THERAPISTS SHARE THEIR EXPERIENCES & INSIGHTS
JOURNEYS TO DIAGNOSES

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ISSUE #19 // WINTER EDITION תשפ"ה

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Neshamale Magazine welcomes your contribution of articles, poems, personal experiences or any material that may inspire our readers. We will respect your request for anonymity. We reserve the right to edit all submissions for clarity, space and sensitivity.

We also request your comments, suggestions and donations. Please contact us if you are interested in the opportunity of sponsoring the next issue.

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In the upcoming issue we plan to focus on

Family Dynamics

How does your special child impact the dynamics in your home? In your role as a... Father? Mother? Sibling? Grandparent? Aunt/Uncle?

What can we do to ensure that these dynamics are strengthened and supported as opposed to being stressed or frayed from the impact of raising a child with special needs? Please share your articles, stories, poems and thoughts.

We always welcome photos, Wow! Stories, Memorable Mishaps stories, Sweet Spices stories, as well as any questions you may have for a Rav, doctor or social worker.

Deadline for submissions: **Feburary 9th**
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Dear Readers,

Welcome to issue #19, marking five years since *Neshamale Magazine* was first published. I feel so much gratitude to Hashem for bringing us to this milestone and hope to continue being *zoche* to bring *chizuk* to us all. I also want to express my appreciation to all of our dear readers who have contributed over the past five years – be it as a submission, sharing a story or a thought, or giving us feedback. It takes time and effort to be involved, and I know that you are some of the busiest people out there! It also takes bravery to share, and we are so grateful to the many of you who overcame your natural hesitations and gave a piece of your heart to your sisters and brothers.

I recently had an experience where I got to feel what it's really like to be asked to share. I was contacted by a representative from a well-known, widely read Jewish publication. She wanted to interview me about my role as editor of *Neshamale Magazine*, as well as about my life experiences raising my own child with special needs. I was unsure if I should agree, as I was truly uncomfortable with the publicity. *Neshamale* has been so well received within the special needs community, and we have always been happy to keep it contained. We never had the need to make ourselves known to a larger audience. On the other hand, this offered a lot of potential to spread the word to many more families who might be helped. We've never had funds to advertise, and have only connected to readers through word of mouth. Here was a chance to let tens of thousands of families know about the magazine, among whom many would surely benefit from receiving it.

After speaking to those wiser than I, I was encouraged to go ahead with the interview. They felt that the opportunity to share *Neshamale's* positive perspective on raising children with special needs would inspire others, and the chance to give the magazine such wide exposure made it worthwhile. So it was with some (okay, a lot!) of nervousness, that I agreed to the interview. We made up a time to talk and then I got busy preparing. Maybe some people can just wing an interview, but I am not an "answer on the spot" type of person. I spent hours typing up what I wanted to say, how I wanted to phrase it, which points I wanted to stress.

As the time of the interview approached, I got more nervous, with my thoughts constantly tied up in planning how to phrase my answers. I cleared my evening, found a quiet spot, and waited for the phone to ring. The time finally arrived, but the phone never rang. I was surprised that such a professional publication was not keeping their appointment, but I understood that mistakes happen. I was even more surprised that there was no sort of communication apologizing for the missed appointment.

I finally reached out to them to ask what happened, whereupon they apologized for missing the appointment, and we rescheduled. Once again, the same scenario played out. I prepared, cleared my schedule, paced nervously, and waited. No phone call, no update. I'll be honest – I was quite upset. I felt that I was agreeing to share something that was personal and important to me, and they were not respecting my time or my feelings. I understand that things can come up in life and appointments need to be cancelled, but their attitude hurt me the most – no real apology, just an unfeeling: "Sorry it didn't work out, can we reschedule?" I knew that the interviewer meant well and was trying; it sounded like she was just overworked.

I decided to give it one more try, agreeing to a time that was better for the interviewer, who lived in a different time zone, although it stretched my schedule a bit. I was desperate to get this talk, that had been hanging over my head for too long, over and done with! But 1 am came and then 2 am came and the phone never rang. I realized then that I was done. Not out of anger or spite. Rather, it was a feeling of: "If you can't respect my story, then you won't do it justice. If you won't do it justice, then you can't be the person to tell my story." I told her so the next day, as nicely as I could. She said she understood and I hope that she will treat the next person she interviews with more consideration.

I felt that Hashem put me through this stressful experience to help me appreciate all of our wonderful contributors. When someone calls me up and volunteers to share their story, they are essentially sharing a piece of themselves. It's never easy. It takes a lot of time. (It can take five hours of conversation to put together a feature story!) It takes a lot of effort. And most of all, it takes guts. It's scary to be vulnerable, to share your feelings with the world: the good, the ugly, and all that's in-between. But it's worth it. Because we all need *chizuk.* And who can give it better than one of us to another? We all have the opportunity to be there for each other. That's the goal of *Neshamale* – to create a warm, safe place where all of us can share our tips, feelings, advice, and stories.

I hope I have never treated any of our readers or writers in the way that I was treated. I have always had respect and appreciation for anyone who has reached out to contribute in any way. But I now have a new level of understanding of what really happens on the other side. So please, reach out and share with all of us! Let me put the lessons I learned to good use for you!

Looking forward to hearing from you, *Chayala*

Chizuk Boost #11

Rabbi Baruch Rabinowitz

Lighting Up Our Neshamos

Hashem gave *Aharon HaKohen* the *mitzva* of lighting the *menorah,* which, as *Ramban* tells us, alludes not only to the *menorah* of the *Mishkan,* but to the *menorah* of the *Chashmona'im* as well. Our Chanukah *menorah* serves as a continuation of *Aharon Hakohen's avoda* of lighting the *menorah* in the *Mishkan*.

The Torah does not say בהדליקך את הנרות but rather בהעלותך את הנרות to teach us that the *Kohen* has an obligation to hold the candle until מאליה שלהבת עולה – until the candle being lit rises and burns independently. Once it can function independently, the *ner* doing the lighting can be removed.

Chinuch HaBanim is a continuation of this *avoda* of בהעלותך. The word *chinuch* means *haschala*, getting my child started. My job is to use my *aish*, my *neshama*, and hold the fire to my child's *neshama* עד שתהא עולה מאליה. My job is to help him become independent so that his own fire, his own *neshama*, his own *avoda*, his own *nefesh,* is ignited with the *ner mitzva* and *ohr* of Torah. At that stage, my *chiyuv* of *chinuch* basically comes to a close.

There are those children, however, who will not be able to rise and become independent and then work, in turn, to ignite the *neshamos* of their own children. My obligation, then, is to hold my *ner*, my *neshama*, to his *neshama* and keep holding it there all the way to the end. Even a child who is limited is still a נר פתיל שמן - נפש- which I can, and must, ignite by holding my *aish* to his.

Aharon HaKohen was told to be מדליק ומיטיב את הנרות – to light and clean out the *menorah* every day. A **constant** involvement, day in and day out. My daily involvement with my child with special needs, holding my *aish* to his, is an *avoda* of מדליק ומיטיב, cleaning and lighting, lighting and cleaning.

It is imperative for me to remember, however, that my *neshama* can only ignite another, if it, itself, is burning with אהבה כשרפי אש - a fervent *ahava* for the child *HaKadosh Baruch Hu* has given to me, challenges and all. Rav Moshe Shapiro zt"l told me many times regarding my son: הוא יודע מי אוהב אותו– he knows who loves him, and he responds best to that *ahava*. He knows. And HE knows.

In order to do our *avoda* in a manner of בהעלותך, we must continually seek our *aish* of connection to Hashem. We ourselves need to constantly desire *aliya,* just like the flame which incessantly strives higher – waxing and waning, and growing again with a new spurt of energy, as it climbs higher.

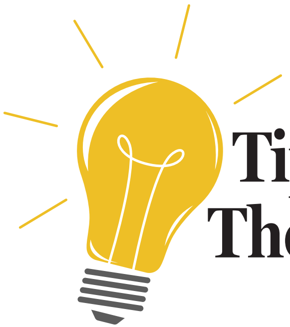
Shemen, with which we light the *menorah,* rises to the top. It is connected to above and beyond. *Shemen* is *shmona* – eight, higher even than 'seven' which represents the *nekuda haruchni* within the six dimensions of nature. Our *avoda* of *aish,* of *shmona*, of working with our *heilege neshamos*, our *neiros* – is an *avoda temidis,* a constant involvement. מדליק ומיטיב. We are privileged to have a mission that doesn't end.

ויעש כן אהרן, says Rashi: שלא שינה – he did his job exactly as *HaKadosh Baruch Hu* wanted. And so, too, must we accept the responsibility Hashem gave us to be *mechanech* our *neiros* with *ahava* and with *deveikus B'Hashem*. בהעלותך – an *aliya* igniting *neshama* to *neshama.*

This Chizuk Boost is excerpted and adapted from one of Rabbi Baruch Rabinowitz's weekly 10 minute Chizuk shiurim for parents of children with special needs. There are now over 250 recordings, which can be accessed on Kol HaLashon (718-906-6400, press 1, 4, 97, 2). They can also be accessed at yedei.org

I am so happy that this question was asked so that I can share a very important answer: Get a Rifton Activity Chair. This chair is very comfortable, is extremely adjustable and has a large heavy duty tray that locks on. This keeps your child contained and restrained during mealtimes. I have tried recommending this to many people and have heard all kinds of excuses: it's expensive, It takes up so much room, My child won't like it, etc. I cannot stress enough how all of that is just excuses and it is so worthwhile to invest in this item. Yes, you will want to go through insurance and it's a pain but most children will end up getting approved. Get in touch with Children's Specialized Hospital and have a rep. there help you. If not, perhaps you can get a used one for a more affordable price. It's very durable and lasts for many years. It does take up a lot of room but it takes away so much stress from mealtimes that it worth it!!! My advice about the child who won't like it is to START YOUNG! If your child is three years old and phasing out of a high chair, NOW is the time to get a Rifton Activity Chair. If the child is always in this chair during mealtimes, they will not know anything different and will be fine with it. It actually is very calming for them to be able to eat without being distracted by all the people and food around them without having to fight their impulsivity every minute. It's true that once a child is used to sitting at the table it would be hard to get them into this chair. It is really for the best of the entire family.

G.W.



Tips From The Experts

hey! that's us!

What do you do about a kid who cannot control his desire for food? He is always taking his siblings' nosh, touching the food on the Shabbos table, grabbing food off other people's supper plates... We often end up with lots of crying kids and it makes mealtimes very unpleasant.

If our son isn't in the kitchen when we start supper (which is often; he's usually playing or reading in a different room), before we let him know that we're eating we serve everyone else, and then take off significant portions for everyone who would want more, or isn't home yet. Those portions are hidden in various cabinets or drawers. Once there's only about 2 portions left in the pans, we call him to supper. This way he can "finish everything left" as he likes to do, but we still have food for everyone else.

When it's not supper - with Shabbos food we leave some in the pan before bringing out a serving platter (which he will finish). We also hide anything that he might crave during night-snack times.

And finally, it's not always perfect. We do have hot-dog meltdowns, pringle frenzies, and entire nut containers depleted at times - but we're doing the best we can and most often keeping everyone else happy. When they see that, it's easier to handle the few times it didn't work.

T.D.

We came up with a simple out-of-the-box solution to this problem and I am so happy to share it with all of the readers. We set aside one drawer in the kitchen and filled it with snacks. Our daughter knows that this drawer is hers and she can always take food from there. Just having the food there greatly reduced her anxiety during mealtimes, as she knows she can always have more food! If she starts grabbing or taking things from the cabinet without permission, we redirect her to her drawer. Miriam G.

The key to dealing with negative behavior is to give the child a replacement behavior. In this case, it would be a sign or a word indicating that they want more food. Every time they start grabbing, you stop them and practice the sign/word and give them more food. After they get the hang of it, you add in a consequence that if they grab, it gets taken away and they get ignored for a minute or two. Then, they can ask for more. With time and patience they will learn to ask instead of grab. This concept can be applied to other negative behaviors as well. A.S.

I don't know what your child diagnosis is. My son is a 12 year old with downs syndrome and over the years we tried implementing some strategies. At the supper table we get one portion only, so he sees what's in front of him - no doubles! All the rest of food - bekelach, challah, dips- we try putting away right away after we are done. During mealtimes, we make sure he sits next to an adult and remind him what he's allowed to have before the meal. The rest of the food stays beyond reach.

It sounds like your child is behavioral and so similar to mine. Most important of all is that parents should stay calm and not make big deal out of behaviors so other kids will eventually learn. Hatzlacha with everything. Chumy Brisk

Question for the next issue:

I read Batya Dancykier's article about toilet training in the last issue. I was already doing much of what she suggested, and I appreciated the extra tips and encouragement. I would love to hear what worked for other parents who are going through this tekufa.

Specifically, when you are following the time-training protocol, or when the child is already officially trained, and then starts having accidents again, with no apparent reason. We can have a few months of staying dry, and then suddenly there are accidents all the time… It's super frustrating.

Thank you in advance for taking the time to share any ideas you have, or tips that have worked for you. --T.K.

Please send us your answers to: neshamalemagazine@gmail.com or text your answers to: 848-299-2908

THE ROAD TO
Raising Eli

Rina Braun

"Perfect, perfect!" the sonographer chirped while viewing the images on her screen. I held on to those words, allowing myself to feel reassured and hopeful. The pregnancy was so difficult, but I would revel in the thoughts of the healthy child that the all-knowing sonographer so confidently proclaimed I would have.

Mazel Tov! It's a Boy!

Eli's labor seemed to take forever, with some added complications and drama. By the time my son was born, I was on oxygen and somewhat disconnected from the reality unfolding around me. As such, I was not even alarmed when they rushed him to the NICU, oblivious to the drama ensuing right under my nose.

I was talking happily on the phone when my husband walked into the room and asked me to please hang up the phone. I did, and he looked at me and said: "They think the baby has Down Syndrome." To this day I am not sure what came over me (although in retrospect it sounds suspiciously like denial!), and I protested: "But he is so cute!"

The next day I went to visit my baby in the NICU, but they did not let me hold him. I looked at him and knew it was official. He really had Down Syndrome. I experienced a mix of panicked denial ("No no no!"), and attempts at determination ("We're going to do this!"). My husband stayed with me over Shabbos at my request, as we need to process this ourselves and together. The other children were shipped off happily to their grandparents.

Over Shabbos, there were words, silence, tears, and laughter. At one point my husband looked at me and said: "We do challenges." It sounded like a mission statement, and at the same time it was very grounding. We were going to do our best.

In the Beginning...

I went home without my baby. I was so sad—and I was so busy! We had other children, so there was no time to be sad, but for several weeks, every time I picked up a fork to eat I would start to cry. I was blessed to have a fairly quick and smooth post-partum recovery, yet I was so sad to be home without my baby. I was so afraid of the present, so afraid of the future.

The sonographer had said the baby was perfect—but here I was, home without my baby, and my baby had Down Syndrome. Where was the perfection?

My baby was in the NICU for five weeks and it was quite an ordeal. They discovered holes in his heart, but wanted to wait until he showed early signs of heart failure before performing surgery to repair them. This baby was our fourth child, with our oldest in Pre1A. Every morning, after the children went off to school, I got a ride to the hospital, usually with the kind *Bikur Cholim* volunteer going to restock the hospital's Kosher Pantry. Once there, I held my baby, sang to him, and cuddled him. Ironically, it was in the NICU, amidst the beeping machinery, wires, tubing and anxiety, that I began to love my baby.

We were determined to bring our son home. We wanted him out of the NICU. The doctors wanted to keep him there and do his heart surgery there, but our baby had a family at home, waiting to get to know him! My husband and I were CPR trained in the hospital and taught how to place an NG tube. By nature I am super-squeamish. I did what I had to do, but knew I was relying heavily on my husband to take on a lot of the medical aspects of this baby's care.

We were so relieved when we were finally able to take him home. And we were scared! We were sent home with a baby with a somewhat functioning heart, who could not go near any other children, and we were awaiting those early signs of heart failure. I remember not knowing how fast things can go downhill, and I worried that, even with all the monitors he was connected to, we could miss an important sign.

It was such a hectic time. Many, many people came to the baby's *bris*—on *Erev Sukkos*. I was afraid that he would cry a lot and his heart would not take it…but I could have had more confidence. Eli cried like any other baby, and was content soon after.

My neighbors arranged meals for about six weeks, and some family members pitched in as well. To this day, I do not know who made that gorgeous salad with all the beautifully cut up vegetables that looked like it came out of a magazine…and lots of other delicious things…but my family had all the food they needed over all the *Yomim Tovim*. At the time, all of these details felt irrelevant compared to the super-medically fragile baby I had brought home. In retrospect, I wish I had the presence of mind to keep track and thank everyone—they took such good care of us!

Moving Along...

During this difficult time, my husband and I made a decision that set the foundation for how Eli integrated so beautifully into our family. We had a playroom off the kitchen, and an extra bedroom with an attached bathroom upstairs. I considered turning that upstairs bedroom into Eli's room, but quickly realized that being isolated upstairs with nurses would be a real barrier to his becoming part of the family. It would also be impossible for me to monitor what was going on with him, as well as the nurse's activities and interactions with my other children. So, playroom it was.

Next, I called the nursing agency and explained that we kept standards of modesty, and that we expected anyone working in our house to be dressed with appropriate coverage. I was very explicit and they respected our values. Unfortunately however, we were sent middle-aged cat ladies—women who constantly needed to share their whole life stories with me. I sometimes felt like they expected me to give them as much attention as I gave my own children!

We split Eli's allotted hours into two eight-hour shifts. I was able to work part-time, and the nurse stayed through the afternoon so I could care for my other children. The night nurse came from 11 PM until 7 AM, so we were able to sleep. This definitely helped us to be more physically and emotionally capable!

Initially, I was afraid to be home alone with Eli, but eventually I got used to it. He came home accompanied by what seemed to be a mini-hospital. My playroom was filled with strange, scary medical equipment. The other kids played "hospital" and "doctor" with dolls for months, processing the experience through play. Keeping Eli on the main floor was simply incredible. My kids took a relatively short time getting used to him, and it felt nice that he was in the playroom like a regular baby. We clearly saw how this set-up was part of Hashem's plan for us.

Now that we were settled into some sort of routine, we were left waiting for early signs of heart failure. When those signs came, we scheduled surgery for Chanukah, and *baruch Hashem* it was successful. Fortunately we had a very experienced and skilled surgeon—who retired almost immediately after our son's surgery. It was as if he waited just for us! After his surgery, Eli started to thrive; he actually smiled his first smile in the hospital! As we emerged from that first year with Eli, he slowly shed his medical issues and graduated to "Normal Down Syndrome" status.

In it for the Long Haul...

Eli joined the world of Early Intervention, and I requested that the therapists take it slowly, providing all the therapy he would need to meet every milestone properly. While I wanted Eli to "hurry up," I also had to remember that the theme with this diagnosis is "slow but steady"—that he would make progress in his own time. He only began walking around his third birthday.

Eli is now a bright, adorable, sociable, and fun eight-year-old. He is loved by his siblings. They expect him to be one of the gang, and they are probably the strongest influencers of his social appropriateness. However, he struggles to focus, which interferes with his learning. We are working to help him become as successful as we know he can be. At the same time, we are grateful for his strengths and for the overabundance of *chein* that Hashem has graced him with.

We try to stay goal-oriented and focus on the big picture. Teaching Eli one skill, one behavior, one boundary at a time, takes a lot of patience…and more patience…and more patience. He is eager to learn, and so sincerely eager to please.

Sometimes it can be hard to remember that he is not TRYING to make life challenging for us; he is merely challenged by his own limitations.

I ask Hashem to help me be patient with him. Although I am by nature a very patient person, it seems that Eli needs a bottomless well of patience. I sometimes feel guilty that I don't have enough of what he seems to need. I have come to accept my own human-ness as part of my full package. On the occasions that I express some frustration, Eli can be ok with it—he is one of the most forgiving people I know.

Eli leads all of us on the road to *shleimus*-the perfection of our own *middos*. He teaches us patience, perseverance, kindness, and acceptance. He is so friendly and outgoing to everyone he meets, never judging others. If someone hurt him in school, he will never say who it was. On the other hand, *shmiras Shabbos* can still be a struggle, as playing piano while he sings enhances his *oneg Shabbos* so much…

My hopes and dreams for Eli are the same, yet different, as they are for the rest of my children. I want him to be content with himself, accepting of himself, and happy with his lot in life. I want him to belong—to our family, to a community, and to *klal Yisroel*. I want him to appreciate his strengths and to be as independent and productive as he can be. Aren't these the things we want for all of our children?

As I watch Eli (slowly!) grow up, I am watching myself grow too—and this mixed challenge is a tremendous *bracha*. I daven that Hashem should continue to give us the strength we need for many years to come. May we greet *Moshiach* soon—all us mothers, fathers, and siblings—escorted by our precious special children!

The author is writing under a pen name. She can be contacted through Neshamale Magazine.

Sensory Bin

- Winter Snow Bin -

Chayala Tawil

I decided to be brave and venture out of rice bins for the first time. The idea of a theme appealed to me and I decided to create a winter-themed bin. I kept thinking of different ideas and couldn't decide which one to go with. So we ended up trying out different variations. The basic idea was to have something white that looked like snow as the main filler, and other smaller pieces (marbles and snowflakes) for decoration, with penguin figures as the focal point of play.

I used the same marbles, snowflakes, and penguins in all of the bins. The only variable was the "snow." In the first bin, we used white pom poms. The pom poms were fun, but they did not have a very sensory feel to them, as they were pretty small and stiff. Another problem was that, for some reason, they were constantly "jumping" out of the bin and landing all over the house. This may have worked out better with larger size pom poms.

I then thought of trying out cotton balls, which are much fluffier. I found extra large cotton balls that were super fluffy, and these filled up more of the bin. Most of my children felt that the cotton balls were a better idea than the pom poms, but feel free to try either one. One thing that's important is to get enough to really fill the bin. When the bin is only surface covered, there is much less sensory exploration and immersion. I was surprised by how much we needed to fill even a medium sized bin.

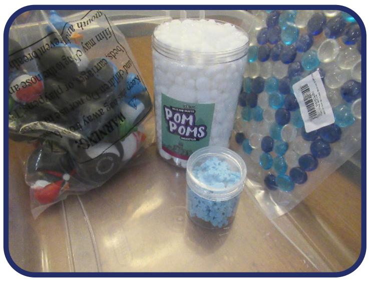
My last form of snow was more closely related to the real thing—it was much messier, and you could even make snowballs with it! We mixed baking soda with water to create "snow." This was by far the most entertaining bin, as the snow felt very soft and inviting to play with. There was so much to do with it, such as burying the penguins inside, and creating "tracks" and "footprints" in the snow. This one

was the winner in terms of the length of time and interest in playing with it, but it is more of an activity, and not the type of sensory bin that you can just pull out and put away at random times throughout the day.

I would suggest making an everyday winter bin with pom poms or cotton balls, and then on a real snow day when you need a new activity, to remove the cotton balls and fill the bin with baking soda snow instead!

As we are starting to expand our bins, I want to mention a note about storage. There are two ways to keep multiple bins. One is to simply stack the bins and make a collection. The other way is to have only one bin in use at a time, with the other bins' components stored in large Ziploc bags. When you want to switch the contents of the bin, simply pour out one filler for another.

Simple Snow Bin



3000 mini pom poms or 300 extra-large cotton balls
20-50 blue marbles
20-50 plastic blue snowflakes
5-10 plastic penguin figures

Snow Activity Bin

Same as above, but substitute pom poms or cotton balls with:
6 cups baking soda
¾ cup water
Mix well and see if you like the consistency. It should not be "wet," but should be able to be formed into "snowballs."

I used a 4 lb. box of baking soda from Walmart. The pom poms, cotton balls, marbles, penguins and snowflakes were bought on Amazon. These items are also available in dollar stores, Walmart, and craft stores.

If you are worried about a child putting small pieces in his mouth, skip the marbles and snowflakes. Although not tasty, it is not a safety concern if a child would taste the baking soda snow.

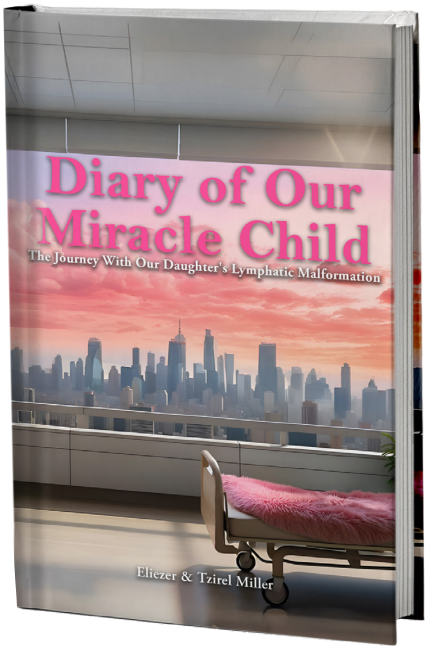
I hope you enjoy this winter fun activity and have a very fun and safe winter, indoors and out!

A Gift Passed Along...

SHARING THROUGH WRITING

Chayala Tawil

Featuring Tzirel Miller, co-author of the book Diary of Our Miracle Child: The Journey with Our Daughter's Lymphatic Malformation.



Hi! Please introduce yourself and tell us something about your background.

I grew up in Brooklyn, married my husband, Eliezer Miller from Monsey, and began married life in Brooklyn. We had five children while living there, the youngest of whom was Shalva, the subject of the book. We moved to Lakewood, NJ about three years ago.

Tell us about how your medical journey began.

When I was expecting Shalva, everything was normal until my 20 week sonogram. A few days before the sonogram, I suddenly started to feel very worried that something was wrong with the baby that I was carrying. My husband dismissed my concerns as baseless, which technically they were, but really, they were a mother's instinct preparing me for the appointment.

At the sonogram, it was clear that something was very wrong. We were sent for further scans and appointments and eventually told that our unborn baby had a rare diagnosis of Lymphatic Malformation of the abdomen. The doctors told us that there was a very slight chance of the baby surviving the pregnancy or the birth and that if she did, she would surely be a vegetable or brain-damaged. They were adamant that we should end the pregnancy *c"v*.

Of course, that was not an option for us, nor did we want it to be. The news was overwhelming and devastating on every level. I did not feel at all equipped to be dealing with such a life-altering situation, and it was an extremely challenging time in our lives.

How did you deal with such a difficult situation?

I'm the type of person who can't handle medical situations; I pass out at the sight of blood. So, something of this proportion felt well beyond my capabilities. I felt very confused—on one hand, I knew Hashem is perfect and gives us only what we can handle, yet on the other hand, I kept questioning Hashem: "How can You give me something that I can't handle?"

I cried to Hashem constantly, asking for help, telling Him my worries and fears. I kept saying: "I know You are perfect; hold me in Your hands, because I can't do this alone." And He did. Once my daughter was born, although it was traumatic and terrifying, I managed. Hashem really gave me the strength I needed to pull through. You think you can't do something because you haven't got the strength yet, but when the time comes, Hashem gives you what you need.

Did the doctor's predictions come true?

B"H not. Hashem runs the world and only He determines the outcomes. If you would see my daughter, Shalva, today, walking down the street, you would have no idea that she has such a diagnosis. She looks adorable and is 100% cognitively normal.

To backtrack, Shalva was born with a huge malformation in her abdomen, just under the skin. It looked like something the size of a watermelon protruding out of her. It was a huge *nes* that it was far enough from her internal organs and did not affect them negatively. She had surgeries, procedures, and many complications. It wasn't simple at all. There were many heart-stopping moments, such as one *Sukkos* when it flared up and we had to rush to the hospital and do an emergency surgery and blood transfusion. The earlier years were filled with medical sagas. Now she is, B"H, much more stable. We just need to be vigilant in observing her to ensure that nothing goes awry.

How did you come to write a book?
Since Shalva was born, people would encourage me to write. I was told numerous times: "You should write a book, you have so much to share!" But I just wasn't comfortable with the idea of sharing my personal life with the world. At one point, I took a life-coaching course. I didn't end up doing any coaching, but the course helped me build up the courage to write the book.

I started writing together with my husband, and it was a great experience for us to do this together. My husband felt that if the book would help even one person, it would be worthwhile. It was harder to convince me, as I was really protective of my privacy. Eventually I came around to my husband's side.

Still, even after the book was set to go to print, I panicked and wanted to back out! The feeling of vulnerability was so strong, and I was so apprehensive about exposing my life. It took a lot of courage to publish it.

How do you feel about it, now that you know people are reading your book?
The encouraging feedback keeps me going.

The book started selling on Amazon on a Friday. The following Tuesday, I received an email from a woman telling me that she bought the book and read it cover to cover. She wanted to connect with me because her daughter suffered from the same diagnosis! The fact that the very first woman who bought my book had a daughter with the same rare diagnosis was so mind-boggling that there was no way not to see the *hashgacha* and feel Hashem's approval. It was like He was telling me that I surely did the right thing by publishing it.

When someone told me that they bought our book, I felt nervous knowing that they were reading it. But as time goes on and I get such good feedback, I have gotten more confident about it. It gives me *chizuk* to know that it was a worthwhile endeavor.

Were there other benefits to writing, aside from the zchus of helping others?
Writing our story was healthy and therapeutic for us. It was very interesting to go back and reread what I wrote – sometimes what came out of my pen was not the way I would have expressed my story in words. The written word can be deep and powerful and sometimes more honest than the spoken word.

Another benefit was looking back and appreciating how far we had come. Though it was actually difficult to write about the doctor's terrible predictions, it also made us realize how many *nisim* Hashem granted us, and how much we have to be grateful for. The fact that we were prepared to expect the absolute worst (which seemed terrible at the time), ended up helping us be so excited about aspects that didn't come true. The fact that Shalva was born being able to eat, see, and move, was so unexpected and gave us such joy. We were able to focus on all of the good, and not only on the challenging aspects.

However, I never would have stuck with writing the book, if not for the goal of helping others. That was my real drive to write it; I would not have done it just for myself. When I get the feedback, it is gratifying to know that my goal was successful, as it is bringing *chizuk* to so many others.

Where is Shalva on her journey today?
Shalva is now a delicious five-year old girl. We are so grateful that she is healthy and able to attend regular school and lead a normal, happy life. These are things we never could have imagined five years ago! As she gets older, she understands more about her condition. We have never hidden anything from her, and she accepts her condition with ease and confidence.

At one point, we had to amputate a toe. One day, I saw her taking off her sock and showing her five-month old baby brother: "Look, I only have four toes!" I always tell her that Hashem made all of us different, and that she was born with a boo boo in her tummy.

We are open with her about procedures in advance, explaining what to expect and normalizing the experience. We hope she will continue to be open and confident as she grows older, showing the world how to handle challenges with grace and acceptance.

Hashem should grant her a refuah shelaima and her parents much *nachas* always!
It's beautiful to see how you've used your challenging experiences to bring *chizuk* to others. We look forward to reading your book!

Have you (or someone you know) used their talents or experiences to help others? Please share with us how you've passed a gift along.

I

WOW! MOMENTS

compiled by Fraydel Dickstein

The following was shared by a caseworker from a respite agency:

I'd like to share with you a noteworthy story we experienced that left us speechless and in awe! It was before *Succos* when we realized that we had a slot available for *Succos* at one of our respite homes, so we reached out to a mother of an 8-year-old recipient who also has another child with special needs, a 7 week old baby, and a couple more children, to offer them the slot at the respite home.

At first, the mother was very excited by the idea of having a somewhat peaceful *Yom Tov* with her daughter away. But then she said that she didn't think it was a good idea, because her daughter had seen all the cooking and baking for *Yom Tov*. Rather than go away, she might want to enjoy all the good food at home. The mother asked her daughter, and the girl actually refused to go away for *Yom Tov*. She remained home with her mother, 7 week old sister and two other siblings! The heart and *mesiras nefesh* of a *Yiddishe Mameh* for her children, regardless of how challenging they are, is indescribable!

* * *

Shortly after we weaned our preemie daughter from her feeding tube, she got a stomach virus and couldn't keep any food down. She became dehydrated and her pediatrician told us: "Your daughter belongs in the hospital now, but what are they going to do with her? They'll give her fluids. You can do that at home. Put her feeding tube back in (She had an NG tube), and if you manage to give her a full bottle of Pedialyte overnight, you can stay home." So we had a continuous feed of Pedialyte overnight, and BH, she was better the next day. To me, the fact that the feeding tube spared us a hospital stay felt like a hug from Hashem!

* * *

As a mother raising a large family that includes a special needs child, I often wonder how everyone is impacted. One night, I was listening to music on my phone, and I hit one of the files. I heard my seven year old, who is right below Shua, our very special needs child, saying: "Hi, my name is Shaindy and I have a special needs brother, but really he is very normal in so many ways...."

It was so beautiful for me to hear these words, as I worry about her thoughts and feelings, especially in her position right under our special needs son. It was especially heartwarming to hear how positive and easy-going she is about Shua.

* * *

A friend of mine has a daughter with Down syndrome, whom they love very much. One of her married daughters gave birth to a baby who has Down syndrome. My friend was so worried that her *mechutanim* would be upset. When she spoke with them, they said: "No, we consider it a privilege to have a child with special needs in our family!"

* * *

One day Yossi came home and told me Morah Goldy was coming. I could not believe what he was saying. Morah Goldy, who had just gotten engaged, called me the day before to ask if she could come visit Yossi. I told her no, as Yossi was not feeling well and needed to go to sleep. She was indeed supposed to come that day. I could not figure out how Yossi knew this, and I asked if anyone had told him, but it didn't seem like it. I couldn't help but think that Yossi's *neshama* is on a higher level and perhaps he really knows things beyond the regular scope.

It brings to mind how no matter what Yossi is doing, he always stops when my husband makes *Kiddush*. He often put his fingers in his ears, as if the *Kedusha* is too much. Other times he listens beautifully, but you can always see how special the *Kiddush* is to him.

* * *

Being that our delicious eight-year-old Avrumi is non-verbal, we never really know what is going on inside his mind. How much does he understand? How much does he remember? Thus, the quintessential "Wow Moment" for us is when he shows us how much he "gets it."

One such moment happened this past *Simchas Torah*. We usually take Avrumi and our younger children to *Bais Medrash Govoha* for the first few *hakafos,* which are absolutely beautiful, and not yet too squishy. There are two or three circles forming a spread-out ring around the outside perimeter of the *Bais Medrash*, encircling a ring of many **Sifrei Torah** in the center of the room. The atmosphere is one of pure joy, as hundreds of men who have dedicated their lives to *Limud HaTorah* rejoice with their very essence.

I parked Avrumi in his wheelchair in the corner of the *Bais Medrash* for him to sit and watch. When I felt that it was safe to take him out, I held his hand and walked him around the dancing circle (I needed to make sure he wouldn't pull anyone's Tallis off!). When I led him into the circle, I was pleasantly surprised when he put out his other hand, and held onto the hand of the man in front of us, joining the dancing circle like everybody else!

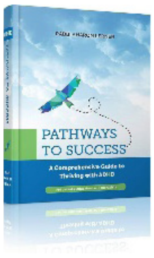
Then came the biggest shock. He started tugging at my hand and pulling me. Curious where he wanted to go, I allowed him to lead me. He marched across to the center of the room and reached his hand out and touched one of the *Sifrei Torah!* He then proceeded to encircle the ring of *Sifrei Torah,* reaching his hand out and touching each one! Did he remember this from last year when I held out his hand to touch each Torah? Was this his *neshama* trying to cling to the Torah? Whatever the reason, it was a moment of personal *simcha,* as my non-verbal son expressed his own form of *ahavas haTorah* in the most beautiful way.

Supportive Reading Material

Book List and Details by Toby Brief | Comments by Chayala Tawil

4

Pathways to Success: A Comprehensive Guide to Thriving with ADHD



Author:
Rabbi Ahron Lerner
Publisher:
Menucha Publishers
518 pages, Adult level

Rabbi Lerner is a psychotherapist based in Ramat Beit Shemesh. His insight provides an eye-opening perspective and practical roadmap to dealing with ADHD.

Publisher's Summary: Pathways to Success offers parents, educators, therapists, and anyone affected by this challenge practical wisdom and firsthand accounts about ADHD in all varied forms - from hyperactivity to daydreaming, from impulsivity to burnout.

With compassion and insight, best-selling author and psychotherapist Rabbi Aharon Lerner offers astute advice, dispels common myths, and explains treatment options for ADHD. He acknowledges the struggle while focusing on the positives that come with this challenge – including enthusiasm, creativity, and determination. This sensitively written book gives hope to parents, teachers, and children – leading everyone on a path to success.

5

The Miracle Next Door

Author: Malka Adler
Publisher: Targum Press
398 pages, Adult level

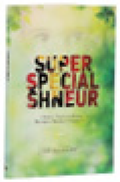
Pierre Robin syndrome and Stikler syndrome is another opportunity for growth, song, and inspiration.

Publisher's Summary: After years of battling a debilitating physical illness and waiting for a child, Yona Yacobowicz – founder of the famous women's musical group *Tofa'ah* – finally gave birth to a baby boy, Yisroel Meir. But could this child survive? In The Miracle Next Door, written together with Malka Adler, Yona's devoted neighbor and best-selling author of A Sunny Slice of Life, we enter the incomparable world of Yisroel Meir Yacobowicz. It's a world where every breath is a blessing. It's an inspiring story of medicine, miracles, music, and love.

My Personal Take: I read and enjoyed this book as a teenager, and it was interesting to go back and read it as a mother of a special needs child myself. Malka describes the trials and tribulations of living with a severely medically challenged child with candid honesty, compassion, and humor.

6

Super Special Shneur

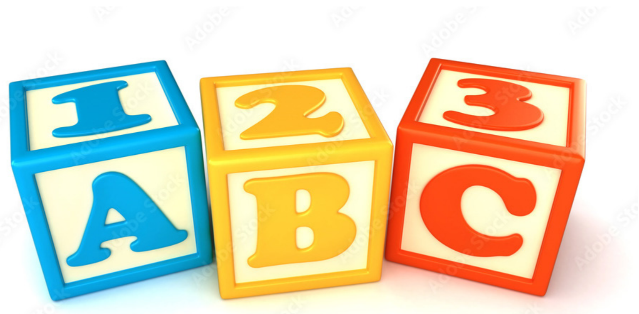


Author:
Sarah Rivkah Lipsh
Publisher:
BSD Publisher
132 pages, Adult Level

A mother shares her journey, beginning with receiving the diagnosis, through caring for her son with Autism those first few years.

Publisher's Summary: A mother's search of hidden blessing in raising an autistic son. A tale of strength and hope. Have you wondered how parents of special needs children cope? What can you say, and what can you do to help? Sara Rivkah Lipsh opens up her heart and draws you in as she traversed difficulties, dilemmas, and decision-making in the early years of her special child's life.

This list will be continued in the next issue.



The Early Years

EARLY INTERVENTION TIPS

Ruchma Baily Lipschitz

Here are some tips that I picked up after my daughter, who has Cerebral Palsy, went through three years of Early Intervention (EI).

1 **View yourself as a customer.** You have rights, you can state your preferences, you can request to change therapists. You can choose any therapist, even if they work through another agency. Tell your service coordinator that you want a different therapist, and they can transfer the mandate for that particular therapy to a different agency, without affecting the other therapies. Communicate pleasantly and firmly, and hopefully your requests will be acknowledged.

2 **Take the initiative.** Don't wait for the agency to find therapists for you. You can do your own research and find your own therapists. The best way to do this is to speak to other parents and hear who they were happy with. The more contacts you have, the greater the chance of finding the right therapist for your child. Read magazines, go to support groups, listen to hotlines, and you will find out more and more valuable information. When you hear someone raving about their therapist, dig deeper than "Are you happy?" Here are some ideas of questions you may want to ask:

- What is their specialty?
- What does the session look like?
- Do they show up consistently? On time?
- How do they handle crying?
- Has there been any measurable progress?

At the same time, realize that no one is perfect, and that each therapist has his own strengths and weaknesses.

If you hear about a therapist that you would like to join your team, you can reach out to her on your own and tell her about your child. Even if she tells you that she doesn't have any slots available, keep checking in with her and be open to taking any slot that becomes available.

3 **You can have multiple therapists addressing the same modality of therapy.** For example,

> **Don’t only share the successes, and don’t build up the child as more than he really is on an average day. It might make you proud, but it’s not in the child’s best interest to get the therapy he needs.**

instead of having the same speech therapist do all four sessions per week, it may be more beneficial to have two different therapists, who have varied specialties or approaches, work twice a week each. This way you get the best from each one’s expertise.

4 **Invest in the relationship with the therapist.** This is basic *middos,* and it will also be to your benefit when the therapist feels appreciated and acknowledged. Share updates and successes that happened over the week. This encourages the therapist to be more invested with your child.

5 **Try to increase the number of sessions you receive.** You can have the therapist ask for increases for your child. This will be work for the therapist, but it is something that your child is entitled to. If a child is severely delayed, you can ask every therapist on the team every few months to write up a justification. Sometimes they will try to push you off and tell you that it won’t go through, but ask nicely and keep trying to make it happen. Keep in mind that the process takes time—once you need it, it’s already late to start, so it’s better to begin the process before it’s a necessity.

6 **Make the most of meetings.**

- Instead of leaving your child as name on a piece of paper, try to bring him to life by sharing a story or some of his characteristics. When the team feels that they are talking about a real child with passionate loving parents, it can motivate them to be more generous.

- Mention which modalities you have been implementing and how they have worked. When you sound like an involved mother who is taking the therapist’s suggestions seriously, it shows that you don’t take the therapy for granted and are utilizing it properly.

- Don’t only share the successes, and don’t build up the child as more than he really is on an average day. It might make you proud, but it’s not in the child’s best interest to get the therapy he needs. At the same time, be honest about the progress that was made, and show that the therapy has the potential to be successful. This conveys how important the therapy is for your child.

- Although the child is making progress, emphasize how hard it is for him to deal with so many challenges, and how painful it is to see how much effort and repetition is necessary to master every skill. This shows the importance of increasing the mandate.

- Leave space for compromise. EIOD’s like to compromise. If you ask for two more sessions, they will usually give you one. So ask for more than you really need, in the hope that you will receive at least a partial yes. Often, they will compromise by granting you another slot in only one modality when you asked for numerous types. So if the PT tells you that you surely will not qualify for more PT, it can still be helpful to request it. Then, when the OD get requests from speech, OT and PT, they may give in on the speech, which is the main one that you really needed.

- When you hear the new mandates, decide if you are ready to accept them. If you feel that they are not acceptable, you can communicate right then and there that you are not comfortable with it. State that you don’t feel that it’s enough to address your child’s needs. Bring up specific examples of where it seems to be deficient, such as more feeding therapy if the child is underweight. It may affect a change on the spot.

- If it does not change, you can bring in mediation. Come prepared with facts and data to prove your point. Letters from the pediatrician, neurologist, or any other relevant professional are especially powerful.

- If your requests are still denied, all hope is not lost. Mentioning (respectfully) that you are not comfortable with the outcome and that you will be going for a fair hearing, is sometimes enough to make a change.

- Realize that the people making these decisions are not trying to be stingy. They must justify their decisions to their superiors and need good reasons to make increases.

- Remember that EI is supposed to address the unique needs of every child. Keep advocating politely, respectfully, and firmly. With Hashem’s help, you will succeed in ensuring your child’s success during these formative years.

Getting a Diagnosis

A Mother's Love and Determination Leaves No Stone Unturned

Esther

Sarah is my adorable six year old who has a chromosomal deletion. I want to share with you my journey to getting her diagnosis and why it was so important for me.

Sarah was born appearing lifeless. She didn't cry, didn't seem to be breathing, and was a terrifying gray color. I must have cried in those first five minutes more than she cried her entire first year! The doctors pinched and smacked her to get a response, and then put her on oxygen when she didn't react. When the NICU doctor finally came in, she turned off the oxygen and told off the doctors, saying that the baby had a pulse and was completely fine.

When they handed her to me, I gave her back and refused to hold her, as she still seemed lifeless, and I was too afraid. Amazingly, they did not take her to the NICU, and sent me home 48 hours later, with a little baby who had just scared all the doctors.

As soon as I got home, I went straight to a doctor, as my baby suddenly looked very yellow. I was terrified to care for her, and the doctor – who was not my regular pediatrician – assured me that her bilirubin would go down, and that I should continue feeding her as much as possible.

Sarah slept a lot in the beginning, and although she wasn't my first child, I believed the people who told me it's ok to let her sleep, because I was exhausted and because feeding her was such an ordeal.

I was constantly running to our pediatrician, a very thorough, very American doctor with a great reputation. One day it was a fever, the next day she was turning colors as she moaned and groaned after eating. She was constantly spitting up and was not gaining any weight. When I told the doctor that she's shrieking in pain, he looked at me and said: "Your baby never cried a day in her life." You're right, Mr. Doctor, she was actually moaning, but to me it was shrieking, since she never made a sound. Why didn't I point out to you that it's not normal for a baby to never cry?

The doctor kept reassuring me that she was fine, until he decided I was just a neurotic mother (and he told me so!), and started charging me for breathing tests just to prove she was fine. He pressured me into vaccinating because he saw no reason not to, and gave Sarah 15 shots by the age of eight months! When I saw another provider, he was outraged that someone would give even a healthy baby so many vaccines, let alone a child who obviously was not thriving.

At a few weeks, I decided to see Dr. W.. Dr. W., a plastic surgeon, is an expert at ear molding, a non-surgical, painless process of fixing ear deformities in babies. On our initial call, the secretary was skeptical that Dr. W. could still work her magic, since Sarah was a little older than the six weeks at which patients typically started the process. When they met Sarah, however, they expressed surprise at how "newborn" she still was, and how moldable her ears still were.

Dr. W. noticed my obvious stress and exhaustion, and was the first person outside of my family to agree that something more serious was going on. She gently encouraged me to bring up with my doctor the markers she saw that could be an indicator of a deeper issue. At that point, I had no idea that Dr. W. had been in special education for years prior, and that she already suspected the very real chance of a chromosomal abnormality.

When I went back to my doctor for his go-ahead for the ear molding and shared Dr. W.'s concerns, he called in a PA, told her what I wanted to do, and asked her to take a look at my ears and tell him if they weren't just as funny as my baby's. I left his office burning with shame. *B'Chasdei Hashem* my 9-year-old, very perceptive, brother made a comment about Sarah's funny ears that Shabbos, and we decided to go ahead with the procedure, regardless of what my doctor thought. But the doctor's laughter was still ringing in my ears.

I started to believe my doctor. At every appointment he reassured me that I was just neurotic—and at the same time, he blamed me for her scrawny arms and legs! I started to feel like he warned all the specialists about the crazy lady he was referring. The GI he sent me to dismissed my concerns, and upped the dosage of Sarah's Nexium, even as I protested that it hadn't been helping, and that everyone around me was warning of its terrible side effects. The GI waved me out of his office with the advice to drink some wine to relax before I fed Sarah—as if my stress was the cause of all her problems. The next GI yelled at me for giving my baby "old-man-medicine" that could kill her!

When I begged for a prescription for evaluations, the doctor was quick to show me how "strong my baby was." She was six months and not moving around at all, but oh boy, was she strong on her stiff, scrawny legs! He sent me to his neurologist colleague, who confirmed what he said. I truly believed at that point that I was just an anxious mother who was way too overwhelmed to take care of a six month old and an 18 month old. I remember dancing to Shwekey's new *"Ani Maamin b'Nisim"* when I got home from the neurologist. He said she was fine! My baby was totally ok! Until I crashed from my high and felt like every doctor was out to get me and prove I was crazy.

I was never a pushover; in fact, you could say I was always very sure of my opinions. Yet, I truly believed I was just not managing to juggle my life, and that I was incapable of caring for my baby's basic needs. Incredibly, it never occurred to me to switch pediatricians, until someone close to me practically forced me to go to her pediatrician's office.

I will never forget the scene, and I am forever grateful to Hashem for giving me the support I needed at that time. I walked into Dr. B,'s office with my daughter in my arms. I held her close to me and briefly told the doctor why I felt something was wrong with her. Without putting her down on the table or undressing her for an examination, the doctor, literally a *tzaddik* who fully believes Hashem is guiding him, looked over at my baby and said: "Mommy, go to Genetics and then come back." I stood there in shocked silence as he pointed out the genetic markers that Dr. W. had hinted at so many months before.

The doctor gave us the phone number for the Genetics department in a local hospital and told me that if I couldn't get an appointment that week, to go to the emergency room and have her taken care of there. When he mentioned the emergency room, I got hysterical. There was no way I would check myself into a hospital! I called the first hospital for an appointment, then made my way through every hospital in the city.

It slowly dawned on me that just getting an appointment was a process. The doctor had to send over Sarah's records, and then, after about three months, I would get a call telling me whether my daughter was eligible for an appointment. I didn't have three months to wait, and anyway, Dr B. didn't have Sarah's records! By the time I called Cohen's Children's Hospital in Long Island, I was crying hysterically. I could barely talk coherently, and they had no idea what I wanted. After sobbing into the phone, a very gentle voice asked me what was the matter and how could he be of help. I hiccupped my way through my story and begged him for an appointment. I had no idea I was talking to a doctor until he asked if I thought it was possible to make time to meet him on his lunch break two days later!

Hashem sent us to the most patient geneticist, who gave us hours of his time once we received the diagnosis. He sent us referrals to every specialty. Suddenly the doctors wanted to hear our concerns! Giving a name to Sarah's condition allowed them to believe all the bizarre things they were hearing from me. And I wasn't neurotic anymore! We went from begging for a prescription for evaluations, to our house becoming a nonstop train station of life-saving therapists coming and going every day.

When people ask why I would want to know what my daughter has, I just tell them that it removes all doubt. We can't know the future, and Sarah doesn't even fit the typical expectations of a child with her diagnosis. But her condition has a name and it's real. I'm not imagining things. I'm not neurotic. And she's *not* fine! That allows me to speak up, to advocate for her, to push for more, and to push for better. And that is worth the world to us!

THE EARLY YEARS

Fraydel Dickstein

The Early Years! Wow! What a subject! The memories blur in my mind of sleepless nights spent crying, of waking up in the early morning and scrubbing accidents out of the carpet. Memories of feeling so alone and so trapped, of being sure the sun would never shine again. Today with the hindsight of twenty twenty, I must share that Bez"H it got much easier. Perhaps it is just by virtue of the journey we travel. Time heals, and even if things don't stabilize, we do. Acceptance is an incredible thing, and it really opens doors, but it takes a lot of time. I can't help but share with you something I wrote much earlier on in my journey:

I am in the airport and our flight is delayed. At some point, I hear the amicable atmosphere rudely interrupted by the cries of what I recognize as an autistic boy. My eyes fill with tears, and they don't stop. What goes through my mind is: "I have one at home, just like that."

I feel the pain of parents who tire endlessly, who carry the crushing burden of caring for a developmentally challenged child. The future, the unknown. The pain of the child who can't express his needs and wants, and certainly cannot understand why his wants can't be met right when he wants them.

I can feel the pain in a safe spot, because at this present moment, and for just a few more hours, I am somewhat free of the constant struggle of trying to fulfill Yehuda's needs, of trying to help him reach his potential, and the worry of: "will I have the strength to do it again tomorrow?"

The pain of watching my child inflict black and blue marks all over himself in frustration. All I want is that magic key, the magic key to his heart. Then I wonder what this magic key will do, and what do I want to do with it.

I want to give him the ability to communicate...... Perhaps I am not crying out of pain, but rather out of being touched by the beauty of people who devote their lives to a child, despite the grueling challenges that come along with it.
Parents who give up their golden years, their chances of careers, freedoms, or what not, to devote all they can to help their child. Parents who nightly go to bed crying, from sheer pain and frustration. Yet they continue heroically marching on. Thoughts of themselves are rarely on the horizon. I believe that it's our chelek elokai mema'al that allows us to engage in such selfish work, allows us to achieve the unimaginable, to scale heights we never thought possible — to live selflessly in the face of darkness, and to accept that it's His will.

When I read this, I felt bad for the letter writer (who was me!), and it was hard to believe that I wrote these words about my happy, handsome son. Does he still bite his hand? Honestly, yes, he does, and he still cannot talk. But I have learned to see the beauty in his life, and there is so much of it. He has a loving family and goes to an incredible school. We really love having him around.

Today I can see so clearly how precisely the things that I found so challenging ended up being the biggest brocha for our family! Another word that screams out at me is I how I called it darkness. There is nothing dark about Yehuda; he is pure light.

This is not to say that it doesn't hurt. There is always that element of pain. I urge you to allow yourself to feel the hurt and simultaneously believe in the power of time and daven for the light to overpower the darkness.

I have heard Dr. David Lieberman describe that those moments when one witnesses an act of *chessed*, and we get misty eyed because we are so touched that one can exceed his natural boundaries and give in such extraordinary ways.

When I read those words I just thought to myself how Yehuda is the conduit to so many such moments. I am often left stupefied by what people do for him. I truly can't wrap my head around such kindness; it astounds me again and again. Dropping him off at SCHI every morning often leaves me misty eyed, and it's not because I am beholding sad scenes. It's because it's so incredible to watch parents and caretakers transcending their natural boundaries, and giving in such a striking manner.

"*Hodu LHashem!*" I can so wholeheartedly say, I am so grateful that I have traveled this journey and am now in a far better place than I was. My perspective has dramatically changed but I still believe that... ***it's our*** *chelek elokai mema'al* that allows us to engage in such selfish work, allows us to achieve the unimaginable, to scale heights we never thought possible — to live selflessly in the face of challenge, and to accept that it's His will.

May we all be *zoche* to live with this reality and to keep climbing higher together!

Type Two x 2

Dini Leifer

When Dr. Papas, the geneticist, walked into my four-month old Rivky's room in NYU, we both recognized each other. The doctor who was sent to examine my daughter was the very same man who had tried, unsuccessfully, to diagnose me years earlier. At that time, I never dreamed that I would see him again, and certainly not under these circumstances. But Hashem runs the world in the most intricate, miraculous way. Not only would Dr. Papas be the *shaliach* to diagnose my daughter, but he would now diagnose me as well.

I was born five weeks premature and stayed in the NICU for four days. There, I was diagnosed with microcephaly and a small VSD (Ventricular Septal Defect—a hole in the heart) that the doctors said might close up on its own, or stay the same size without side effects. I was brought home amidst much happiness to my loving family. I had delays and difficulties meeting milestones and was constantly going to doctors and therapy appointments. This was in an era when special needs was still considered taboo, and kids who weren't typical were locked away from public view. It also pre-dated all of the wonderful agencies that exist today to assist families raising special needs children, such as HCS, Rayim and Hamaspik. There were almost no schools for kids who didn't fit into the mainstream setting. In short, special needs was not in style.

> *The gray clouds of confusion and doubt that had followed me for 25 years suddenly lifted, as I learned what I had been living with all my life.*

My devoted parents took excellent care of me and gave me a very normal childhood. Despite their best efforts, I remember some very painful times when I just didn't fit in and didn't feel understood by those around me. I still remember a second-grade teacher who sent me to the principal's office on a daily basis, just because I had a hard time understanding her lessons. I was challenged academically, as well as physically, and found it hard to keep up with my peers.

As a teenager, I got pneumonia far too often. My doctor ordered a biopsy of my lungs to try to understand what was causing the pneumonia. The biopsy was done as an outpatient at NYU, but when the doctor saw the results, he immediately admitted me. I stayed there for a few days while many specialists tried to figure out what was causing my issues. It was during that time that I met the geneticist, Dr. Papas. He ran all the available tests, but everything came back clear. I was sent home without further clarity.

Life continued in a normal fashion, the only constant impediment being my lack of physical strength. Stairs were always difficult, and I would think twice before walking long distances. I needed a lot of sleep to keep my strength up. A dancer I was not, but I had many other talents, including writing and sewing.

After my marriage, we waited almost five years to be blessed with a child. Needless to say, they were very difficult, painful years, full of longing and many heartfelt *tefillos*. Our precious Rivky was born *Sukkos* time four years ago. We were elated to be parents of such a gorgeous, healthy- looking baby. Life finally seemed to be settling down.

When Rivky was four months old, I noticed her having tremors. The pediatrician sent us to NYU to investigate. They did a two-hour EEG to rule out epilepsy. She was diagnosed with tremors, microcephaly, and developmental delays. They advised us to begin therapy right away, and to see the geneticist, as well. That was how I found myself meeting Dr. Papas once again.

Ten years is a long time in the ever-evolving world of science and medicine. The level of genetic tests that were now available surpassed those with which I had been tested as a teenager. When Rivky tested positive for Rubinstein Taybi Syndrome Type 2*, inherited from her mother, it was a double whammy.

Type Two x 2... continued on page 21

The Blessings of a Child with Down Syndrome

Sheva Givre

Today I was shopping at my home away from home, also known as Target, and I got sucked into the tiny aisle. You know, the one in the baby section with all the little newborn socks, mini sandals that fit in your palm, and one-pieces that could fit a doll.

I looked at my big girl, and I felt like I had just been there buying her tiny sandals. Then I realized, "Hey, I *was* just here!" Rozie just recently grew out of newborn-size shoes, and she wore 0-3 month stuff for most of her first year. Rozie will be three in a few months, and we are just now fitting into 24-month size. Honestly, I'm loving every minute of it.

I sat through a few very long appointments, and trust me, the tiny shoes were never mentioned. This got me thinking about all those simple, wonderful things that go along with having a child with Down syndrome. The stuff they don't tell you when the genetic counselor is sitting there with a flip board explaining chromosomes and whatnot.

Trust me, there is no page they suddenly flip to with a picture of a tiny shoe that could melt even the most non-maternal heart. They don't look at you and say: "See these little heart-melting wonders? Your baby will wear them for at least two wonderful years! Every time you put them on her, you will be forced to kiss her tiny toes, and most likely you may buy a few pair and arrange them on a shelf so that when she is not wearing them you can look at them anytime you want."

So here are the top five things I'd like to add to those flip boards, the wonderful things they never tell you about having a child with Down syndrome:

1 Children with Down syndrome typically have smaller statures, causing them to keep a "baby" appearance for longer. Low muscle tone also contributes to this. I'm one of those mothers who sniffles over the fact that her baby with the soft blond curls is actually now taller than I am. I can look my big teenager in the eyes and say with all my heart that he was just a baby a few years ago; I was just holding that hand with the baby dimples last month. It all flew by too quickly. Rozie is staying in this stage a lot longer, and I relish each and every minute of it. Give me baby fat, give me tiny clothes, give me soft baby snuggles!

2 Children with Down syndrome need a little more help reaching their milestones. They do everything a bit later on the developmental charts. But the wait and extra effort make every milestone a cause for celebration. When a child becomes a Bar Mitzvah, we celebrate the achievement and all the hard work he put in. For a child with Down syndrome, every milestone feels like a Bar Mitzvah. No joke, I almost rented a hall to celebrate when Rozie walked. I love this, and I wish I celebrated like that with my other children. I wish I jumped for joy when my boys first tracked a mobile with their eyes, or batted at a toy for the first time, but I honestly don't remember when that happened. For Rozie, I know the exact time and date. The wait and extra effort make every milestone a cause for celebration.

3 Having a child with Down syndrome will soften your heart, allowing you to accept people as they are, regardless of their abilities. I've noticed that since I had Rozie, I am more accepting of people in general, and particularly of those who have intellectual disabilities. One time a homeless man came into a store where I was shopping and started yelling at everyone. Nothing scary, just loud. Usually I would avoid this type of situation like the plague, but this time, I was able to see right through the behavior to the beautiful soul within. I did not run, I just went on with my shopping. Thank you Rozie for giving me that gift. I plan to treasure it always.

4 When you have a child with Down syndrome, new people come into your life. I have made friends across the country whom I genuinely cherish. I met these women on online forums, through my blog, and just in real life. It's like when you drive a fancy car, other

people with the same car will honk or flash their lights at you to acknowledge that you both have the same impeccable taste, or maybe to say: “Look at us, we are so lucky to have these fancy cars!” Having a child with Down syndrome breaks down social barriers, and you find yourself flashing your lights at other parents of children with Down syndrome, acknowledging that you both have something great to share with each other.

Without that little extra chromosome, I doubt that this *chassidishe* mommy would have ever met amazing women from places like Kokomo, Indiana, Ohio, Westminster, and many other places that I never even heard of. And since we are talking about the people in our lives, have I mentioned Rozie’s therapists? It will be a tear-filled day when Rozie is no longer eligible for services through Infants and Toddlers. I cannot imagine what our lives will be like without weekly visits from some of our favorite people.

5 Last but not least, raising a child with Down syndrome is wonderful and amazing because having children is wonderful and amazing. It makes you realize that a mother’s love is not based on a child’s ability, but on your own ability to accept and give. Having a child with disabilities can sometimes be hard, but it isn’t always. And after you realize this, then you realize this is true for all children. You realize that children with disabilities are not beings that walk around suffering from an illness, but special *neshamos* that learn and do things differently. I love celebrating the difference.

Sometimes I sit and wonder when the other shoe is going to drop. When is this going to really get hard? I remember saying to people when Rozie was a newborn and had a lot of medical issues that, actually, it really wasn’t that bad. “Wait until she is a toddler and the differences become more significant,” they said. Then she turned two, and I thought: “Hey, this is actually getting easier!” Then they said: “Wait till she is three. That is when the cognitive differences really become prevalent.”

Rozie will be three in two months. Now they tell me to wait till she gets to elementary school… Well I’m done waiting, because I have news folks; get ready, it may be groundbreaking: Parenting is hard, period. I have yet to hear a parent say: “Oh, parenting is a breeze, I whizzed right through it without a hitch.” But parenting is also eye-opening, life-changing, and worth every minute. The same goes for raising a little one with a bit extra.

May we merit the coming of *Moshiach* soon in our days, when every *neshama*, regardless of ability, will shine bright.

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Type Two x 2... continued from page 19

The gray clouds of confusion and doubt that had followed me for 25 years suddenly lifted, as I learned what I had been living with all my life.

Realizing that my daughter had the very same condition as I did was emotionally overwhelming. On the one hand, it was devastating to know exactly how difficult it was going to be for her to reach her milestones, to be academically challenged and physically compromised. On the other hand, it was a relief to know that, despite the hardships, she would, with Hashem’s help, get through it and emerge as a confident, capable, contributing member of *Klal Yisroel,* just like I was.

Rivky has come a long way. With intensive therapy, she has learned to sit, crawl, and walk on her own. She understands a lot, but has a very difficult time expressing herself. We are working hard to give her extra speech therapy and celebrate each small accomplishment. She attends a high-functioning special education preschool. *Baruch Hashem*, she has no medical issues at all. It is astounding to see the differences in the educational options, the support, and the huge shift in perspective in the *frum* world over the past twenty-five years regarding the special needs population. What my parents had to fight for and figure out on their own, is handed to us on a silver platter. We are grateful for our precious daughter, for the opportunity to raise her to be her very best self, and for the knowledge that Hashem runs a perfect world.

*This is not to be confused with the more common Rubinstein Taybi Syndrome Type 1, which usually comes along with medical issues and a lower level of functioning.

SPECIAL THERAPISTS *of* SPECIAL CHILDREN:

Interview by: Chayala Tawil

***Interview with Mrs. Elana Kosofsky**, Speech Language Pathologist (SLP) of Oak Park, MI has been practicing speech therapy for over 30 years. She worked with the 0-3 age group for 17 years. She is the mother of a lovely family, which includes a child with Cerebral Palsy (CP).*

What pointed you in this career direction in general, and specifically, what led you to work with this age group?

I knew early on that I wanted to support a husband in *kollel*. I looked into different kinds of therapy, and choose speech therapy as a modality that offers reasonable pay with the ability to work part-time. As a natural communicator, I was drawn toward helping others succeed in this area of life. As far as the age preference, I've always adored babies, and wanted to work with them in such a foundational and moldable time their lives.

How did having your own child with special needs affect your role as a therapist?

My experience as a therapist is actually what led me to my son's diagnosis. He was in the NICU for ten days after birth, and was then sent home with a clean bill of health. Already then, the thought crossed my mind that he may have CP. As time passed, he seemed to be developing typically, aside from having low muscle tone. I asked his PT if she thought it possible for him to have CP, and although she was adamant that he was fine, I was not convinced. When he was eighteen months old, I took him to a private neurologist, paid $500 for a ten minute session, and asked the doctor if my son could possibly have CP. He looked at me in wonder and said: "Can't you see that he's already talking? He's fine!" It was only because of my extensive experience with so many special needs children, that I was still sure that something was not 100%.

A woman in my community organized an event for parents of children with special needs and flew in a speaker from New York. She invited me to join, saying that since I was so involved with families who were in this situation, it would be good for me to hear what the speaker had to say. I went, and was blown away by his warm words. I found his speech to be so inspiring and uplifting. There was to be a follow-up with him in a few days' time.

In the interim, we had an evaluation scheduled for my son with a top PT. She was not allowed to diagnose him, but it was clear that she knew something wasn't okay. She sent us for further testing, and a few days later the diagnosis of CP was finally confirmed as a fact. The evening after we received the news was the second talk with the rabbi from New York. I went. But this time I was not there only as a professional, I was there as a parent. And suddenly, his words didn't seem as easy to accept. He spoke beautifully once again, but it felt very heavy for me.

I had always been such a proud partner in the special needs community, but I suddenly realized that being a parent is a whole different world. I had always adored kids with special needs, yet it was still very difficult to accept our new reality. This was without even knowing about the many layers to come, as my son has been given multiple diagnoses over the years. This humbling experience made me into a more understanding, empathetic therapist. I was able to relate better to the parents, as well as to my clients themselves.

Hashem sends the *refuah* before the *makah*. At one point, I specialized in social skills for children on the spectrum. Little did I know that my son would eventually receive another diagnosis of autism, and my knowledge and experience in teaching social skills to this population would prove to be invaluable.

What are some of the challenges specific to this age group?

One of the hardest parts was being a part of the process of watching my clients being diagnosed, and the parents' devastation at this trying time in their lives. In fact, many times it was I, as an experienced therapist, who noticed certain markers that I knew warranted further testing. When I would point out certain symptoms to parents, such as their child never making eye contact or engaging in repetitive behaviors, and suggest that they see a neurologist, there were many difficult reactions. Parents who had either been clueless or had been trying to ignore these signs and hope for the best, were suddenly forced to confront the possibility that their child had more to their challenges than a speech impediment. Some parents' first reactions were to be angry at me, the messenger, for opening their eyes. I was privy to some very unpleasant responses, which I understood was their pain, shock, and fear speaking. Down the line, these parents would come back and thank me for saying what needed to be said, and for helping them find a diagnosis for their child.

Another aspect was dealing with parents' unrealistic expectations. I try to explain to parents that therapy is slow and steady; it's not magic. We can always hope for better, but we should not be setting ourselves up for disappointment by wishing for miracles. I have worked with parents who had the unhealthy attitude of "We have to fix up this child really quick – before anyone realizes that there was ever a problem." This is generally when the child does not yet have a diagnosis, and the parents are still in denial that their child has a real disability and are still hoping to keep it all a secret. I hope that our generation has advanced enough to understand that there is no such thing as a "perfect" family. It's okay for every child to be unique, and there is no need to be ashamed or hide them. We need to stop being concerned about what others think, and concentrate on getting our child the services he needs in a healthy manner. Sometimes this intensity stems from a parent's anxiety, and this is their way of trying to feel in control. We need to remember that Hashem alone determines the outcomes. Therefore, we should focus on doing healthy and positive *hishtadlus* and leave the rest to Him.

> *I had always been such a proud partner in the special needs community, but I suddenly realized that being a parent is a whole different world.*

What are the most rewarding parts?

Working with children in this age group is a special opportunity, because every step of progress makes a monumental difference in their future development. They are also so cute and adorable, which is helpful, too! I have a very soft spot for children with special needs, and have been so inspired by them over the years. Their ability to be happy in the moment, to work incredibly hard and take their challenges in stride, are some of the characteristics that have always amazed me. I really enjoyed building a relationship with my precious clients, and sometimes becoming close with their mothers, as well.

It was so rewarding to create therapy sessions that were fun and exciting for the children, that they enjoyed and didn't look at like work. I believe that this is a very important point. Therapy – of all kinds – should be enjoyable and pleasant for the client. I tried to never give the parents "homework" to do with their children. Instead, I would suggest ways in which to naturally incorporate skills and practice into their daily routine in a fun, normal way. For example, a friend recently told me about her baby who had very low muscle tone and drooled a lot. I gave her some whistles and other toys that she could do with him to strengthen his muscles. She keeps these toys as rewards; i.e.: after he cleans up, he gets to blow a whistle! Keeping therapy positive, fun, and functional will ultimately make it most effective!

What is your perspective on how central therapy should be in a young child's life?

Before we even talk about therapy, we need to talk about our general attitude towards the child with special needs. More than therapy, they need love and acceptance. Our feeling has to be one of: "This child is perfect. I love him the way he is right now." We need to celebrate who they are today instead of focusing on their deficits. We also need to be realistic about our expectations of what therapy can achieve and what is out of that realm. I have had parents come to me with an attitude of: "If I pay you enough money, then you will solve my child's problem." This was unfair and counter-productive to me and to the child, as that kind of pressure doesn't allow for success. When we are calm and accepting, when we have realistic expectations, that is when the child is free to thrive, and the therapy actually has the highest chance of success. This can take a lot of inner work on the parent's part, and may not come naturally to all parents. However, the effort invested is a tremendous gift to the child, greater than the best therapy out there!

We can ruin a child's childhood by taking it away from them and substituting it with non-stop pressure and therapy. It's a balance to give therapy its proper place, and hold on to a happy, healthy childhood. Expressing positive reinforcement and loving messages goes a long way. Our children with special needs have very high radars – they sense our feelings. If they feel that we are disappointed in them, that will affect their self-confidence. Naturally, we would love for them to keep progressing, and should be there to support them in this, but the results should not impact our love for them.

Special Therapist... continued on page 25

SPECIAL THERAPISTS *of* SPECIAL CHILDREN:

Interview by: Chayala Tawil

Interview with Mrs. Malka Breitman OT, of Chicago, IL has been practicing Occupational Therapy for over 40 years. She worked with the 0-3 age group for 15 years.

What pointed you in this career direction in general, and specifically, what led you to work with this age group?

I was in Israel during one of the very first terror attacks, which took place in Lod (now Ben Gurion) airport, in 1973. I volunteered to help out in the hospital, and became an assistant to the overwhelmed nurses there, who were treating the many wounded in the attack. I was fascinated by what I saw, and decided to pursue a career in the medical field.
During my schooling, I spent time observing therapists. From all of the various professionals that I followed, I was most interested in Occupational Therapy (OT), and decided to specialize in this field.

My first job was working with children who had severe autism. It was a fascinating job, very demanding and rewarding. I then worked in Israel with blind children, part time, while attending Neve Yerushalayim. When I moved to California, I worked in adult rehab, mostly in hospitals. I was pulled toward working with young children, as I loved the idea of facilitating the early developmental process. I got further training to enter this specific niche in the field. I worked with babies and toddlers through the early intervention process for 15 years. Although I am now retired, I still volunteer to work with children in a wonderful school for children with special needs. We may stop working but we never stop giving!

What are some of the challenges specific to this age group?

The most challenging part of working with such young children is that they cry when they are even slightly uncomfortable. This is understandable, and I am fine with that. The problem is when the parents get involved, and take every kvetch that the baby makes to heart, and don't allow me to continue working with them. If a baby is uncomfortable being on his stomach, he will be vocal about it. I would try to distract him with toys and make it as pleasant as possible. I would pick him up every few minutes to give him a break. But he might still complain, and many parents just couldn't handle that, and took me to task for it. I wish they would just understand that discomfort is okay, and that this is for the baby's good.

> *I wish they would just understand that discomfort is okay, and that this is for the baby's good.*

What are the most rewarding parts?

Watching a baby grow and develop is really miraculous. Being in a role in which I can help facilitate that growth is very rewarding. I also enjoyed getting to know the families that I worked with. As a therapist of young children, the therapy often took place inside the home. Part of my job is training the parents to continue the therapy with their children during their daily interactions. I got to know many special devoted families who inspired me.

What is your perspective on how central therapy should be in a young child's life?

Therapy during the early years is the basis for their future development and should be taken seriously. I was able to see immense differences between the families who took their "homework" seriously and those who didn't. The children who were doing the exercises each week progressed much faster than those who waited for me to come and do the work. Most children only get OT once or twice a week, and that's not really enough on its own to make consistent changes.

That being said, it's even more important to be emotionally healthy and happy. If a family feels that they need a vacation, therapy should not hold them back. It's okay to cancel a session if there's a good reason. There has to be a balance between taking it seriously and not letting it take over other parts of life.

Where did your sessions take place and how did that impact the effect of the therapy?

Many sessions took place in the home, which was very beneficial in terms of carry-over. I also visited many daycare centers. Some were simple facilities with just a few toys, but had very loving, caring, and capable caregivers. Others were state-of-the-art, very impressive premises, but the care was sub-par. The main thing a parent should look for in a daycare is the staff's responsibility and attitude towards the children.

It is understandable that it's not always feasible to have the therapy sessions in the home. There are steps that can be taken to maintain contact with the parents in this situation. We can have a monthly Zoom or phone conversation in which I catch them up and model for them what we are working on. There are always ways to make things work when both sides have the child's best interests in mind.

What message do you have for parents of special needs children?

It's important to have a happy home and enjoy your children. My favorite homes that I worked in, were those where the entire family embraced the child with special needs. They considered it a privilege to be involved in their child's therapy, and this created a healthy, wholesome, happy atmosphere that bred success on all levels.

Special Therapist... continued from page 23

This is especially true as our children get older. Once they are adults, it is time to really step back and stop pressuring them to change behaviors that are simply a part of them. There are children with Down syndrome who hear: "Stick your tongue in your mouth" from the time they are little until they are adults. There are children with autism who have been told for years on end to stop stimming or to make eye contact. These instructions, which they are incapable of obeying, only serve to make them feel bad about themselves, with no productive outcome. The criticism and negativity are way worse for them than the unwanted behaviors. Emotional health comes before physical and cognitive health.

Where did your sessions take place and how did that impact the effect of the therapy?

When I first starting treating young children, I would see them at their home or in a daycare setting. I found the home was not conducive to therapy, as it was usually noisy, and the children were always running back to their mother. In the daycares, I was usually able to find a quiet place to work.

When I opened up my private practice, I created a beautiful therapy room in a detached office in my backyard. It was decorated as a cheerful, colorful, nursery-style room. I also had lots of nice outdoor equipment in the backyard. When I wanted some social interaction for the client, I would call in my own two-year-old, who was in the house with a babysitter. He would come and join the session when it was appropriate and helpful for the client. It was amazing to see how his young, playful nature brought out the clients in a way that I could not always accomplish on my own. Adults don't play like kids!

In those days (about 15 years ago), it was normal for parents to leave their child for the session and pick them up at the end. Looking back, I should have enforced that the parents stayed, and I would recommend that parents do stay with their children whenever possible at therapy sessions. First, to ensure the child's basic safety, as not all of the therapists that we use are people that we know and trust. Second, I am sure it would be beneficial for the parent's carry-over to be present and see all of the techniques in action.

What message do you have for parents of special needs children?

First, I want to mention the tremendous *siyata di'shmaya* that our special *neshamos* have, and that their families have, as well. There is an extra sensitivity and emotional maturity that is typical of siblings of children with special needs. Hashem sends special strength to those who are caring for His holiest *neshamos.* I believe that Hashem has a special love and protection for those parents entrusted with these special *neshamos*.

Next, I urge you to find and use all of the resources that you can. It's especially helpful to connect with a parent who is ahead of you on a similar journey and can advise you.

Finally, take one day at a time. Hashem gives us everything we need – the strength, the resources, the ideas – for today. He's holding our hands today. Look for the daily *hashgacha* and you will feel His presence. When we worry about next year, we feel overwhelmed because we haven't been given the tools we need for that part yet. Hashem has a plan for us, and He loves our children more than we do! Trust that He will always be there, caring for all of us.

Smart & Safe

BABY PRODUCTS

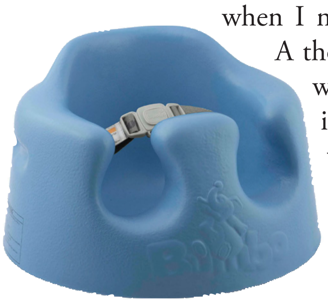
Chayala Tawil

Nowadays, researching and buying special products for Avrumi is par for the course. I don't think twice about ordering something he needs to help him get through his day in an easier fashion. But I still remember the very first purchase I made especially for him. As a little baby, he was impossible to hold. He switched back and forth from being very floppy to extremely rigid, and had no control over any part of his body. One activity that was very challenging was diaper changing. When I put him down and started touching him, he went so rigid that I couldn't lift his legs without his whole body arching into the air and flipping around. I seriously needed someone to hold him down every time he needed a diaper change.

I finally realized that there must be something out there to help me out. I searched online and found an item called The Papoose. With a name like that, how could I not buy it? I ordered it, and it made things so much easier. We used it for him for many years. I found it helpful for my other babies, as well. It fits perfectly on a regular sized changing table. It is super comfortable for the baby, and really keeps them in place. It is easy to wash when it gets dirty.

The Papoose Baby Changing Pad *$36.99 on Amazon*

We found our next item for Avrumi without even looking for it! I was buying some bikes for my kids at the flea market, when I noticed an interesting looking seat. A thought popped into my head that it would be perfect for Avrumi to sit in. At that time, he could not sit unassisted, but he enjoyed being in an upright position to see what was going on around him. I bought it on the spot for less than $10. It was a real bargain, and an even better investment. The therapists were thrilled with the seat, as it was great exercise for him to balance himself in it, yet it still gave him enough support to be safe. In case you don't see this at the flea market, you can also order it from Target. It is made of durable foam and is also very easy to clean.



Bumbo Floor Seat *$49.99 in Target*

The Bumbo was Avrumi's play chair, but we wanted something with a tray for mealtime. The highchair that my older children had used did not have enough support for Avrumi. Despite the buckle, he just slumped over and couldn't stay upright. I remember researching highchairs for weeks! I walked into every store that sold baby gear and studied every highchair possible. My main criteria were: it needed to have a big tray, it could not have any fabric on it (which would get dirty in a minute!), and it needed to have a five-point harness. After weeks of searching and debating which one to settle on (as none seemed to be perfect), I finally stumbled across my dream high chair. Ironically, it was the least expensive option of anything else I had been considering!

I didn't know a soul who had it, but it looked right, so I bought it and never looked back. It turned out to be almost perfect. Avrumi sat in it for many years, and he slowly (sooooo slowly!) learned how to swallow, chew, drink, and eat.

One of the unique aspects of this chair is that so many parts of can be easily disassembled for easy cleaning. (In case you are getting the feeling that Avrumi was a very messy baby, and that I spent a good part of my day cleaning up after him, you are right!) I threw the foam pieces into the washing machine, and the tray into the dishwasher, and they came out sparking clean. The harness is adjustable in height, and the whole chair can tilt back to find the most comfortable position. There is also an option to buy only the top piece and put it on a chair, as a booster seat. We used it with the wheels when Avrumi was a baby, then took off the top piece and used it on a chair when he got older.

Ingenuity SmartClean Trio Elite 3-in-1 High Chair, Toddler Chair, & Booster Seat *$99.99 on Amazon*

While we are on the topic of feeding, I want to mention bibs. Avrumi was such a messy eater that there was no way his clothing could be clean after a single bite, let alone a whole meal. We couldn't get over how much one bite of cookie could spread all over his hands, face, and clothing! We tried so many different bibs. Fabric ones were pointless, as they got soaked and filthy within minutes. The plastic bibs were usually much smaller, and didn't cover enough area to be useful. At one point, we were undressing him before each meal! He ate in his undershirt, then we would hose him down in the sink and get him dressed again. When my mother-in-law gave me these bibs from IKEA, they were a real winner. They are more like smocks, and did quite a decent job.

Bibs/Smocks *$15.00 for a set of 4 from Ikea*

Other readers mentioned the Bear Cup as their favorite piece of baby gear. This cup did not work for Avrumi, but since so many others benefitted from it, I will share the information. It is supposed to be very helpful in teaching babies how to drink from a straw, which is a great skill that Avurmi has yet to master.

Honey Bear Straw Cups for Babies 8oz straw bear cup with improved safety lid design. *$8.99 Amazon*

Another topic is ambulatory equipment. We could probably write a whole column about strollers. I would like to mention one idea which I saw being used recently. When our children don't walk at one years of age, we may want some more ideas of how to go outside with them other than a typical stroller. This wagon doesn't have that "special needs look", comes with a 5-point harness and, is best of all, is fun to ride in! There is space for two children in here! There are various styles and prices available. The general price range is $200 and up.

Radio Flyer Collapsible Folding Push and Pull Stroller Kids Wagon

Thank you S.B. for sharing what looks like an ingenious solution to getting meds into baby's mouth. The baby sucks the pacifier and swallows the medicine. I wish I would have known about this one years ago!

MediFrida, the Accu-Dose Pacifier
$6.99 on Amazon

Here is another interesting idea from a reader. He says that their baby with CP used this inside a regular bathtub. It's like a mini swimming pool in which the baby can be independent. Their child wore a neck floatie and floated around inside.

Swimava Baby Spa Kit - Large (86 Gallons) Size Swimava Baby Pool Home Spa with Baby Float & Swim Diaper included.
$101 on Amazon.

I'm sure there's a lot more baby equipment that I don't yet know about. The main thing is to realize that there is so much out there, and that it's worthwhile to look for answers to our challenges. Finding the right piece of equipment can make our lives so much easier and more functional, and that's worth a lot!

Consider It Done

A single mother of a special needs child tells of an episode in her life that gave her a lot of *chizuk*. A few years ago, she was told that her daughter needed a very complicated surgery which was not covered by her health insurance. Although a local hospital could do the surgery, there was a specialist in New York who was highly recommended for this particular procedure.

The woman did not have anywhere near the money needed for the procedure, let alone the flight to New York, but she knew she had to do the best for her child. She was able to raise part of the money, and then, through an *askan*, got the hospital to agree to take just a down payment, allowing her to pay the rest over time. Although it would be an exorbitant amount of money, she knew she had to do it for her daughter.

So she flew with her daughter to New York, which was, itself, a very difficult experience. The girl must be held down to prevent her from doing damage, which was extremely difficult in an airport and on a plane. They finally arrived at the hospital and prepared to meet the doctor who would perform the surgery. When the doctor checked her daughter, he said he saw some congestion, and thus couldn't do the surgery. The woman told him how difficult it had been for her to get there with her daughter, and offered to stay somewhere local for the next couple of days, until the congestion went away.

The doctor then said he wouldn't be able to do the surgery for another three months. The woman said she felt like the worst thing possible had happened. Aside from all of the time and money she had spent getting there, and all of the difficulties in transporting her daughter, now she was going to have to do it again? To make matters worse, the doctor told her that he wouldn't do the surgery until he was paid in full. The woman said she was told she could pay later, but the doctor, as well as the other hospital staff there, treated her very nastily, and she left very upset. She told the *askan,* who got her the appointment, how she had been treated.

Eventually, she went back and had the surgery done according to the terms of the original agreement, paying only a portion of the cost up front. Baruch Hashem, the surgery went well, and afterward she received a phone call from one of the heads of the hospital, apologizing for the way she had been treated three months previously.

This person told her that she didn't want anyone walking away from their hospital with negative feelings, so she asked if there was anything they could do to make it up to her. The woman replied she couldn't afford the large balance that she owed the doctor and the hospital, and would be very appreciative if she could help her with that. The woman said: "Consider it done," and just like that, her entire bill was erased!

What the mother thought was the worst thing was really a salvation for her. She would have been in tremendous debt for a long time in order to pay off her bill, and now it was finished in a second. She says that even when things get very difficult for her, she recalls this story, and reminds herself of Hashem's *chesed*, even when we don't expect it.

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SWEET SPICES

"Sweet Spices," is about seeing the hashgacha/providence in everyday encounters with our special children. The title is based on the following Torah medresh:

When Yosef's brothers sold him into slavery, the Torah mentions that the caravan in which he traveled down to Mitzrayim carried sweet-smelling spices, as opposed to the foul-smelling cargo usually transported on that route. Rashi points out that this brought comfort and encouragement to Yosef, who understood that Hashem prepared these sweet spices to accompany him on his journey, and to teach him an important lesson: Although it was painful that he had been sold into slavery and sent down to Mitzrayim, it was not random. It was orchestrated by Hashem, down to the very last detail, and Yosef knew that he would not suffer an iota more than was destined for him.

As we journey through life with our special children, we need to remember that Hashem is the One planning this journey, with all of the bumps and jolts we may encounter. Let's try to smell the sweet spices along the way, and be encouraged by the knowledge that nothing is random, and that we are on a journey to greatness!

Illuminations

SPECIAL WOMAN, SPECIAL CHILDREN

Genendel Krohn

After many decades of being single, Ms. Claire Schneider came to terms with the sad reality that she would probably never get married, and would certainly never mother a child. When her twin sister, Adele, lost her husband, Claire moved in with her to help raise her young son. Still, a deep void remained in Claire's heart as she desperately yearned to nurture a child of her own. After careful consideration, she decided to retire early and foster a child. But it wasn't a typical child that she wished to raise; she specifically wanted a child with a disability.

One day, Claire heard of a baby boy with spina bifida who had been born to the Freunds, a Chassidic family in New York. At that time, children with disabilities were viewed by certain communities as a source of shame for their families. As such, many parents would lock away their special children or offer them up for foster care. Rabbi Freund and his wife likewise worried that their severely handicapped son, Refael, would tarnish their family's reputation, and sought a *frum* home to care for him.

> **ALTHOUGH I FELT MY CHEEKS FLUSH, I WANTED EVERYONE TO SEE HIM SO THAT I WOULD NEVER FEEL THE NEED TO HIDE HIS EXISTENCE AGAIN.**

Claire took the little baby home from the hospital and treated him as if he were her own child, lavishing him with all the love and attention that had lain dormant within her for so many years. Although Claire was of Lithuanian descent, she was sensitive to the Chassidic preferences of the Freunds, and consulted with them even about which *hechsherim* to serve Refael.

When it was time for his *upshurin*, she invited Rabbi Freund to take the first snip, and saw to it that the young boy's hair was cut very short, leaving Chassidic *payos,* in deference to the *minhag* of his family.

Throughout the years, Claire carried Refael up and down three flights of stairs each day, to and from her apartment. Although it wasn't easy for her, she cared for him happily, routinely bringing him to therapists and doctor appointments. Determined to make him as high-functioning as possible, she did everything in her power to help him learn and grow.

When Refael was seven years old, the Freunds made the bold decision to bring their son back into their home, and Claire reluctantly parted with the child she had come to adore. The Freunds lovingly cared for him until he passed away at the young age of sixteen, due to his serious medical condition.

At Claire's funeral in June 2013, Rabbi Avraham Shia Freund spoke movingly about the special woman who had raised his son for so many years. He thanked her for the kindness and devotion that she had displayed toward Refael, and for caring for him as if he were her own child. Then he said: "One would think that Claire left this world without any children. In reality, when she gets to *Shamayim*, she'll see that she has many children."

Everyone at the *levayah* was confused. What could Rabbi Freund possibly have meant by that?

Then he explained: "For many years, it was very difficult for people in our community to come to terms with having a child with special needs in their family. No one wanted to ruin their family's reputation."

"Originally, when our Refael was born, we too, were ashamed of his disabilities. But after Claire shamelessly took him out in public and loved him despite his disabilities, we felt that we could do the same."

"The first Shabbos after we brought Refael home, I wheeled him to *shul*, determined to quell the stigma that had heretofore been associated with such a child. Although *Shacharis* begins at 9:30 on Shabbos morning, I deliberately waited until 9:45 to enter the large *shul* so that it would be filled to capacity. I lifted my son in my arms and carried him through the main door in the back until I reached the front of the *shul,* where I sit. Although I felt my cheeks flush, I wanted everyone to see him so that I would never feel the need to hide his existence again. Amazingly, ten or fifteen children gathered around Refael after *davening* and spoke to him."

"The following Shabbos, a friend of mine, whose wife had just given birth to a little girl with Down syndrome, told me that seeing me with my son gave him the courage to bring his daughter home from the hospital, instead of offering her as a foster child."

"There were many children I never knew of, since they had been hidden away for years. All of a sudden, parents were willing to acknowledge the existence of these special children.

Illuminations continued on page 31

Let's Get Educated

Neutralizing Explosive Behaviors—In a Nutshell

Batya Dancykier M.Ed-SpEd/BiL

Children with special needs show up with all sorts of behaviors. Some of the behaviors are tame and easily addressed, while others are more challenging. Some children's behaviors can be so explosive that handling them can seem impossible in the moment. When children show up with high-intensity behavior, those behaviors can be multi-dimensional, hurtful to self or others, and prolonged. What can we do for a child who is impulsive and out of control? What can we do for our children to help them regain control of themselves in those heated moments? What can we do to help them feel calm?

I am going to break it down into two key components. The first being how you handle yourself (the caretaker), and the second, how you handle your child. Before being able to address any behavior of any child, it's important to do a self-check. A self-litmus test, if you will. Am I breathing? Am I in control of myself? Am I calm? Am I reactive, have I been caught off guard? Based on the answers you find, you will know if it's the right time to carefully deactivate the behavioral "threat."

Once the self-litmus test has been given the green light, then, and only then, do you step in to help the child. If your child has exploded, there is the nearby threat of triggering a larger explosion. Showing up for high intensity behaviors is hard work, and it is sensitive work. If you are shaky, nervous, upset, or scared, you may trigger other areas. It is much easier to neutralize the behavior from a calm and levelheaded place. From a regulated position, you are setting yourself up for success, and will thus be able to help your child.

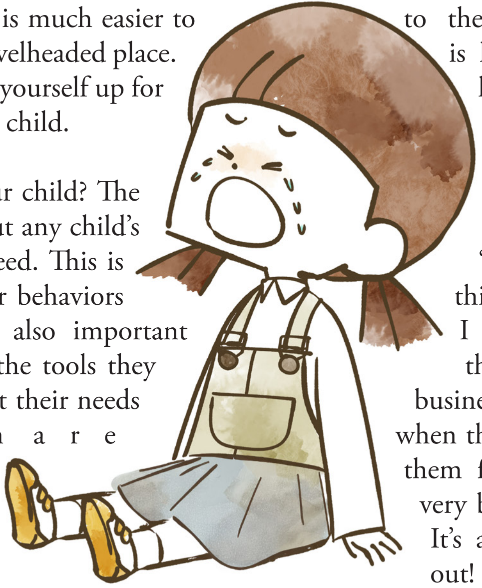
Now for part two: How do you help your child? The most important thing to understand about any child's behavior is that there is an underlying need. This is important, because we can then use their behaviors as roadmaps to meet that need. It is also important because it reminds us that children use the tools they have to express themselves, in order to get their needs met. When we remember that children are LEARNING to be responsible for their behaviors, we are inclined to lean into kindness and patience.

Now for the plan. The trick is to recognize at least one or two of the child's behaviors that show up when there are great needs present, and then to plan in advance. In all good behavior plans, you start with one or two target behaviors. We are not all behavior therapists or educators, but we know how our children act when they get angry or upset. So pick the biggies, ie: screaming, yelling, getting physical, running away.

Plan ahead. What will I offer to my child when he screams? How will I address it? Empower yourself to offer your child a tool so that he feels supported. Model emotional regulation when your children are dysregulated. Big feelings are scary for children. They need to know that there is an adult in the room who will guide them through rough waters. For every need you meet, the explosion diminishes.

Our reaction is the toolbox that will shape our children. I will outline some of the tools that kick into gear for me when handling a child with intense and extreme behavior.

One tool I enjoy using to distract a student from the state of chaos he is in, is humor. For example, when I have a child screaming because he doesn't feel heard, I will respond very calmly: "I'm an old lady and I can only hear you when you whisper." It's amazing to watch children get back to themselves when they recognize someone is listening and they aren't in "trouble" for having lost control of themselves. They are children! Children need to hear they are good, even when they do "bad" things.



Another handy dandy tool I use is "business voice." I explain that when I use this voice, it means I am very, very serious. I remind my students that I love them all the while, but I need them to know I mean business. Remarkably, it calms students down when they are in a state of great distress. It makes them feel like someone can take care of their very big emotions. It isn't yelling, it isn't mean. It's a very serious, strict *Morah* voice. Try it out! Disciplining children is to protect them, teach them, and empower them. We create "disciples" when we give boundaries.

Another effective tool I use is charts. It takes five minutes to draw a quick chart. Make smiley faces, draw stick figures, you don't need to be Rembrandt. Reward with ice cream or stickers, kick it old school. Encourage, reinforce, remind! It's a simple tool that goes a long way. Catch your children when they are NOT doing the bad behavior and reward them for those moments!

My best and most frequently used secret weapon, is none other than having a conversation. When a child is out of control, I will calmly sit on the floor "criss-cross apple sauce," and invite him to tell me what is going on. Get in there with him. Ask questions, be curious. It works wonders. Nine times out of ten it disarms the student, in even the most aggressive state, and brings him back to the present moment. You are essentially opening a space where all of your child's feelings are welcome, and you are offering a calm platform to share those feelings.

A note on time outs: The idea behind time-outs is for a child to calm down, reflect, and ultimately understand that he should stop the behavior that got him in there in the first place. However, when children lose touch with themselves because they are frustrated or overwhelmed, the last thing they need is to be left alone. What they need is a TIME IN. They need support, guidance, and most importantly, connection, so they can get back in control of themselves. The next time your child "deserves" a time out, jump in there with him.

When all else fails, give yourself and your child a big hug. Help him physically calm down. Sometimes children get so lost in their big emotions, that they need to feel safe. Let them actually feel it, in the form of a hug. Perhaps sing a song while you hug.

In a nutshell, when a child is explosive, or if you know that your child gets explosive, be prepared to be the ultimate bomb de-activator. Check in with yourself, plan for the behaviors you will address, choose how you will address them, and support your child as he rides the wave of some very scary emotions and learns to come back to himself. Gentle guidance in a steady voice, with humor, with acceptance, with clear expectations, will produce results.

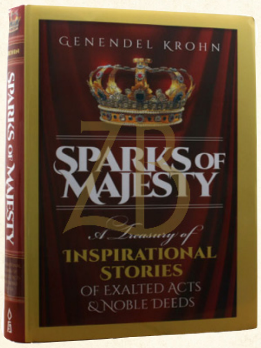
Illuminations continued from page 29

Slowly, parents brought their children out of the woodwork, finally allowing them to become a part of the community. For the first time, these children were brought to *shul* and had a chance to answer: "*Amen. Yehei Shemei rabbah*.""

"I want everyone here to know," continued Rabbi Freund, "that this is all because of Ms. Claire Schneider. She enabled me to come to terms with my son's disabilities, and gave me *chizuk* to bring him to *shul*. This served as the impetus for all these other families to accept their children for who they are. All these children have been embraced by our community because of her."

"And it goes beyond that," concluded Rabbi Freund. "I wanted my child to get the proper *chinuch*, but no *frum* institution was willing to accept him, because no one was equipped to deal with his severe handicaps. Determined to do whatever I could for my child, I started a school called *Sha'arei Chemlah* for children with disabilities. By now, hundreds of children have passed through its doors, and it's all because of what Claire Schneider did for my son. All the children who benefited – and continue to benefit – from *Sha'arei Chemlah* are, in essence, her children."

As Rabbi Freund stepped down from the podium, there wasn't a dry eye in the crowd. No one could possibly imagine the impact that this seemingly simple woman had made on so many special children and their families.



(Heard from Rabbi Avraham Shia Freund) Reprinted from Sparks of Majesty by Genendel Krohn, with permission from Feldheim Publishers.

SNIPPETS

Spinning Sweet Dreams

IN SESSION

Q **Dear Shira,**

My brother was born prematurely when I was quite young. I understand that his prognosis was not clear in the beginning, but preemies do sometimes "turn out fine." Throughout the very scary months of his NICU stay, my family looked to my neighbor's son (himself a micro-preemie) as our source of *chizuk* -- he was by then walking, talking, and attending a regular school. Our repeated mantra was something along the lines of: "he just needs extra time..."

I became my brother's #3 caregiver (after my dedicated parents, of course), as I had only older brothers who were in *yeshiva* most of the day. As I got older, I spent hours and hours caring for him and learning all of the therapies to do with him. I was young and trusting, and I truly believed that all of our efforts would result in a normal brother at some point.

As I am sure you have guessed, my brother never did become "normal." He has very severe CP, which I now know, was known by the time he was 18 months. I was not aware of this until my friend (in middle school) informed me one day that my brother must have CP, because her mother "is a speech therapist, and she said preemies who still don't walk or talk by the age of 5 most probably have CP." Needless to say, I was shocked, and shattered.

Over the next few years, I fought his diagnosis with every ounce of strength I had. I did every single exercise the therapists recommended, researched equipment that could be helpful, as well as grants and funding sources for him. Along with that, I cried every time there were setbacks, or I felt not enough was being done. I was constantly plagued by feelings of guilt for not trying harder when he was little (when he was still a floppy baby, I had loved to just cuddle him, and hated making him do tummy time).

My brother experienced many challenging experiences, and during one particularly daunting crisis, it all became too much for me. In His great kindness, Hashem sent me a truly special *shaliach*, in the form of a *machaneches*, who saw beyond the crisis I was facing. She realized that I had never accepted my brother's disability altogether, and that I was dealing with many years of pain and isolation in fighting his diagnosis. She continued helping me face the truth over the next few years, as I went away to seminary and began lessening my highly involved and emotional role in my brother's development.

Acceptance takes time, and over the years, as things change, it continues to be a dynamic process. However, the excruciating pain of finding out, years later, about my brother's disabilities could have been avoided. The loss of trust in everyone around me, for hiding that information, could have been avoided. Had someone explained to me as a child what was in store for my brother, and explained that therapy could help him but not fix him, I could have started the process of accepting him for who he truly was, right from the start.

The reason I was not clued in was that my help was very much needed, and my parents felt that I would be more motivated and interested if I believed he was a normal child. They were afraid that I would be too scared to be involved if I knew things were "different." And once my brother graduated babyhood, everyone assumed I had "figured out what was going on" -- but no one wanted to reduce my motivation in helping my brother. After all, how do you explain to a young child that you need her to keep helping with the exercises, but that she that shouldn't expect to see any progress?

Working with families now, I always want to spare others the suffering I went through. **My question is: How should the special child's prognosis be shared with family members to afford them hope and expectation, and motivate them to promote the child's development, yet prevent the expectation of the child being "fixable"?**

Name Withheld

A Dear Devoted and Disillusioned,

I hope I can use this name when responding to you. Thank you for submitting your question, as it is an extremely important one. As usual, I will try to answer you personally, and generalize it for the <u>*Neshamale*</u> readership. This is the first time a question was submitted by a child/family member (not an adult), which gives a completely different perspective.

When reading your letter, quite a few themes were brought to my attention, some subtly, others more directly. First, I want to commend you on your steadfast devotion to your brother for **SO** many years. You did it so selflessly; daily/weekly/yearly,

In Session... continued on page 35

Memorable MISHAPS

Compiled by Fraydel Dickstein

This column lets us laugh about the hilariously funny things our children do (although they may not always seem so hilarious in the moment!). It's also nice to know that this is our "normal", and that we and our families will be OK!

Boruch

Boruch has many hang-ups. Some are downright cute, and others are – what can I say? – rather annoying. Avi, the owner of *Seman Tov* bus company, is a true *tzadik* and gave Boruch his phone number so they can be in touch. Boruch sure does call him, but Avi handles it with tremendous grace. Now Boruch had this great idea he would get Arnie, the bus driver's, phone number. When Boruch wants something, he persists and persists. Finally, in desperation, Arnie said: "My number is 9-1-1." What a whopping mistake! Boruch dialed, but B"H, the police understood what happened, and did not come down.

Chanoch

The new neighbors on the block were so nice and so giving, so of course they let my Chanoch inside. I followed him in, as I know how this can end up... He helped himself to the food that they clearly had prepared for their Shabbos *seuda*. I was mortified and felt bad as to what they would eat. I had no choice but to turn my brain off and just not think about it.

Chana

I have many children, and the majority of them do not know how to strike a match at age three. Somehow, however, my super-delayed Chana seemed to have had this skill. I once walked into the kitchen to see Chana literally on fire! With Hashem's great kindness, there was no harm done to any part of her body!

Chaim

The kids came in and reported that my Chaim was at the Adlers, our neighbors. I ran out to get him, but I was too late – he was already taking a shower in their bathroom!

Boruch II

It was a Friday night and pouring rain outside, but B"H, we live in a house that protects us from the rain. I heard Boruch downstairs, so I went down to see what was going on. My dear Boruch had opened all the windows and was watching in delight as the room filled with water! How could I get upset at a boy who does not know any better?

Trivia Question:

The above picture is:

a) A shampoo store

b) A Walmart shampoo give-away

c) The results of a day with no respite programs open!

STRESS BUSTER TIPS

BUSHAH MECHAPERES

(Embarrassment is an atonement)

Sometimes, when I go through scenes similar to those above, I think that perhaps this is Hashem's way of giving me *kaparah*, and that I will be spared elsewhere. Or that maybe everyone has a *bushah* quota, and perhaps this is Hashem's way of fulfilling mine. Obviously, I don't know Hashem's *cheshbonos,* but in any case, *Chazal* say: *"Bushah michaperes."* (Sometimes I am left wondering: "Did I really do that many *aveiros*?") One time, when we were trying to get accepted into places, and my son was so embarrassed about it, I told him: "Perhaps you filled your *bushah* quota, and now it will be easy to get accepted where you want." And sure enough, he got in right away!

Please send your Memorable Mishaps and/or stress-buster tips to: Neshamalemagazine@gmail.com, or text to: 848-299-2908. You can also leave a message. Give everyone a good laugh, and let us know that it's OK when these things happen—stuff happens to everyone!

I Wish Someone Had Told Me

C.T. inspired by M.G.

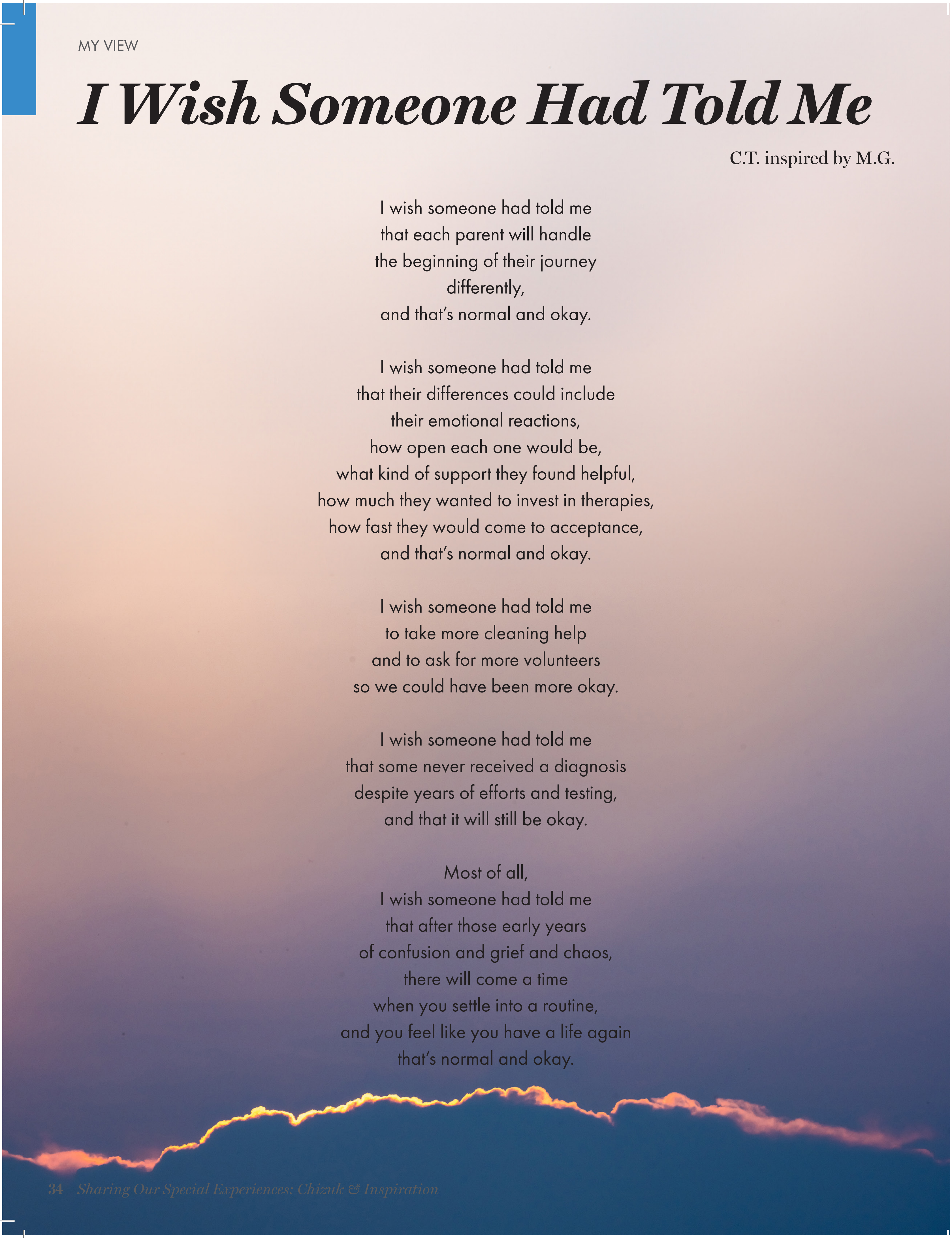
I wish someone had told me
that each parent will handle
the beginning of their journey
differently,
and that's normal and okay.

I wish someone had told me
that their differences could include
their emotional reactions,
how open each one would be,
what kind of support they found helpful,
how much they wanted to invest in therapies,
how fast they would come to acceptance,
and that's normal and okay.

I wish someone had told me
to take more cleaning help
and to ask for more volunteers
so we could have been more okay.

I wish someone had told me
that some never received a diagnosis
despite years of efforts and testing,
and that it will still be okay.

Most of all,
I wish someone had told me
that after those early years
of confusion and grief and chaos,
there will come a time
when you settle into a routine,
and you feel like you have a life again
that's normal and okay.



In Session... continued from page 32

without stopping, and you were able to achieve so many beneficial opportunities for him.

The expression “Hindsight is 20:20” (vision), means that it is always easier to recognize information or perspective after the event occurs, though not beforehand. Although adults are usually well-intentioned and typically want to shield children from anything negative and to protect them, in your case it backfired. Probably your parents wanted to ‘shield’ you, and withheld the information about your brother. Although they wanted to save you from suffering, look what happened. You suffered **MUCH** more. Additionally, you lost trust in your parents.

Perhaps your letter and experience can help another child, to tell him the truth, 100%, and prevent future suffering. Here is a ‘simple’ example, but its message can be applied on so many levels. When a child must get an immunization shot, frequently, s/he is very scared. The well-intentioned parent might say: “Don’t worry. It’s not going to hurt.” However, to the child it KILLS. It is better for the parent to tell the child that when the needle goes in, it hurts, but it will be over quickly, and afterward the child can get a band aid, ice can be applied, etc. This scenario allows for the parent to be 100% truthful, and the child can trust the information s/he receives, and will trust the parent in the future.

How can this be applied in your situation? In an informational, but developmentally appropriate conversation, a child can be informed of the disability, and still have hope. Hope is an essential perspective, but there must be a balance of reality vs 100% truth, and be optimistic. All your efforts were not for naught, but it is so sad that you had to suffer for so many years.

Wishing you continued *hatzlacha*. Know that your efforts are never forgotten by Hashem, Who sees the entire picture.

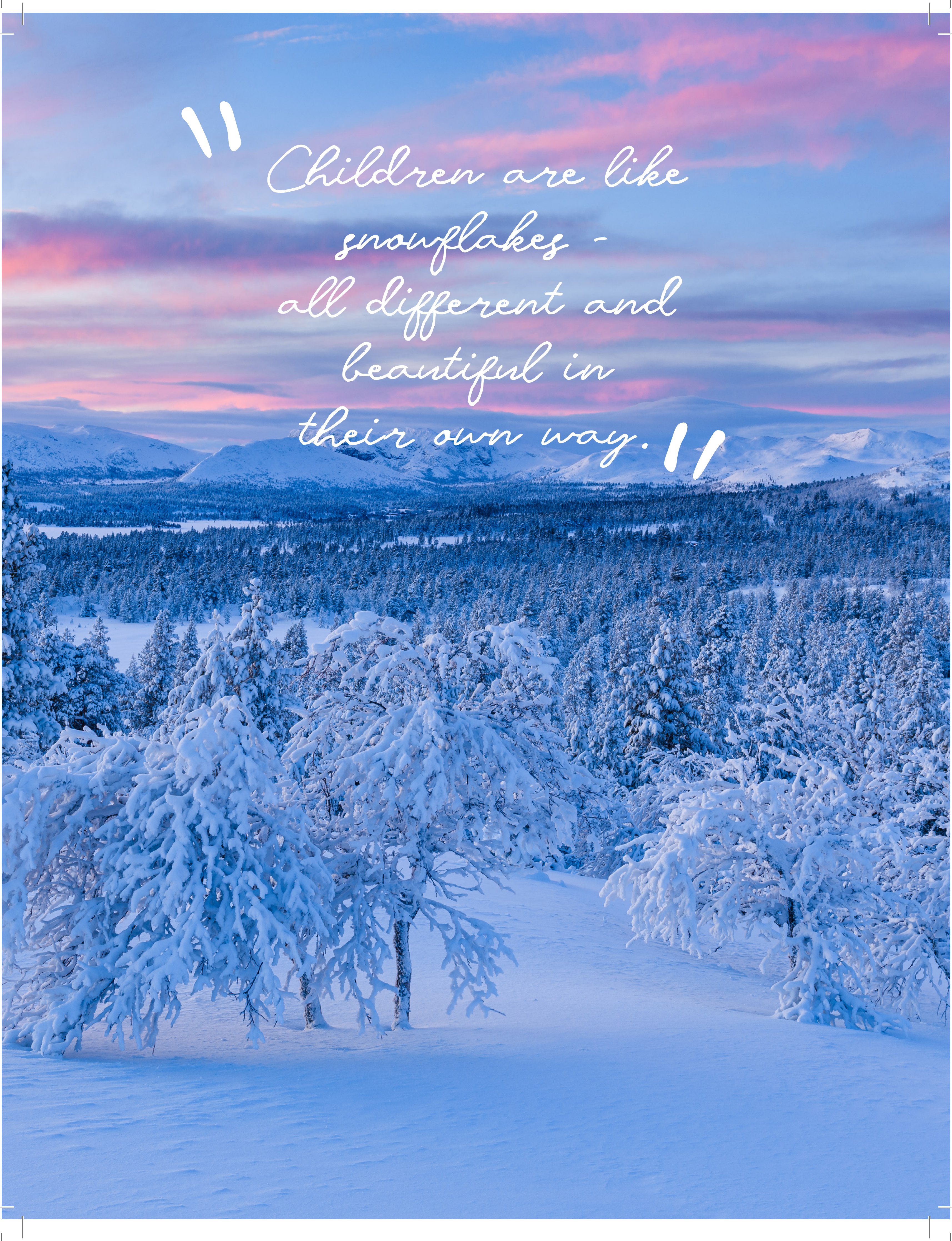
Shira Speiser, LCSW

Shira Speiser is a social worker in Lakewood, New Jersey and has helped children and families for many years. You can contact her with your own individual concerns and needs at: (732) 367-1503 or shira732@live.com

GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

Note: All words are in Ashkenasic (Eastern European) pronunciation. (Y) indicates term is Yiddish (A) indicates Aramaic

Ahava – Love
Ahavas HaTorah – Love of Torah
Aish – Fire
Askan – Jewish Community Leader
Aveiros – Sins
Avoda – 1) Work 2) Worship
B’chasdei Hashem – With G-d’s Kindness
Bais Medrash – Torah study hall
Boruch Hashem – Thank G-d
Chashmona’im – Heros of the Chanukah story
Chein – Grace
Cheshbonos – Accountings
Chinuch – Education
Chinuch HaBanim – Children’s education
Chiyuv – Obligation
Deveikus B’Hashem – Closeness to G-d
Frum – Religious (Y)
HaKadosh Baruch Hu – The Holy One, Blessed is He
Hakafos – Dancing with Torahs around the synagogue on Simchas Torah
Haschala - Beginning
Hashgacha – Supervision, ie: for Kashrus
Hatzlacha - Success
Hechsherim – Symbol indicating Kosher supervision
Heilege – Holy (Y)
Hishtadlus – Effort
Kaparah – Attonement
Kedusha – Holiness
Kiddush – Sanctification ceremony, ie: on Shabbos
Klal Yisroel – The Jewish People
Kohen – Jewish Preistly tribe
Kollel – Institute for advanced Jewish learning
Levaya – Funeral
Limud HaTorah – Torah study
Makkah – Plague, disease
Mechaneches – Female teacher
Mechutanim – Son in law or daughter in law’s parents
Menorah – Candelabra used for Chanukah
Mesiras Nefesh – Self-sacrifice
Middos – Character traits, manners
Mishkan – Tabernacle
Mitzva – Torah Commandment
Nekuda HaRuchni - Spiritual point
Ner – Candle
Nes/Nissim – Miracle/s
Neshama – Soul
Ohr – Light
Oneg Shabbos – Friday night Shabbos celebration
Refuah - Healing
Refuah Shelaima – Complete healing
Seuda – Festive meal
Shaliach – Emmisary
Shemen – Oil
Shleimus – Perfection, wholeness
Shmiras Shabbos – Shabbos observance
Sifrei Torah – Torah scrolls
Siyata Di’Shmaya – With the help of Heaven (A)
Tekufa – Time period
Tzadik – Righteous person
Upshurin – Celebration of 3 year old boy’s first haircut (Y)
Yiddishe – Jewish (Y)
Yiddishe Mameh – Jewish mother (Y)
Yomim Tovim – Jewish holidays
Zoche – Meritorious



"Children are like
snowflakes -
all different and
beautiful in
their own way."