

# נשמהלה

*Sharing Our Special Experiences: Chizuk & Inspiration*

# Neshamale

## magazine

## SOUVENIRS /4

A 30+ YEAR JOURNEY YIELDS  
VALUABLE SOUVENIRS...

LET'S GET EDUCATED:  
AQUA THERAPY /34

## RESPIRE HELP FOR YOUR CHILD /24

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Dear Readers,

The dreaded phone call came at 11:25 on a Thursday morning. Although the nurses from Avrumi's school call fairly frequently, whenever the name of his school pops up on my screen, my heart goes cold. What now? Did he have a seizure? Another non-stoppable nosebleed? Or are we just behind on paperwork? Of course, the kind nurses always preface the call with: "Avrohom is here and everything is ok..." Yet this does nothing to calm me down until I actually hear why they are calling! On this particular day, the nurse explained that a classmate had just tested positive for Covid-19 and therefore the entire class was being sent home to quarantine.

My first reaction was relief that nothing bad had happened to Avrumi himself. But as her words sank in, so did the panic. Help! Was I really going to be locked-down at home with Avrumi? How in the world were we going to manage?

I left work and picked him up from school. We arrived home at noon, and so began a new and unique set-up in our lives: Avrumi and I, home together. The uniqueness of the situation was that it was Avrumi and I, home together *by ourselves*. While we were in quarantine for months at the onset of Covid, that was with the rest of the family at home too, an entirely different situation.

However, what I envisioned to be a nightmare turned out to be a dream come true. I was quite simply stuck at home, with nothing to do other than spend time with my son. It was a quiet time of year, there was nothing major on my to-do list, and we couldn't even go on errands. So, we just... spent time together. It's not the easiest thing to "play" with Avrumi, as he does not play or interact in the typical ways of children, so I let him lead the way on how we spent our day. If he wanted to endlessly transfer toys from one bin to another and back again, then that's what we did. And if he just wanted to sit on the couch and cuddle, well, there was no reason why we couldn't do that for the next hour, either. The weather was unseasonably mild, so we were able to take short walks to air out, too.

I spent a lot of time just observing Avrumi, enjoying his personality and appreciating his specialness. I realized that this experience was sorely lacking until then. I realized that most of my previous interaction with him was for discipline ("Stop kicking!") or simply practical ("Time to eat!"). Of course, I always told him I loved him and gave him lots of hugs as well as special moments of connection. It's not like he lacked attention or was ignored. But while I had been very busy taking care *of* him, I hadn't been connecting *to* him.

I always thought that spending quality time with one's child was for *their* sake; that it was good for *them*. Now I realized that it was good for *me*. It was important and healthy for *me* to have that relationship, to feel a loving connection, to appreciate my son's uniqueness. It made me a better, happier mother. Being forced into quarantine with Avrumi turned out to be a very enjoyable and rewarding vacation for both of us! It's not something I would have wished for and I'd be very glad not to get any more phone calls about quarantines, but I am thankful that it happened. I'd like to think that the lessons I learned then impact the way I continue to interact with him until today. Although we are not staying home all day together now, I try to grab a few minutes at a time, whenever I can, just to focus on Avrumi in a positive, loving way.

Summertime is here, and that means different things to different families. It's usually not a quiet season, as we get sucked into camp carpool schedules, packing and travel plans, and feel like we are drowning in bubbles, bathing suits, and sun-screen. But there is still something relaxing and laid back about the summer, as opposed to the rest of the school-year schedule. I'm hoping we can all have a taste of my quarantine experience, in the sense of being fully present and attentive to our precious children and the special *neshamales* we are privileged to have in our homes. When we take the time just to be together, without an agenda, to appreciate and enjoy each other's company, it can add a very special dynamic to our relationship.

Wishing all of our readers a relaxing, fulfilling, and enjoyable summer,

*Chayala*

# Souvenirs

Miriam Apfel

Even today, I remember speaking to my mother about our year and a half old daughter. Deena had just been diagnosed as developmentally delayed. I was bothered that my friends would now pity me, and didn't understand why this was happening. "Maybe I didn't eat well during pregnancy," I speculated. "Or maybe I had some virus while I was expecting." My mother put it into perspective for me: "Do you know why Deena is the way she is? Because HaShem wants her to be!"

It's true that I had trouble with eating while I was expecting, and I was overdue. I may have had a virus, and there were other possibilities. But my mother directed my focus to the Source of all circumstances. Everything is perfect; Hashem is the One in control.

I didn't realize then, that I was starting out on a special journey. Over the next 30-plus years, I learned new skills, have been inspired, and grown in ways I could not have imagined. I think of the transformative pieces of advice I received as souvenirs, collected along the way. My mother's words became my first souvenir.

The next souvenir came from my cousin, a pioneer in special education. After meeting Deena, she told me in no uncertain terms: "You need a support group!" She arranged for me to speak to Mrs. Betty Pollack of Otsar (Hebrew for "treasure"), an organization in Brooklyn that serves families impacted by developmental disabilities. Mrs. Pollack guided me in starting a support group in Lakewood.

Our Otsar group established Sunday Respite, a part-time integrated playgroup, and eventually a school called *Raishis Chochma*. The group also initiated a program to help families of children with special needs as part of the high school *Chesed* program—they referred to it as "doing Otsar."

That was

over 30 years ago. Many programs in Lakewood today are offshoots of our group, including: One Day at a Time, Sibshops, The Special Children's Center, and SCHI (School for Children with Hidden Intelligence).

Back then, the Early Intervention (EI) Program was a group that met for two hours, once a week, in a building at Georgian Court University. The mothers stayed with their children and did the activities/exercises with them. It was important for me to continue doing what we learned on a daily basis. A child cannot learn enough life skills in two hours a week; putting them into daily practice makes a huge difference. Instead of doing therapy exercises for hours at home, I asked Deena's therapists to show me ways to incorporate her therapy into the daily activities we were already doing.

In special education, the concept of a "free and appropriate education" at public expense had been U.S. law for only about a decade. Our community was actually ahead of many places in the US. The *Cheder* had trailers for remedial reading and math, as well as Pearl Blau Learning Center for help with *Limudai Kodesh*. However, if a child had greater "special needs," the options were limited. Public school, private/home schooling, or moving to New York were the basic options. In general, interacting with people with special needs was uncommon, because there were few in our community.

I once noticed a group of children shouting at a young woman who was obviously "different." I felt strongly that if children who couldn't learn in a regular class could somehow be included in the "mainstream" when they were young, our "typical" kids - and adults - would be more comfortable with them. I had a mission. And our Otsar group was the vehicle to set it in motion.

We organized a group of preschoolers, two "special" and two "typical." They met with Mrs. Cirel Septimus, their *morah*, for a few hours, a couple of times a week. Deena was then around 2-1/2 years old. She could sit independently, and crawled with an unusual gait that we called "bunny-hopping." One day, at *Morah* Cirel's house, Deena pulled herself up to stand next to the couch. "Look, *Morah*! Deena's standing!" Another little girl had noticed and felt the specialness of her friend's achievement! This memory is another of my souvenirs.



After Deena turned three, she attended the Lakewood school district's Preschool Handicapped Program. She was in the morning class, from 8:30 to 11:30. She had some individual speech therapy and Adaptive Phys-Ed (gym) twice a week. Individual Physical Therapy (PT) was only once a week. At the end of the year, Deena was still not walking or talking at all. At the IEP (Individualized Education Plan) assessment meeting, the teacher told me that Deena really needed more PT, but since the therapist was only in the building once a week, she did not put that recommendation into the IEP. That didn't sound right to me, certainly not according to how I understood the law. Before I left the building, I went to Deena's classroom to observe. It was snack time, and the staff gave out cookies, handing some to the other *frum* child in the class. I intervened, asking if she had her own kosher snack. The staff corrected the error, but I had heard and seen enough.

A voice in my head proclaimed: "We need a program where we don't have to worry about *kashrus* and our kids can get the therapy they really need." Although we had sent Deena to Public School with the approval of my husband's *Rosh Yeshiva*, we received backing from *da'as Torah* to start our own program. I had almost no background in special-ed, but I had dreamed of being a Teacher-of-the-Deaf and a school principal. I like to think that Hashem put those ideas into my head to prepare me for what I would now need to undertake.

Our school was named *Raishis Chochma*. Our slogan was: "Special Jewish children have special Jewish needs." We had huge *siyata d'shmaya* in finding our first teacher and we opened with three students. We were a non-public school, so our students, all classified, could get services from the school district. We bought toys in the flea market and paid the first payroll with our *chasuna* money. We hired an educational consultant and had regular meetings to keep on top of each child's development. At one point, we had seven students in three classes and were mainstreaming in the Bais Faiga girl's school, and in two of Lakewood's kindergarten classes.

Bais Faiga hosted our girls in their Primary classes for lunch and recess. We realized that some of our students would likely be able to handle academics in a regular classroom, with support. One set of parents approached the *hanbala* of Bais Faiga, who took the question very seriously and consulted Rav Pam, *zt"l*. Should they accept this child into their school if they weren't sure they could meet her needs? Rav Pam answered: "They should accept her, even if the only gain is that the other students will learn to do *chesed!*" We worked closely with the principals and the classroom teachers, who put their hearts into helping our girls succeed.

Over the next six years, it became harder to juggle all the myriad details of running a school and taking care of my growing family,

## More souvenirs I've collected:

If someone offers you help, just say: "YES!"

- my husband

Whatever you do, someone will think you should have done something else. Be sure that Hashem will be happy with it, and don't listen to your detractors.

- my sister

It's not a mitzvah to make things harder for yourself.

- Morah Bashie

Hashem does not expect you to do the absolute best. He wants you to do the best you can with the resources He gave you.

- Mrs. Chana Dowek a"h

SEE the good.

- Rochie Pfeffer

Everything we do for our special child is a mitzvah.

- our Rav

Don't think so much!

- my husband's Rosh Yeshiva

Be grateful for all the things that other people do to make things nice for you.

- Yudi Pfeffer

Bochurim who are sibs also need a support group.

- one of my sons

You gotta do what you gotta do!

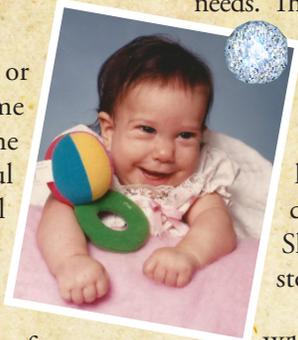
- me!

You don't stop acquiring new skills at age 18. Or 25. Or whenever.

- Deena

*ka”h*. Hashem sent Rabbi Osher Eisemann to the rescue. He told my husband that he was filing the necessary paperwork to open a School for the Handicapped. Our students became part of Rabbi Eisemann’s school, SCHI - School for Children with Hidden Intelligence, and today, Deena is part of the adult program - SCHI Disability Services (SDS).

Over the years, we noticed that when parents or staff complimented Rabbi Eisemann for some achievement, he simply declared: “It’s all the *Eibishter!*” How’s that for a souvenir? We are grateful that we had the *zechus* to be part of the initial planning of this special school, that has grown to service so many of Lakewood’s special children.



When Deena was around 9 years old, the idea of sending her to camp came up. I was horrified! How could I send such a young and helpless child away from home? It’s not like all her friends were going and she was begging to go, too. Sure, I could use a break, but what kind of mother needs a break from her own child?! Mrs. Leah Trenk, my parenting mentor, reassured me that it’s ok for me to have a break, and convinced me that it would benefit everyone. So we sent Deena to camp. She enjoyed it, and grew from the experience. And I discovered that taking a break gave me a chance to recharge my patience, energy, and love, so I could take better care of Deena the rest of the year. That concept is another of my souvenirs.



At the end of each summer, when Deena returned from Camp HASC (Hebrew Academy for Special Children), we would notice tremendous growth. Sometimes we worked on something all year, but wouldn’t see a change until after the summer. I was intrigued, so

I observed the counselors on Visiting Day. They were constantly praising Deena. And hugging her. And giving her High-5’s. I realized then, that I was so busy with my daughter’s physical and educational needs that I often neglected affection and praise.

For the next ten months, that was my focus. It wasn’t easy. I had to look past the extra work she created, her less than pristine hygiene, and the lack of feedback.

But I knew it was the right thing, so I kept it up. On the next

Visiting Day, the teacher asked me: “What did you do with Deena this past year? I never saw a student this age (mid-teens) improve so much in one year!”

Our special kids have special needs, but they also have regular needs. The dividends for showing affection and approval are exponential (for the “typicals,” too)! This is a souvenir we should all cherish.

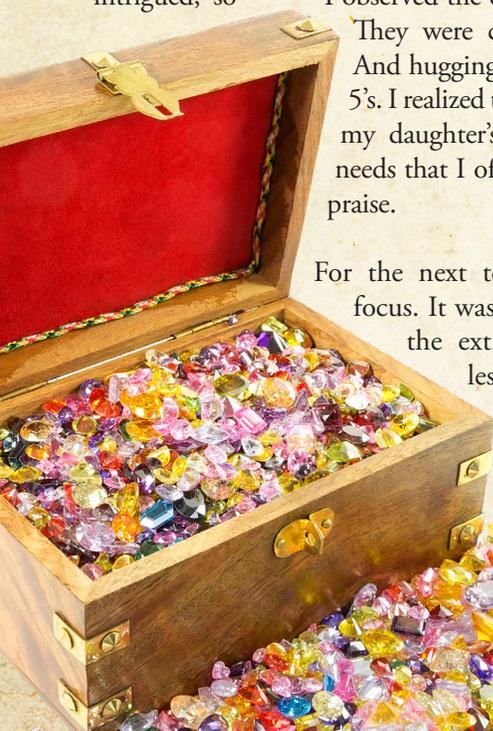
Because Deena is basically nonverbal, it’s hard to know what she really understands. One thing is certain—she knows more than we think she does! She keeps surprising us. Here are a few of the souvenir stories that I have collected about her:

When Deena was in her 20’s, her siblings decided that if she could make the sounds “buh” and “bee,” she could learn to say “Bubby.” They had her make each sound on command, then say them one after the other, then blend them together. *Chasdei HaShem* – success! Recently, I mentioned something about my mother, and Deena said: “Bubby!” I hadn’t realized that she understood!

A few weeks ago, I told Deena that it was almost time for supper. She said: “Totty! Totty!” I told her that I would get Totty when everything was ready. When I told her that everything was ready, she jumped up and went quickly out of the kitchen saying: “Totty, come! Totty, come!” I followed her as she went to husband. She told him: “Totty, come!” He asked her: “Did Mommy send you to tell me that supper is ready?” I walked into the room and told him that it was her own initiative. We were both floored!

Math seems to be a weak point for Deena. She’s been able to identify numerals for years, but could only count 1 object. I started counting out loud when washing *negel vasser*, when going down the steps of the bus, etc. Deena likes to “set the table” for supper, but she was putting out way too many forks, napkins and cups. So I would say: “We need 1 for Totty, 1 for Mommy, and 1 for Deena. 1,2,3,” as I put them on the table. After a while, I would tell her: “We only need 1 for Totty, 1 for Mommy, and 1 for Deena. 1,2,3,” and sometimes she would put just 3 or 4. Last night, she put about 6-8 cups on the table. I said: “We need 1 for Totty, 1 for Mommy, and 1 for Deena. 1,2,3. Please put the rest back.” And she DID!

It takes patience to teach Deena the right way to do things. Every day, Deena used to load up her backpack with Legos and mentchies, and every day, I would remove them before she went to school. Every evening, she would put them back. As I took them out for the umpteenth time, I thought: “Doesn’t she get it? I don’t want her to take this to school!” Then it hit me—she must be thinking: “Doesn’t Mommy get it? I WANT



to keep that in my backpack!" It's so important to try to see things from her perspective!

I find it helpful to be aware of Deena's cognitive level. I know how much to expect from her, what skills to work on, and it helps me not get upset when she acts like a three year old. Once, one of my grown daughters told me about some cute things her kids had done, and I told her some of Deena's *chochmas*. My daughter laughed. "This is great! I share stories about my preschoolers, and you share stories about Deena!" Although they are all younger than her, Deena's siblings are really proud of her progress and appreciate her cuteness.

I noticed, long ago, that my kids reflected my attitude and behavior toward Deena. When I heard them being impatient with her, I knew it was time for me to practice patience. When I heard my youngest talking to her in a higher-pitched voice, I realized that I needed to focus on speaking to her in a normal voice. (It also made me aware that the kids listen to and copy me—always!) Each of our children went through a stage of finding Deena's differences and behaviors distressing. Mrs. Trenk guided me to highlight her capabilities by creating opportunities for her to help them. *Baruch HaShem*, Deena's siblings accept her and are proud of her. It is truly a *nachas* to see this passed down to the next generation.

HaRav Shmuel Kamenetsky shlita once came to Lakewood to speak to parents of children with special needs. One of his points was that the *hashgacha protis* that puts a special *neshama* into a particular family is the same *hashgacha protis* that is *m'zavaig zivugin*, so we need not worry about *shidduchim* for our healthy children. We saw this clearly with our first *shidduch*: Our daughter's *shadchan* was a friend she met at Sibshops, a workshop for siblings of children with special needs.

Many years ago, when we made a parlor meeting for our school, *Raishis Chochma*, my husband told me that he was going to publicly thank Hashem for giving us Deena. I myself didn't yet feel I was on that level. Fast forward to today. Being Deena's mother still has challenges, but I choose to focus on the rewards, like appreciating the tiniest steps of development, seeing my other children's sensitivity to others, etc. Because of Deena, I've added to my souvenir collection with the many amazing people I've gotten to know who work in SCHI, the Center, and HASC, the *Chesed* girls from our school programs and from "Lev With Luv," and so many wonderful friends. So I would like to say: "Thank you Hashem for giving Deena to me!"

When my daughter Devora came back from seminary, she told Deena that when she learns to talk, she will take her to *Eretz Yisroel* to *daven* at the *Kosel haMaaravi*. I *daven* that we will all go together *al kanfei nesharim* to the *Bais HaMikdash* very soon! Looking forward to meeting you all there, *bim'haina b'yameinu, Amen!*



# WOW! MOMENTS

## Tante Deena & Yanky

### WOW #1:

Deena was in her 20's when her nephew Yanky was born. As Yanky became a toddler, we realized we had a problem: Deena got very upset when Yanky played with her toys, and then Yanky got upset and confused because he had nothing to play with. Reasoning with either of them wasn't possible, so I decided to designate a box of Lego as Deena's "special toy," and the play dishes as Yanky's "special toy." I hoped that enforcing this rule would teach them to respect each other's right of possession, but I wasn't sure if it would work. *B'Chasdei Hashem*, it worked beyond my expectations! They both learned to say and accept each other's "NO." They also learned to say: "Yes, I will share with you." They became very close friends, always happy to see each other.



### WOW #2:

When my grandson Yanky was almost three years old, his family joined us for Pesach. During the seder, his *Abba* gave him squares of chocolate to encourage his participation. When he said the *Mah Nishtana*, he got a chocolate square; when he asked a question, he got more chocolate. When he answered a question, he got another chocolate. After a couple of recitations of the *Ma Nishtana* (to earn a more chocolate!), I noticed that each time Yanky received a square of chocolate, he broke off a piece and gave it to Tante Deena!



### WOW #3

When Yanky was in first grade, his younger brother went with his family to Yanky's primary classroom to celebrate his *upsherin*. The *rebbe* gave the *upsherin yingel* a lollipop to dip into the honey that was placed on each letter of the *Alef-Bais*, and gave Yanky a lollipop too. After the special event, as we prepared to leave, Yanky asked his *rebbe* for a second lollipop. He then turned to my husband, handed him the lollipop, and said: "Here, Zaidy, please give this to Tante Deena when you get home."

# את פתח לו

Leah Tawil, SLP

You have it in you to help your child open his mouth, so to speak, and enable him to communicate. Here are some tips to incorporate even more communication into what you are already doing during your day. Try to establish predictable routines throughout your day which naturally present built-in communication opportunities.

## Hard at Play

“Oh, it’s child’s play!” people scoff. I don’t know who coined the term, but I can assure you that a child’s play is anything *but*... “child’s play.” Playtime is serious stuff! Children *need* play in order to develop. And here’s something interesting: Studies that looked at the early development of criminals found that some were what researchers have termed “play-deprived.” Lack of play really stunted their development in many ways (apparently!). Can you imagine that? So play is really important. But *how* to play, shall we say, productively? Here are some tips on how you can use play to engage your child.

- » There are various developmental stages of play, the lowest being “sensory-motor” and the highest being “complex pretend.”
- » Some children have favorite items they enjoy playing with, even fixating on them. We can use these “comfort zones” to transition them to higher levels of play.
- » Try to follow your child’s lead and get involved in his/her play.
- » Once you have gotten into his world, you can turn it into a game of sorts. This can be a game of peek-a-boo, tickling, spinning the child, or something else he enjoys.
- » The object of the “game” is to open and close as many communication circles as possible. You want your child to “open” by initiating a conversation, and “close” by responding to you.
- » Once your child has gotten the hang of the game that you have set up, pause and wait for your child to initiate.
- » As your child becomes more comfortable initiating more and more, you can introduce pretend play, incorporate different language, sentence, and grammatical structures, and eventually add emotional exploration.

*Tzvi loves to play with trains, but by himself. He builds the tracks, and can arrange and rearrange them for hours, making the train travel along the tracks, around and around, almost endlessly. His mother sits next to him and takes the other train. She moves it in the way of Tzvi’s train, and bumps into it playfully. He looks surprised, but then returns the bump.*

*Soon, it turns into a game of train tag. Every time she bumps into his train, she says: “Got you!” Then she makes her train “run away,” saying: “Oh no!” or “Uh-oh!” She also says: “I’m coming to get you...!” He is laughing, making eye contact, and having FUN! So is Mom.*

*Now, Mom is going to try to bring it to the next level. She wants him to initiate. She’s going to play dumb and just sit there. He’ll bring his train close, but she won’t react. When he bumps into her train, she’ll put her hands on her cheeks and look at him expectantly, then WAIT. If he doesn’t say anything, she may model: “Uh-oh!” She wants to make the game predictable, but then does something unpredictable, or just stops and waits for him to initiate.*

The ideas in this article were taken (in very abbreviated form) from a course by the Play Project organization. Visit [PlayProject.org](http://PlayProject.org) for more information.



**Life is just full of surprises!**



# VALIDATION Corner



David Rose

## ♥ YOU ARE DOING A GREAT JOB!

The start of our home buying journey began as a dream. We had no idea what we were getting ourselves into. People were saying the time was ripe. Rates were good. Prices were low. We took our first tentative steps forward—and dropped into a big, deep hole! A world full of utter confusion, indecision, and tremendous pressure. Trying to swim through the tide, we were constantly second-guessing ourselves, due to our inexperience. “Do the numbers really add up?” “Are we really making a smart decision?” etc.

I remember one day talking on the phone with my father-in-law. I told him the steps we had taken, the different options we were looking at, and the price bargaining we had done, and he exclaimed: “You are doing a great job! You are doing everything right!” Wow! With those few words, my *shver* made me feel so secure and reassured! I hung up after that phone call with my heart full of relief and clarity, instilled with confidence.

Though it was not the end of the road, his encouragement made our journey so much smoother.

The *zman* of *Tamuz* leading into *Av* is incorrectly viewed by many people as a very depressing time. However, *chazal* paint us a different picture. The *Gemara Ta’anis* describes this time period in a positive way, quoting the *posuk*: “*Haysa k’almanah*” (You will be like a widow). Regarding our connection to Hashem, *chazal* explain that we “are *like* a widow, but not actually a widow.” Our relationship with Hashem, though hidden, remains strong, even in *galus*. Indeed, we must reflect on and invest in our relationship, and see where we can improve, yet realize that this is a time that should be very encouraging.

Years ago, my father shared with me a gorgeous *vort*. After hours of sitting on the ground saying *kinos* and mourning

the *galus* on *Tisha b’Av*, what is the first *tefilla* we say? “*Ashrei yoshvei veisecha...*” “*Ashrei ha’am shekacha lo...*” (“Fortunate are those who sit in Your house; Fortunate are those for whom Hashem is their G-d!”) These words at the culmination of our mourning express such a bright and positive note, affirming our special relationship with Hashem, our loving Father!

It certainly is not easy when a person goes through a difficult *nisayon*. I have personally experienced, and many friends have

shared with me as well, times when the situation seems to hit rock bottom. The only option left is to turn to Hashem. At these moments, we bare your emotions and pour out our hearts; we talk to Him and unleash all the hurt and confusion we feel. Afterward, we feel so light, with an incredibly tangible feeling of *emuna*, of pure clarity and closeness to Hashem. It is as if we’re surrounded by Hashem’s love and warmth, secure in the knowledge just

gained, that everything is in Hashem’s caring, capable hands. The *Gemara* in *Brachos* says: “Hashem gives *yisurim* to those He *desires*.” Perhaps it means this, as there is no feeling as beautiful in the world!

My father in law’s encouraging phone call during our house negotiation mirrors the underlying theme of *Tamuz* and *Av*, the message that we can always tap into the warm relationship we have with Hashem. To anyone who is going through difficulty, may you feel Hashem patting you on the head, saying: “My dear child, I realize it is hard at times, but I know that you are doing a great job; you are doing things right.”

*I hung up after  
that phone call  
with my heart  
full of relief and  
clarity, instilled  
with confidence.*

# From The Doctor's Desk

## | *Insight beyond Eyesight*

Shani Chill

I am a teacher of students, ages 5-21, who all have visual impairments, as well as other significant disabilities. Most of them are wheelchair bound, non-verbal, and require a lot of assistance to do things. My primary goal is to give my students as much access to the world around them as possible. With their visual impairment, this means bringing the world to them. My second goal, due to their disabilities and need for assistance, is to give them as much opportunity as possible to make choices and decisions to affect the world around them.

My students' visual disorders include CVI (Cortical Visual Impairment) and other ocular disorders. I would like to share some simple things that I do to help them use their vision more effectively. I hope that these ideas will be helpful for you with your own children.

### **Lighting.**

I often dim the lights or close the shades if there's bright light coming in the windows. I also use light to get their attention, such as a light box, or a flashlight. I may even use my phone light to shine on something that I want my students to look at.

### **Fields.**

It is important to know which field of vision each child prefers, where he can see best. If it's the right side, make sure to always place materials on that side. A lot of my students have difficulty seeing things that are in their lower field of vision (below chin level). If they are sitting in their wheelchair and trying to see something on their tray, I use a basic slant board or book stands to raise things up. Otherwise, I find that they tend to slump over, which is bad for their posture.

### **Colors.**

Some children have a specific color that they gravitate to, such as red or yellow, or neon or bright colors. I use color as a way to bring specific things into their focus. If we are reading a book and there's a certain character I want them to focus on, I will outline one image on each page in their favorite color to help them focus on it.

### **Movement.**

My students tend to rock back and forth or shake their heads around a lot. Often, they are using movement to help them regulate the world around them and it can actually help them see things better. I try to work with the occupational therapist to come up with appropriate ways to use movement, such as in a swing, a rocking chair, or a rocking horse. We provide these items for them to sit on if they feel they need to move around a lot. I also use movement to help them see things. When I hold up an object, I move it gently. I find that they look towards it more frequently when I move it than when it is still.

### **Internal complications.**

When a child is upset, tired, or stressed, I don't ask them to use their vision at all. I say: "We are having a vision break now. Maybe you need a nap or a snack, or we can find another activity."

### **Timing.**

Visual processing can take time. When I hold something up to my students, I hold it there for a significant amount of time and I make sure *not to talk* during that time. For instance, if I am showing Chana a red teddy bear, I'll say, "Chana, I have a red teddy bear here for you." Then, I'll hold it up in her right

field of vision, and just keep it there, or maybe shake it gently. Eventually, she will turn and look at it. Giving the children this time to turn and look is really important.

### **Distractions.**

#### **Others' movements.**

As opposed to the movement of the child himself, which helps him focus, realize that the movements of other children can be very distracting. You want to minimize others moving about in the room, and avoid facing open doorways where there may be foot traffic. It is not easy to do this when you're in a classroom or in a home with lots of people around, but it's still an important point to keep in mind.

#### **Visual distractions.**

Aside from people moving around, a lot of visual input (such as facing a shelf full of colorful toys) can also be distracting, especially in children with CVI. All of these visual cues are coming at them, and they may not have the ability to choose which are the important things to look at and which belong in the background. Everything they see has the same priority to them. It can be helpful to face children towards a blank wall, use a room divider, or stand up a mat to block out extra visual clutter.

#### **Noise.**

Noise can be one of the biggest distractions for children with visual deficiencies. Something as simple as music playing in the background, or other people having a conversation nearby, make it harder for our children to use their vision.

For students who have very little or no use of vision, we use a multi-sensory approach. We use a lot of crafting material, textures, and simple braille books with tactile images on them. My second goal is to give as much opportunity as possible for my students to make choices. I see that, most of the time, things are done to them or for them without their having the chance to make any personal decisions. So, when I have sessions with them, I try to build in choice-making as much as possible. Obviously, this can be kind of tricky if they can't see clearly between two pictures, can't talk, or maybe can't reach out their hand to choose something. I need to be creative to help my students make choices. Here an example of how I do this.

*David is 15, has CVI, pretty low vision, is non-verbal, can't move his arms, and doesn't have great head control. I wanted to give him a choice of activities: either to play with a musical toy or to play a*

*game of bowling. The first step was to present the choices. I dimmed the lights, closed the door, and made sure it was quiet. I held up a light box on his left side (which is his preferred side) and put the music toy in front of it. I guided his hands to feel it. I then did the same thing with the bowling toy, showing him one bowling pin in front of the light box and guiding him to feel it.*

*The next step was to present him with a way of communication. David has a couple of different ways that he expresses pleasure. He can grunt or give a giant smile, and he also has a switch on his tray which is connected to a voice program called "Step By Step." (You can record whatever you want on the program, with different variations. I had previously set it up with options such as: "I like that one," "That one is fun," etc.)*

*I said to him: "I'm going to show you each toy again. You have different ways to tell me which one you want to play with. You can use your voice, you can use your smile, or you can use your switch." I made sure to clearly explain to him how to choose.*

*I held up the musical toy again and asked: "Do you want to use the musical toy?" David did not respond at all, as I slowly counted to ten in my head. Then I held up the bowling pin and asked: "Do you want to do bowling?" He gave me a big smile and also hit his switch. It could be that he hit the switch accidentally, but together with the smile, I knew for certain that he had chosen the bowling pin.*

Here are two amazing resources that can be very helpful:

#### **The APH (American Printing House) Quota Fund**

Once you register, your vision teacher or anyone from the school can order things such as a light box, flashlights, slant boards, braille books, different textures, as well as a small assortment of toys.

#### **The Commission for the Blind**

Once you register, you or any of the therapists can order up to \$400 of products from certain catalogs. It doesn't even have to be vision related, but can be anything helpful for various kinds of therapy. They have great toys. The "Step By Step" switch that I mentioned can be ordered here.

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*Shani Chill is the Director of Vision Services at iHOPE Academy, and works with children and young adults who have visual impairments. This article is an overview of a talk she gave to parents through the Insight Beyond Eyesight organization. For more information about this organization, please contact rybodek@gmail.com.*



# The Sound of *Silence*

Yitti Berkovic

Ezriel is missing. It's time for me to serve supper, and though I've called his name what feels like a million times, he and his rosy cheeks have yet to make an appearance. Our house is not that big, and there aren't any crawl spaces or deep closets in which a five-year-old can find haven from the green beans he refuses to eat. ("They're totally gross, Ma."). Thanks.

Plus, it's freezing cold outside and his coat is still on its hook, so I'm pretty sure he didn't make a fast break into the great outdoors to escape those vexing vegetables. My level of frustration is rising like the tide. Where on earth is he? "Ezriel Berkovic, your supper is getting cold. You have five seconds to get to the table before I –"

*Hiccup.*

Wait a second. I'm pretty sure the couch pillow just hiccupped. I need to handle this carefully. I tiptoe toward the couch.

*Hiccup.*

"Ezriel, is that you?" I whisper.

*Hiccup.*

This time, I see the pillow jump a little, as if there's a frog buried beneath it. A frog - or a little boy who doesn't want to be found. (Are my green beans *that* unappealing?). Trying to mask my impatience, I lift up the pillow and find Ezriel. Though I'm relieved there is no frog (I don't put anything past my kids), I'm concerned to see that Ezriel is looking a little the worse for wear.

He is curled up into a ball, and his eyes and fists are squeezed shut. He's doing everything in his little body's power to keep from crying, but every now and then, a sneaky hiccup escapes

his pursed white lips. "Ez! Are you okay?"

He shakes his head no, but he won't open his eyes. His body remains as taut as a bowstring, and I can see he's struggling to swallow his sobs. "I banged my knee against the glass table," he manages to hiccup, and my heart breaks into a million little pieces.

He's hurt himself badly, but he refuses to cry – and I know exactly why. I forget about the supper growing cold in the kitchen. Instead, I scoot Ezriel a little further down the couch so there's room for me to squeeze in next to him, and I hold him tightly against me.

With his head safely cushioned, he begins to bawl, the sounds mercifully muffled in my shoulder. He can cry now – because he knows no one can hear him. He can cry now - because he knows *Naftali* can't hear him.

There are certain things about living with a child with special needs that many people don't realize. Ezriel, though only five years-old, is a veteran sibling of an autistic older brother, and he's learned what many adults don't even know. This little guy could give a course on sensory integration disorder to a room of seasoned professionals.

*Ezriel, at age five, has reached heights of self-control that I, as an adult, have yet to achieve. Though it breaks my heart, it also makes me incredibly proud.*

And even Ezriel could tell you Naftali is sensory to the extreme. He can only wear certain clothing. He can only eat certain foods. He hates when he is dirty and washes his hands constantly. But he is most sensory when it comes to sounds.

Very often, if you see Naftali in public, he'll have his hands pressed up against his ears, doing his best to silence the world around him, his only defense against the cacophony of sounds that torture him.

He hates the sound of someone chewing. He hates the sound of someone snoring. He hates the sound of my singing voice (can't really blame him for that one), and he begs me to stop when I sing along with music in the car. He begs like his life depends on it, so I've learned to just mouth the words. My kids have learned the same.

You know how you cringe when someone runs his nails against a blackboard? For Naftali, that discomfort is amplified by a thousand, and it's from sounds that are common and expected, the soundtrack of everyday life. Can you guess the hardest sound for him to take? It's the sound of another child crying.

I know. It sounds sweet. It sounds compassionate. It sounds like he can't tolerate seeing another child in pain. But crying

is the background music of a busy and, yes, happy home, and Naftali is unable to deal with it.

As soon as he hears someone crying, he lashes out. Sometimes he hits himself. Sometimes he punches a wall (we have a few holes to show for it). Sometimes he'll throw things and break them (even things he loves), and sometimes he'll try to hit the crying child (even a child he loves).

It's a compulsive reaction – one he seems to have no control over - and he always feels terrible once his rage subsides. He'll apologize profusely and hug the terrified child, but usually it's too little, too late. The damage is done. It's tough for my kids. It's tough for me.

No matter how uncomfortable it is for Naftali, I can't silence the inevitable. Kids are going to fight, kids are going to be overtired, kids are going to trip and fall, and kids are going to cry for *no good reason*. That's just life.

And no matter how uncomfortable this is for the rest of my kids, I can't change the child Naftali is. Even with years of therapy and behavioral plans, there are certain behaviors he struggles to control, and there is always the risk that he'll respond in a way we wish he wouldn't. That's just life. And life can be painful.

Like every mother, I wish there was a way I could make everything perfect for all my children. I wish there was a way they could cry at the top of their lungs whenever they hurt themselves, whenever they feel hurt, or whenever they just need to blow off steam. But Hashem chose Naftali to be their brother, and though this presents certain challenges, it also presents remarkable opportunities for growth.

Ezriel, at age five, has reached heights of self-control that I, as an adult, have yet to achieve. Though it breaks my heart, it also makes me incredibly proud. No one goes through life without challenges, challenges designed for us by *HaKadosh Baruch Hu*, and it is up to us to respond with grace, with strength, and with growth.

We can learn from the littlest people in our life, and tonight, I learned from my five-year-old son. It's okay to cry – but sometimes we need to quiet our sobs to avoid causing someone else pain. That's a powerful lesson of growth to learn from a kid who still thinks green beans are “totally gross.”

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*This article was originally printed in The Voice of Lakewood.*



דברי חיזוק וברכה  
מאת הרב שמואל בלעך שליט"א

Words of Inspiration Especially for Our Readers  
From HaRav Shmuel Blech, *sblita*  
Rav of Anshei Sefard, Lakewood, NJ

It is difficult to find words to express *divrei chizuk* to the outstanding families whose *nisayon ha'chaim* is to care for the well-being of challenged children.

The areas in which parents of typical children are ordinarily rewarded with *nachas* for their endless and all-encompassing devotion, are precisely the areas which pose uncertainty and disappointment for parents of special-needs children. These parents must be strong, and find encouragement in smaller, but memorable, accomplishments. Their reward cannot be measured by standard superficial criteria. Only *Hakadosh Baruch Hu* can be *meshalem s'charam* in the “*olam sh'kulo emes v'kulo tov*” (*the world that is all true and good, Olam HaBa*).

*Chazal* teach us that we are not privileged to access the secrets of our complex world. It is all much greater than ourselves, and our understanding is painfully limited. The “hidden” is the sole province of the “*Yodeia Kol Ta'alumos, Boruch Hu*” (*the Blessed One, Who knows all secrets*).

It is, however, comforting and important to know that *Chazal* tell us that the time before *Moshiach* arrives has been proclaimed to be unusual. In many ways, this phase will bear a strong resemblance to the final period before *Yetzias Mitzrayim*. In order to hasten the *geula* and shorten the *galus Mitzrayim* from the original 400 years destined, things became much more difficult for the *Yidden*.

Moshe himself wondered: **וּמֵאֵז בָּאתִי אֶל פְּרַעַה לְדַבֵּר בְּשִׁמְךָ הָרַע, לֵעֵם הַזֶּה וְכוּ.** There was no visible change for the better after Moshe appeared to Pharaoh, only more intense suffering. It was only later, after *Kriyas Yam Suf*, when Moshe and *B'nei Yisroel* sang the *shira* and used the word “אז” once again (*Az Yashir*), did they correct the original misunderstanding. *Az Yashir* alludes to the fact that *B'nei Yisroel* now understood, in retrospect, how all the pieces of the giant puzzle fit together; they now saw how the difficulties themselves became part of the *shira*.

Likewise, we can assume that the challenging events and experiences of the *klal* and individuals are all part of a tapestry that is being created thread by thread, which will ultimately be revealed clearly as one of beauty and great meaning.

Specifically, in this *tekufa* of *acharis ha'yamim*, there are so many *neshamos* who require a *tikkun*, including those of great *tzadikim*. It may very well be that raising these *heilige neshamos* of special needs children is providing a *tikkun* and *hatavah* to great people of previous *doros*. The families of these children should see themselves as fulfilling this *tafkid* that Hashem deems necessary, so that we can bring about the long-awaited *geulah*.

May these families, who live their lives dedicated to hastening the *geulah*, have *hatzlacha* and *bracha*. May we all be *zoche* to see “*ye'shuas Hashem k'heref ayin*” (*the salvation of Hashem in the blink of an eye*).

With the summer is approaching, making late Shabbos and eating a late *Shalosh Seudos* goes a long way. When our special son is awake for only one meal, it makes a big difference. Also, I would spend \$10-\$20 every week on a new toy or book, which I gave my son at the beginning of the meal. This was a lifesaver and well worth the money. (I used to say that they were the flowers on my Shabbos table!)

-D. P.

Use all disposables! I splurge on nice paper goods so I feel like I still have my gorgeous Shabbos table.

I try to prepare *everything* before Shabbos, like cutting up the cucumbers, buying ready-made salad dressing, etc.

Even so, sometimes parents do need to take turns watching the special needs child away from the table so that everyone else will be able to eat in peace.

-F. D.

For tough issues, I have found *Transforming the Difficult Child—the Nurtured Heart Approach* to be invaluable. With past behavior issues, my son went from being super-troublesome to super-compliant, as I highlighted and enthusiastically praised what I wanted to see. For example, in this scenario, I would catch him sitting calmly at the table, and say: “I see you’re sitting with your whole body calm/I see you are eating your food/I see when you are done with your food you are using your words to tell me...” etc. I highly recommend this very helpful book.

- P. J.



## Tips From The Experts *hey! that's us!*

**I find the most challenging time of the whole week to be the Shabbos Seudah. Between serving, eating, clearing and trying to give everyone some attention (parsha questions or just making conversation), I am overwhelmed just trying to juggle it all. Then my special needs son acts up by throwing food and screaming, and the meal dissolves into chaos... Any tips for how to set up a better system?**

During serving and clearing, I try to keep everyone busy. I either tell them to help out, or I ask them to sing. Instead of the parents having to entertain them, I ask them to participate.

During meal time, everyone has to say something about the *Parasha*. Those who do so nicely, get to pick a treat from our Shabbos treat bag after *bentching*.

- Bracha

A simple and easy tip is to feed your special child before the *seudah*. When children are hungry, they usually have less self-control and frustration tolerance than if they are well-fed. You don't have to feed them the actual *fleishig seudah* (*cholent*, etc.). I give my son a challah roll, string cheese, and fruit before we start. Then he can eat whatever else he wants during the *seudah*, without the pressure of feeding a starving child during a hectic time.

- D. W.

It is very tough! Practically, we do all the *parasha* questions, *divrei Torah*, etc, on Friday night when the child is (hopefully!) sleeping. During the day we have singing, and even dancing, which my special child enjoys. We usually send the child to play with an older sibling, or even a parent, as soon and as much as necessary, before things get too crazy. I think it's important to remember that as long as *you* are calm and in control, your *seuda* is *not* out of control but actually very beautiful to Hashem. Adapting to the situation means giving up our idea of a picture perfect *seuda* and, instead, enjoying what Hashem gave us. That said, I know it's easier said than done!

-A mother struggling with this, too :)

Question for the next issue:

**We just found out that my son cannot see well at all and needs to wear glasses. He totally refuses to wear them and just flings them off every time we try to put them on. How do you train a kid to wear glasses?** – submitted by G.W.

**The doctor says that my son has to practice his eye exercises every night for at least 10 minutes. He is very uncooperative about it. Any ideas on how to motivate him?** – submitted by S.M.

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

First of all, you're not alone. Shabbos is the hardest time of the week for most families with special needs children. They miss the structure of the rest of their week, and the ability to give appropriate attention to other family members is a massive juggling act. Baruch Hashem for each precious *neshama* with which you have been blessed!

The behaviors you are describing are common indicators of several possible challenges:

- (1) Avoidance: Your child may want to avoid sitting so long in one place, especially when he doesn't understand the conversation, or feels he is receiving inadequate attention.
- (2) Attention-seeking: Your child may perceive the gathering as an opportunity to get attention, or he may not want to share your attention with his siblings.
- (3) Skills not yet learned: Your child may not yet have the skill set to sit so long and/or listen to others, especially if he can't understand everything.

You can set up a positive reward system so your special needs child will be invested in the *seudah*. Make sure that your expectations are realistic, be ready to re-direct, create a team effort, and reward the positive behavior. This applies not only to your child with special needs, but to *all* of your family members. You can model and teach your special needs child the skills necessary to be part of the family *seudah*. Accept that the timetable for this child may be slower and that it may take longer for him to acquire the skills you seek to teach.

Often, when one has a child with special needs, it's easy to see and focus on his limitations. The goal is to focus and build on his capabilities. What can your child do? Is he able to help set the table by bringing in plates? (It may be worthwhile to use disposable ware as he learns.) Giving jobs to all the children teaches them responsibility, while teaching them that they too, have a vested interest. (Counting out plates or napkins helps children with their 1:1 correspondence skills for counting, too.) Children can make place cards to put at each family member's seat. Give them every possible job that they *can* do, and praise them for their positive appropriate actions. This sets the tone for them to be invested in the *seudah*.

During the actual *seudah*, be realistic about your special child's attention span. In order to give the necessary attention to your other children and their *divrei Torah*, be strategic. It may be appropriate for your special needs child to learn to sit patiently through only one *d'var Torah* until he builds up his ability to sit longer. Rotate the order of who presents his *d'var Torah* first each week. As soon as he finishes, praise the child who shared it, and praise the rest of your children, especially your child with special needs, for their good listening.

Listening is a learned skill. Your special child needs to first learn and gradually work on his "listening muscles." Sometimes it's a good idea to give small treats (a single jelly bean, a small pretzel, etc.) to all of your "good listeners." Have your child with special needs attend just one sibling's *d'var Torah* and then send him off to play. If he needs supervision, the other kids can rotate watching him while the rest of the children share their *divrei Torah*. You can also prepare a basket of "quiet toys" for him to play with near the table, so he and his designated supervisor can still be part of the meal.

Give your special child a warning prior to each course, to prepare him to leave his play and return to the table. As soon as he has eaten what he needs to, try to engage him with one question he can answer, like: "Who made the world?" "Hashem!" If your child is nonverbal, have pictures or other artwork made prior to Shabbos that he can share at the *seudah*. Over time, you can gradually increase the length of time your child is at the table.

Ideally, praise your child with special needs for his appropriate behaviors and excuse him to go play *before* he reaches his frustration point. If you overestimate his present ability and your child begins to throw food, then silently, with your hands over his hands, "help him" to clean it up (This is certainly easier with smaller children). While helping your child to clean his mess, give extra attention to the other children who are sitting, eating, talking, and sharing appropriately. If your special needs child is seeking attention, he will find that the only way to obtain it is through positive, appropriate behaviors.

Lastly, use the opportunity to model and teach your other children to unconditionally love each other. Teach them to look for and praise positive behavior and actions, while not tolerating what is unacceptable. If you lose your patience, be honest with yourself and your family. Say something like: "I'm sorry I lost my patience. I wanted to keep my cool and only compliment the way so and so is sitting so nicely and sharing such a gorgeous piece of Torah. It's hard, but I'll keep working on my patience and, with Hashem's help, I'll do better. I need to thank Hashem so much for His patience with me, even when I mess up, and daven to be more like Him!" Your family can only benefit by hearing such messages! This is a process. We are all works in progress, in need of Hashem's help!

If you would like further assistance with specifics, I'm always happy to help.

Eliza Jordan, MA.ED.

Tailor-made Tutoring and Consulting

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## Encouraging Words from an Older Sibling

Shaindy W.

I am also a sibling  
And I want to let you know  
That are we are all so lucky  
To have this chance to grow.

Although at times it's hard  
And it just seems so unfair  
Hashem knew what He was doing  
When He put your special sib there.

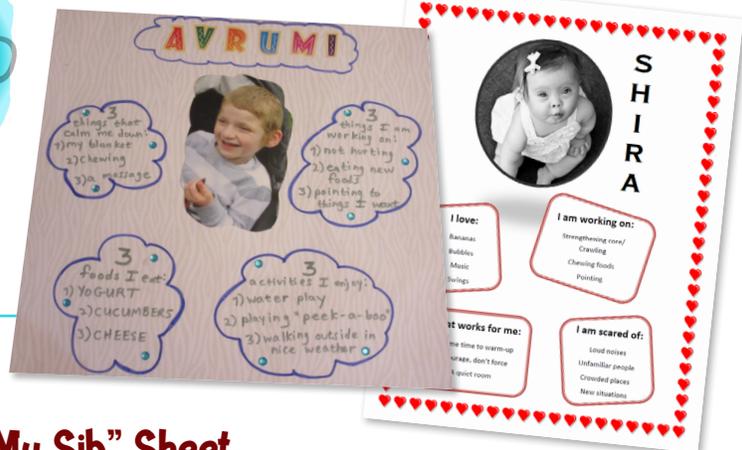
It's a test that's made for you  
And I'm sure that you'll pull through  
And even if you fall and cry  
Get up and don't be blue.

One day you will look back  
And be very glad to see  
That having a special sib  
Is the best for your family!

color me in!



# Activity Time!



## Make a "Meet My Sib" Sheet

If you enjoy scrapbooking, writing, or arts 'n crafts, then this one is for you! Create a "Meet My Sib" sheet that you can send along with your special brother or sister when he/she goes into a new environment. Whether it's to sleep-away camp or to the first day of a new school year, you'll feel good knowing that you helped your special sibling "communicate" their specialness to their new caregivers.

The idea is to create one page that contains important information about your sib in a nice format. You can make it simple, in black and white, or you can have fun and make a real scrap-book style colorful page.

Start with a picture and your sibling's name on top.

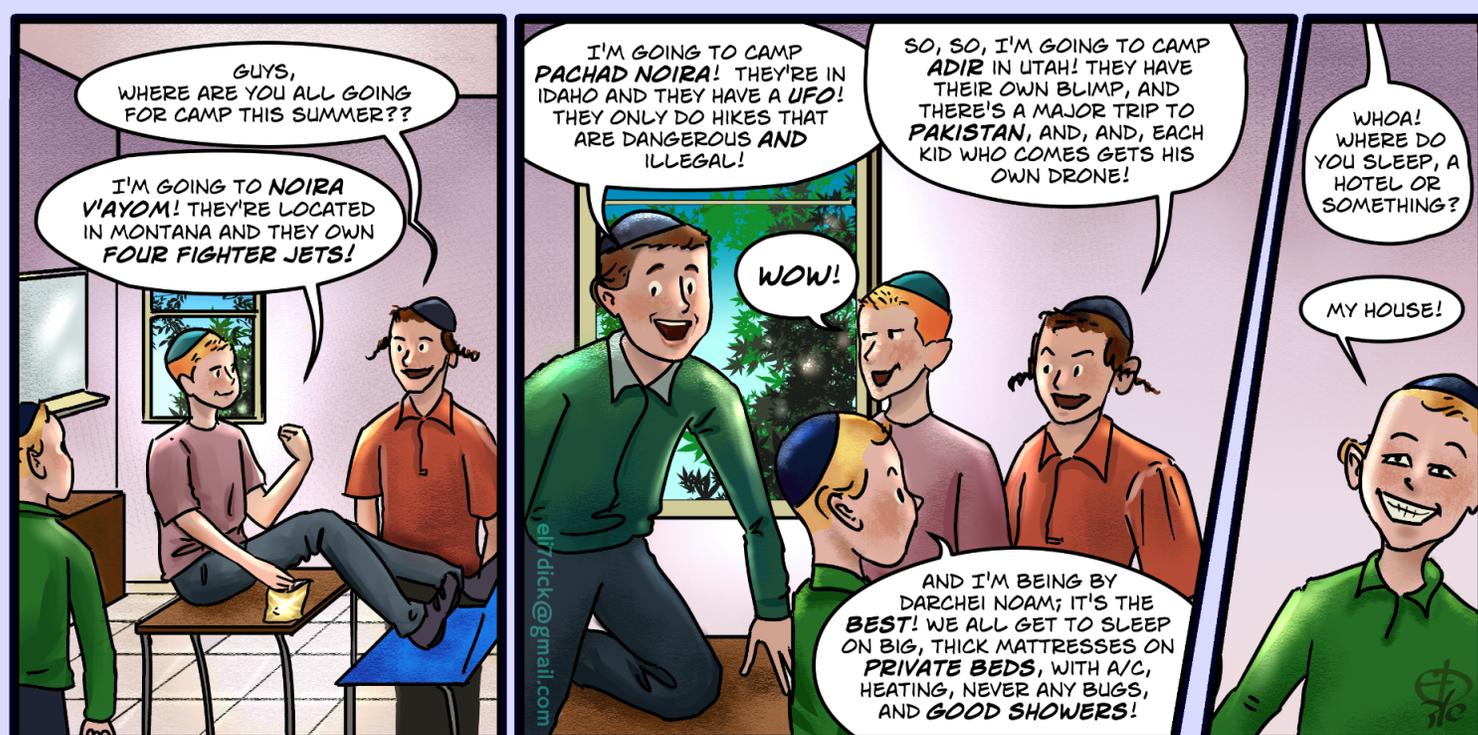
Ideas for lists to include can be titled:

- I love:**
- I'm working on:**
- What doesn't work:**
- My favorite foods:**
- Some of my strengths:**
- What works for me:**
- I'm scared of:**

Enjoy!

## Camp Plans

By Devora Arnstein





# Sibs Spot Interview: Tzipporah Tannenbaum

Fraydel Dickstein

*Tzipporah wrote the words to “Little Sister” in honor of her special needs sister, Bassy. The words were later composed into a song by Leora Gorin.*

**Q: The song “Little Sister” is so heartwarming and beautiful that it brought tears to my eyes. Can you share some background with us?**

My sister Bassy is five years younger than I am. When she was born, each of my siblings was staying with a different relative who told them that Bassy had Down Syndrome. When my siblings now talk about this time, one said he felt as if the baby had died; another wanted her to be given away. But once she came home, we all fell in love with her right away.

She was a beautiful baby. I remember a close relative who seemed shocked when she saw her and could not get over how gorgeous she was. It’s almost as if she was surprised that a Down Syndrome baby could be so cute!

Personally, I never found Bassy’s syndrome to be a big deal. I never thought much about it; she was just the prized princess of our family. Everything Bassy did was an occasion. When she got glasses, the whole family showed up at the optical store. The year Bassy was being mainstreamed, we went to buy her a uniform in the middle of the year and, of course, it was a family event.

When we left, my brother commented that the people in the store must think it’s weird to be buying uniforms in the middle of the year. I told him that no one would think it’s weird, since Bassy has Down Syndrome. He was totally surprised; he was sure that no one noticed that she had Down Syndrome. He said that other kids look like they have Down Syndrome, but not Bassy.

I also never thought much about her being different than others. The song was inspired when I started working with kids, and it hit me for the first time that others see my sister as imperfect. During the time I was composing the song, I encountered someone being mean to Bassy for my first time.

My father is a *Kashrus Mashgiach*, and we sometimes get the opportunity to go along with him to the hotels he supervises. At one of these hotels, I heard a woman saying nasty things to my mother about Bassy. It was very painful, and I watched my sister being rejected again and again on that Shabbos by people there who did not appreciate my

sister. It hurt me deeply and gave me a different perspective. After that not-so-wonderful Shabbos, I wrote the second part of the song.

**Q: Where does your sister go to school?**

Many people are into mainstreaming, placing special needs children into the regular school system, but I think Bassy is fortunate to have a special school to attend. She goes to SCHI (School for Children with Hidden Intelligence) and has the nicest group of real, genuine friends there. She is so happy with them, and they really care about each other.

One day when Bassy had an appointment, my father went to pick her up, but Bassy would not go. I came into her classroom and saw a most heartwarming sight: Bassy was sitting at her desk with her head down, and all her classmates were surrounding her and telling her that they would save the project for her. They offered to walk out with her, and told her that her appointment wouldn’t hurt. The care and concern were beautiful to see.

There are also benefits to mainstreaming. Bassy goes to a club on Sunday where she performs plays with other typical girls. It’s a beautiful mainstream opportunity for her. When Bassy is in a normal group, she tries to be like the others and learns good behaviors.

**Q: How does Bassy feel about herself?**

In general, Bassy is very happy with herself. She used to look at pictures and any time she saw someone with Down syndrome, she would exclaim: “That’s me!” Once at a wedding, a woman came over to my mother and told her that she has a son with Down syndrome. Bassy overheard and said: “I love Down syndrome!” At another wedding, she met someone else with Down syndrome and they partied together the whole time.

I realized, though, that Bassy knows that she is different, even though she is so carefree and happy. She is an eternal child—sometimes I am even jealous, but then I realize the pain she carries, like when her younger nieces and nephews surpass her. And there are those rare occasions, like the one mentioned above, where she is not accepted.

**Q: Can you tell us some of your experiences with Bassy?**

Sure! Here are a few:



Once I told Bassy she had to fast and she said, no she doesn't, because she is special.

One Yom Kippur I told her she has to act normal in *shul*. She looked at me and said: "But I am not normal!"

Once, during *Neilah* on Yom Kippur, Bassy decided that she spotted Avraham Fried (a popular Jewish singer). She kept jumping up and down in excitement, loudly shouting: "Avraham Fried! I see him!" It was really embarrassing for me.

You can't yell at Bassy when she diverts your attention. I remember trying to get her to bed when she was younger and she knew exactly how to put on a cute act to distract us and crack us all up. Before we knew it, it was very late!

After I got married, she gave me the cold shoulder. I teach in the school she attends, and when I would meet her, she would barely say "Hi." When I came to visit my parent's home, I said: "Bassy doesn't care about me anymore." Bassy turned to me and said: "No, I love you!"

Once, I was taking care of Bassy while on the phone with one of my friends. She commented about my seemingly endless patience, and I explained that losing patience with Bassy is a lose-lose situation for all involved. Patience is a gift Bassy gave us.

**Q: What is your main message to other siblings?**

I would say: **Love your sibling and don't be embarrassed.**

I wanted Bassy to be that picture-perfect Down Syndrome girl, but the reality was not like that. Her nose ran a lot and she threw plenty of tantrums in public. It took me years to get past all of that. Now I have learned to accept her not-so-perfect appearance and behavior, and to just enjoy the adorable, lovable person that she is.

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Please contact us if you would like to be interviewed for the *Sibs Spot*.

Little sister I know,  
That when some people look into your eyes,  
They see imperfection.  
They see a child,  
Who will never amount to anything,  
Never achieve what others do.  
Never build future generations.  
And they wonder- why are you here?

But, know little sister  
That when I look into your eyes I see,  
The greatest gift Hashem has given me!  
And now I know that after one hundred and twenty,  
I will go up to the heavens and proudly say,  
I was your sister!

**I want to lift you high and dance 'till my heart is full.  
I want to tell the world how much I love you!  
And that instead of pitying you,  
They should envy you,  
Because you have a special *Neshama* that can do no wrong.**

Little sister, I watch.  
As you struggle through life,  
Never achieving perfection.  
Overcoming challenges that are sent your way,  
Only to encounter more.  
Branded, without knowing why.  
And you question, why don't they care?  
But I watch little sister,  
How you confront it all smiling,  
Never failing to attempt again.  
Even as you know, that you will never be like them.  
Your love, your care, your empathy  
Will never fail to push me to do more.

**I want to lift you high and dance 'till my heart is full.  
I want to tell the world how much I love you!  
And that instead of pitying you,  
They should envy you,  
Because you have a special *Neshama* that can do no wrong.**

And when *Moshiach* comes,  
We'll carry you on our shoulders.  
And we'll dance with you.  
And everyone will vie to hold your hand.  
Because they'll understand what I know now.  
It will be you who will bring *Moshiach*.

**I want to lift you high and dance 'till my heart is full.  
I want to tell the world how much I love you!  
And that instead of pitying you,  
They should envy you,  
Because you have a special *Neshama* that can do no wrong.**

Little sister, I love you. You're special.

# What Would You Do?

What is something  
that you like to do together  
with your special sib?

I like to tickle my  
brother and make  
him laugh!

Malky

I like to jump  
with my sister  
at SkyZone.

Mendy

I like to go to Six Flags  
and go to the front  
of the lines with him  
(although he doesn't  
like scary rides!).

Sara Laya S.

I like to cuddle with  
my sister Yehudis.

Malky

I love sleeping in the same room as  
my brother and waving to him every  
morning when we both wake up!

Yaakov

My special needs sister is only  
a baby, so I like to sing songs  
with her, rock her to sleep,  
and practice therapy with her.

Best Big Sister

I love to schmooze with my  
sister. Even though she says  
silly things, it's funny!

Chaya

**Neshamale Magazine needs you! We are looking for a  
Sib Spot story writer, as well as writers for other articles.**

**Please let us know if you are able to volunteer at [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com)**



## On the Lighter Side...

### Insurance Insanity

Moishy's Mommy

Does having a special needs child and the stress that often accompanies it make one go insane? I am beginning to think that it does. Ostensibly, I am not in full possession of my mind, and unable to make sound judgements. At least the insurance company seems to think so.

We've been fighting a lot, recently, me and the insurance company. First, we fought over a bed. I remember fighting with my sisters over who got the bed by the window, or who got the top of the bunk bed. I thought I was long past fighting over beds, but apparently, we can regress.

Moishy, at age five, still sleeps in a crib. It's high time for something larger. I contacted a highly recommended equipment rep. and started the process of buying him a bed through insurance. After many deliberations, we settled on what we hoped would be a safe and comfortable place for Moishy to spend his nights (asleep or awake!). I won't bore you with all the various steps and forms that had to be completed for us to send in the claim, but suffice it to say that it was promptly denied. "We do not see any need for Moshe to have the bed you requested. He can sleep in a regular bed." Ok... I guess we didn't explain it well enough. We resubmitted a much more detailed request, stressing seizure concerns and dangerous midnight wanderings. This time, to their "credit" the answer was pending for many months. At least they were considering it (or maybe just ignoring it!). But after all due consideration, their answer was an unapologetic refusal.

I guess the next step is buying a lottery ticket so we can buy the \$9,000 bed on our own. Until that happens, we

have other things to fight about. Friends had mentioned to me that they are part of a program in which the insurance pays for a caregiver for the disabled child. I thought this was something that would be rather helpful, and called to apply. I spent hours answering interview questions about my son's abilities, challenges, detailed schedule information, favorite foods, and number of diapers per day. I thought they got every possible detail about us, and that it was obvious how much assistance was truly needed.

I should have known whom we were dealing with. The same people who think that my son can sleep in a regular bed also believe that he can get through the day without assistance. Apparently, I, the mother, am in denial!

In the words of the insurance denial: "The request is denied. We have reviewed the case for medical necessity. Your child does not need excess help to bathe. Your child does not need excess help to use the toilet. Your child does not need excess help to dress. Your child does not need help with mobility. Your child does not need help to eat."

When I read those words, I laughed out loud (Rule in life: laughter beats tears)! In truth, it sounds amazing—like a dream come true. Except that it's not the reality. At least I'm pretty sure it's not. It's confusing being told so confidently that you don't really know your child's abilities. You start to doubt your own sanity. Maybe someone sitting in an office in India knows Moishy better than his own mother? Maybe I should let my son try bathing, eating, and dressing on his own—then I will likely have a seriously funny article to write about for the next issue of *Neshamale*!



**If you're wondering how my mother has time to work on this magazine, it's because I'm so self sufficient!**



# A Positive Twist To Life: Covid-19

A.R.

## SWEET SPICES

Introducing “Sweet Spices,” our new column 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!

### ◆ Frustration

“Just to be double-sure,” I thought to myself, as I hurriedly logged-in to access my son’s Covid test results. “I’ll sleep better knowing that the whole morning wasn’t a waste.” Earlier that day, my husband drove our four-year son, Yisrael Meir, to the Children’s Hospital of Philadelphia. CHOP required every child to be tested for Covid-19, at the hospital itself, within 72 hours of surgery.

I felt the trip was a waste of time, and explained to the surgical coordinator that our family had “been through” Corona already. Since we were coming all the way from Lakewood, couldn’t we just do a rapid Covid test the morning of the surgery? They wouldn’t hear of it, so my husband travelled to Philly early Sunday for our son’s 9 AM Covid test, administered in the CHOP parking garage.

### ◆ History

Yisrael Meir was born in Eretz Yisrael. When he was 15 months old, we moved back to the US so that he could get the medical care and therapies that he needed. When he was a baby, we had a concern about an eye weakness, but we were told by two different ophthalmologists in Israel that it was of no concern. Therefore, when we moved back to the US it went to the bottom of the list, as there were other more important medical issues to address. When Yisrael Meir’s therapists started asking about his vision about a year and half ago, we knew that it was time to revisit the situation.

### ◆ More Frustration

The therapists noted that our son’s focusing and eye coordination were impacting his gross motor skills and balance. They urged us to take care of his vision as soon as possible, so that his therapy could be effective. We felt pressured to have it checked out right away. He was already so far behind; if we waited any longer, I thought, how could he ever catch up?

After researching ophthalmologists, we had to wait several months for an appointment. Yisrael Meir’s surgery was finally scheduled two months later, but then Corona hit, the country shut down, and the surgery was canceled.

### ◆ Reset

As our shuls and schools were closed and Corona spread, we were just happy to be alive, and the surgery was the last thing on our mind. But, as the weather got warmer and things started looking better, elective surgeries became available once again. We went to a developmental optometrist for a second opinion, but he concurred that the surgery was necessary.

B”H, since many people were being Covid-cautious, the surgery schedule was now wide open. We chose a date at the end of the summer, in between camp and school. This way, Yisrael Meir would not need to miss school, and it was *Bein haZmanim*, a good time for my husband.

Summer camps opened and the summer flew by uneventfully. We even went away to the Poconos for a few days, and came back refreshed and ready to start anew.

### ◆ Test Results

I stared at the CHOP test results on my computer in disbelief. “Positive? Corona?” I was shocked. The thought of a two-week quarantine paled in comparison to the surgery that would obviously not take place. Yisrael Meir had no symptoms. “It can’t be,” said my husband. “It must be a mistake!”

After wrestling through the last six months, we were trying to get back to normal, only to be caught in the clutches of a *positive* Corona test—we were both frustrated. But we reminded ourselves that we are not running the show. Hashem has everything under control, and the *hashgacha* that guided us until now would continue to guide us, even in inexplicable ways.

Convinced it was a false positive, and not wanting to quarantine my whole family for two weeks, we went to the nearest Urgent Care for another Covid test. B”H, the test came back negative. Yisrael Meir’s quarantine was over, but we had missed the surgery yet again!

Maybe the surgery was not meant to be, I thought. Maybe Hashem, the *Rofei kol basar*, would heal Yisrael Meir’s eyes some other way. We felt discouraged, but asked *daas Torah*, and were told to reschedule the

eye surgery. The next availability was not until December. Until then, Yisrael Meir would be back in school, and our concern now focused on his successful adaptation to his new class.

### ◆ **School and Covid**

The school year started and Yisrael Meir entered a new class, together with some of his friends from last year. He seemed to be doing pretty well, but was reserved and didn't interact socially as much as at home. His teacher had a sterling reputation, and we hoped he would acclimate with time.

After Succos, Covid surged again, and many classes in Yisrael Meir's school had to close temporarily when a teacher or student tested positive. At the end of November, I got a phone call from the school nurse. "One of Yisrael Meir's teachers tested positive for Covid. Unfortunately, the entire class will have to quarantine for the next 14 days."

"Help!" I thought. To have any child home from school for two weeks is never an easy situation, but to have Yisrael Meir home would be much more challenging. I thought about taking off the next two weeks from work, but then I had an idea.

### ◆ **A Reason for Everything**

"You know," I told the nurse, "he's already had Corona."

"Well, the health department is very strict," she explained. "Antibodies do not help. The only way he can skip quarantine is if he had a *positive* Corona test within the past three months."

"But he did!" I exclaimed excitedly. The Covid test he took at CHOP that (falsely) read positive had been just three months earlier! So, the drive to Philadelphia had NOT been for nothing. Yisrael Meir was allowed back at school!

### ◆ **A New Class**

Although our son could return to school, his class was still closed. All his teachers and friends were home. The school needed to find Yisrael Meir another class to join for the next two weeks, which was not so simple. Tremendous effort is expended to place each student in the setting that helps them grow to the best of their ability. Adding a temporary student to a class in the middle of the year can really set off the equilibrium.

That being said, when the Preschool Director heard that Yisrael Meir was allowed back at school, she did everything possible, making phone calls and trying to find the right class for him. She called me late at night with news that she found a teacher who agreed to take Yisrael Meir for two weeks. She assured me that it was a very "high-functioning, verbal, social class."

While I was happy to hear that, I was still nervous. Yisrael Meir has a hard time adjusting to new situations, and I didn't think he knew any of the kids in that class. But the alternative was for him

to stay home, so we decided to try it out.

I tried to explain to Yisrael Meir the night before that he would be in a new class for now, but I could not tell if he understood. I arranged for an assistant teacher he knew to take him off the bus and bring him to his new class. I davened and waited with bated breath to hear how his day was going.

### ◆ **The Right Fit**

Finally, the new teacher called: "I want to let you know how much we are enjoying Yisrael Meir in our classroom. He is adorable and is doing so well! He looks totally comfortable and is so involved!" I felt a rush of relief. I was so happy for him.

We later got a report from the Floor Time therapist, who told us that she was shocked to see Yisrael Meir playing so much more functionally with the new children than how she had seen him in his old class. She said: "He was a different kid!"

The new teacher emphasized how happy and calm he looked in his new environment, and how good his transition was. She said Yisrael Meir really complemented her class and that she wouldn't want to give him up at the end of two weeks! I thought she was joking, doubting the school would allow it.

### ◆ **All Worth It**

As the two weeks ended, the Preschool Director called. "We would like Yisrael Meir to stay in this class for the remainder of the year. He is really thriving and making excellent progress. The teacher really loves him."

I was shocked and excited, but I wanted to think about it. Although he seemed so happy, there were some things that I liked about his old class. I decided to wait until his old teacher and therapists came back to school, to have them observe Yisrael Meir in the new class.

Finally, the class's quarantine ended and all the staff came back. Yisrael Meir's speech therapist and teacher were both pleasantly surprised to see how nicely he interacted socially with his friends in the new class. They all felt that if he could manage the slightly higher level of the class, then we should keep him there.

After yet another Covid test (this time negative!), the surgery finally took place in December. Yisrael Meir recovered quickly and was happy to be back with his friends in school a few days later. I realized that not only did Yisroel Meir's vision improve—so did mine.

Everything became clear, as the pieces of the previous months began to fit into place. Although it seemed at first that our son's progress was being delayed, that positive Covid test at CHOP actually resulted in his placement in a much more suitable class. It was all part of the Master Plan, guided by the *hashgacha* of the *Eibishter*, Who orchestrates everything for our benefit.

# Respite Help for Your Child

Tova Wacholder, Special Needs Coach

## *Meet some great kids:*

**Rivky** is an eight-year-old child with high functioning autism. She is verbal, outgoing, and gregarious. When she is home, the home is always semi-centered on her. She needs center stage, and wants attention 100% of the time.

**Moishy** is a three-year old child diagnosed with a rare syndrome. He is an only child. Moishy loves cars, trucks, planes, and puzzles. When Moishy is bored, he begs for stimulation. He always wants to play with others.

**Alicia** is twenty-one-years old. Alicia is a beautiful girl, with blond hair and blue eyes. After a rare infection when she was an infant, she lost her ability to breathe and eat independently. She is vented and eats through a g-tube. She doesn't ask for much, and has a full-time nurse with her at home.

**Chaim** is thirteen-years old. He is bright, quick-witted, and fast paced. His diagnosis of ADHD makes him constantly seek entertainment, often not the kind of entertainment that his parents envision him participating in.

## *Meet some great parents:*

As a parent of a child with special needs; you are the CEO of your child's company, and you do everything possible so that your child can succeed.

You are your child's first advocate, protector, encourager, supporter, life manager, caregiver, and so much more.

All this advocating, protecting, encouraging, supporting, managing, and caregiving takes its toll on you as a parent, and on the family unit as a whole.

## *Great parents need great support:*

Studies have shown that the stress of a parent raising a special needs child is comparative to the stress of a soldier in active battle.

People who endure long-term stress without a break have an increased risk of mental health challenges such as anxiety, depression, PTSD (post-traumatic stress disorder), and increased risk of physical health challenges such as heart failure, stroke, and more.

Your child, your family, and you, need you healthy and whole so you can continue to be the great parent you are to your child!

No matter the diagnosis, a child with special needs takes a toll on the family.

Respite help is a necessity—not a luxury.

Often, parents don't realize how much attention and energy the child takes until they take respite help for the first time.

## *The good news:*

There is respite help available for your child, in your neighborhood.

## *Tell me more! What kind of respite is available?*

There are three types of respite available:

Hourly respite is when you get support respite staff for a few hours at a time, to give you a short break.

Overnight respite is when a support respite staff sleeps over at your home to cover the night shift and/or to watch your child when you're away.

Overnight respite can also occur in a respite center, such as a respite home, or a respite bed in a medical center.

Program respite can be overnight or hourly. Respite programs give you a scheduled break, with a program for your child.

This includes: after school programs, Sunday programs, legal holiday programs, Shabbatons, overnight trips, daycamp, and sleepaway camp.

## *What? There is help available? Why didn't anybody tell me this earlier?*

They should have told you this when they gave your child the diagnosis.

They should have at least taught you this in the Special Needs 101 course that your developmental pediatrician didn't offer...

It could be you heard about it, but maybe you were too overwhelmed to listen. So it's great that you're reading this now!

## *Where do I find this help?*

No matter where you live, there is something for your child.

Many of the larger Jewish communities have established central organizations that can help you get the right respite help.

For example, there are after-school programs, volunteers, mother's helpers, and holiday trips.

If you don't know where to start, reach out to your child's school or case manager.

Other times, it is best to reach out to others in the community who have children with special needs.

Even if their child is different than yours, they may have information that can be helpful to guide you where to start and whom to ask.

If you are the only family in your community who has a special needs child, your local community center may be able to arrange a respite program for you.

***I feel weird about taking chesed. I may have a child with special needs, but I'm not a nebach!***

Getting help brings up different feelings for different people. Parents who pride themselves as being givers may feel uncomfortable changing roles to that of accepting help from others.

Some parents feel that they don't need or deserve the help, since others have it so much worse!

Jewish guilt is a constant companion for parents. It takes on many forms: "My child is so young!" "I'm meant to do everything myself!" "Why should somebody else take care of my child?"

Shame and guilt are friends. "I'm embarrassed that I need help with my child."

All feelings are normal and okay!

Feelings are okay, but it's better if they don't control our decisions.

***Who wants to work with my child anyway?***

It happens to be that there are many people who are interested!

Some people volunteer their time, others charge.

High school girls gain tremendous skills, *middos*, and self-esteem when working with children with special needs. Most would say that you are doing them the *chesed*, not the other way around.

*Bochurim* are happy to give to your child, too.

There are families and individuals who are thrilled to have your child when you need the break.

But who can take care of my child like me, anyway?

Nobody can take care of your child like you can!

There are others who come in a close second, though!

Mothers who have taken help from a volunteer or camp counselor often feel like their child has gained a second mother, in the form of his camp counselor.

***How can I afford to pay for respite care?***

Most states and countries have some sort of government assistance for respite help.

Reach out to others in your community for assistance.

***Okay, I get it! I want respite! So, can I send my child to the program that I just heard about?***

It's great that you're on board! Respite will change the life of your child and family.

It's still great to ask some questions before you send your child with anybody, anywhere.

You can and should ask questions.

***What are some questions that I should ask?***

Great question!

***For a respite program, here are a few questions to ask:***

Who is the supervisor at this program?

What kind of experience does the supervisor have?

What is the staff-to-child ratio in this program?

What kind of training does the staff receive?

Are the staff ever left alone with the child?

What kind of behavioral support is available?

What kind of medical support is available?

What safety protocols are in place to protect the child?

***For a respite worker, here are a few questions:***

How many years have you worked with children?

How many years have you worked with special needs children?

What type of special needs children have you worked with?

What would you do if... (provide a scenario)

If the respite care is in the provider's home: How many children do you care for at a time?

***Share your expectations with the worker. Some examples (every home is different!):***

I need you to be on time and reliable.

Please don't feed my child anything I don't approve.

If you are assisting my child with bathing or toileting, I would like you to leave the door slightly ajar at all times.

Please actively play with my child, don't just "watch" him.

***How can I be calm when I can't really know what is happening when my child is in respite care?***

Trust your instincts. If something feels right, it probably is. And if something feels wrong, it probably is, too.

You've tried your best. As a parent of a child with special needs, you probably have learned that the effort is ours; the outcome is Hashem's alone.

Most providers are wonderful, kind, people.

I join you in your tefillos that your child is safe, happy, and cared for, in every place he is.

Meanwhile, go ahead and take that break, vacation, or respite time that you need and are waiting for!

# Illuminations

An Interview with Dayan Dunner, the Rav of London

Rabbi Avrohom Birnbaum

*Dayan Aharon Dovid Dunner has a unique life experience in understanding the singular challenge (and bracha) of those who have a special needs child. For nearly seventy years, he has been intimately involved in this sugya, as his younger brother, Shimi Dunner, a”h, was born with Down syndrome.*

*In those days, things were completely different than they are today, as the Dayan explains in this article. As a result of his own personal experience, Dayan Dunner has often been consulted by parents and organizations that deal with this area for both practical, halachic, and hashkafic advice.*

**How should new parents of a special child deal with their questions of: “Why did Hashem choose us to have a child with Down syndrome?”**

**Dayan Aharon Dovid Dunner:** I would like to step back for a moment and give a bit of my own background in this *inyan*, and then share with you the *hanbaga* and *shimush* that I received just from observing how my parents lovingly approached this *sugyah*. Some seventy years ago, my brother Shimi was born with Down syndrome. In those days, the term ‘Down syndrome’ didn’t exist. At that time, the children were either called ‘Mongols’ or ‘Rejects.’ Having such a child was often a family’s ‘private dirty little secret,’ not to be publicized. There was shame associated with having such a child.

My parents, however, were the exception to the prevailing attitude. Right when he was born, the message that we got, just from observing them, was that this was our wonderful brother. Yes, he was different, but we would accept him and never be ashamed of him. Yes, indeed, there were awkward moments, even some very embarrassing moments, over the years, but there was never a question of hiding him, of not loving him, or not recognizing him as a beloved, integral part of our family. That doesn’t mean that we, the children, didn’t periodically cry in grief and frustration—We did!

Now to your question of why Hashem chose you to have a child with Down syndrome or, for that matter, any special child. The truth is, we never had that question, because we were given to understand that this is a *chelek* that the *Ribono Shel Olam* gave us. It is not an unlike any other *nisayon* for which we don’t

have a clear answer as to why – Why did Hashem make this family involved in a terrible car accident? Why did this family’s house burn down? Why did this *Yid* lose his once thriving business? As *maaminim bnei maaminim*, we understand that Hashem sends all of us various trials in life. Often, we cannot understand the reasons, but we know that He has a *cheshbon*, and it is our task to accept the *nisayon* as we would accept any other very difficult *nisayon*.

That does not, however, mean that it is not difficult. Nor does it mean that there is anything wrong with becoming frustrated and crying when things are hard. Hashem understands our difficulties. We can cry, we can be distraught. We are human beings, and the challenges of life can sometimes be overwhelming! Nevertheless, at the end of the day, we must approach this special task that Hashem has given us, with *emunah*, with the deep-seated knowledge that Hashem Himself sent this wonderful child to us and, if He sent him to us, it is something that we can be *mekabel*.

**What thought should parents have in mind at the *bris* of a special child? How should they accept *mazal tov* wishes/ *brachos* and what should they do if they feel embarrassed by their special child?**

This question is really an extension of your first question, and needs both a practical answer as well as its *hashkafic* underpinnings. With regard to what to think and how to accept people’s wishes at the *bris*, or when the child is born, my experience is that parents of the newborn special child should neither run away nor obfuscate. They should be up-front with others about their new situation right away. They can tell people: “We have a lovely piece of news that is bittersweet for us. *Boruch Hashem*, we were blessed with a child, but the child has Downs syndrome. This is what Hashem sent us, and we know that what He does is for the good.” My experience is that when parents start hiding or denying either the fact that the child was born, or the fact that it will be a significant challenge, it is not good.

**So, the Dayan is saying that parents and families who are given a special child from Hashem should not deny the challenge that they face and should not exude a false front indicating that everything is perfect. At the same time, they should accept the *nisayon* and realize that, in many ways, they will grow from it.**

Exactly! The classic example of this is *Yosef HaTzadik*. Here he was, living a wonderful life, basking in the light of his father, *Yaakov Avinu*, learning with him, when suddenly, his own brothers sell him as a slave! Can one even imagine how difficult this was for him? Rabbeinu Yonah asks: “Why didn’t Yosef tell the *Yishmaelim* to whom he was sold: ‘Excuse me! This was all a mistake! I am Yosef. My father is Yaakov. I am not a slave. I

was kidnapped!” Furthermore, he asks: “Why didn’t Yosef send a message to his father that he was alive and well?” Rabbeinu Yonah answers: “From the minute this sequence of events happened, Yosef realized that there must be a reason for it. He thought: “Hashem must have a plan for me. I will therefore not fight it. I will accept it, difficult as it is.” He understood that he had a *shelichus* to spread Hashem’s name in *Mitzrayim*, even in the dark dungeon of prison!”

What I am saying is that we are not downplaying that there will be difficulties at times. I can tell you from experience that there are aspects that are demanding. Simultaneously, we have to understand that there is a *shelichus* inherent in this *nisayon*. I also want to say that it has been my experience that a Down syndrome child usually unites a family, bringing them closer together. That child arouses much *simcha* and *nachas*, together with the hard work. With special children, there is often less *nachas* and *simcha*, but when a person accepts this challenge as a *shelichus* and an opportunity to perform pure *chessed* every single day, it transforms the often arduous task into a holy mission, a *shelichus* from Hashem.

**Often people try to ‘comfort’ the new parents by saying that “the baby has a special *neshama* and Hashem chose you...” What does a ‘special *neshama*’ mean?**

First, let me address the beginning of your question by sharing what most people do NOT want to hear! They do not want to hear that “there was this special *neshama* up in *shamayim* that wanted to be placed in a family, and Hashem looked and picked you because you are that special father/mother/family that is up to the task.” Perhaps, seventy years ago, when these children were a rarity, one could say such a thing, but today, when these children are fairly common in our collective communities, I don’t know if that is true. I think it is better to convey to families that “Hashem gave you this challenge and, like any other hurdle, it has the ability to bring you closer to Hashem, to greater levels of *emunah*.”

With regard to the second part of your question, about the specialness of the *neshama*, I will tell you a personal story. One of my duties as *dayan* is that I oversee exhumations of *meisim*, dead bodies, that, for whatever reason, need to be exhumed from the ground and transported elsewhere. I can tell you that after a few years, there is almost nothing left. All that is left are some bones and some earth. There is a certain *Chassidische Yid* who has made it his mission to search for the estates of *Yidden* who died without *yorshim*, and to try to transfer the money they left to worthy causes that will help *Yidden*. He found out about a special needs child who was born to Jewish parents, but when the parents passed away, the child was adopted by Christians. Eventually, when the child died, he was buried in a Christian cemetery. This *Yid* heard about it and felt very strongly that this Jewish *neshama* should be buried in a Jewish *bais hakevaros*. He fought in the courts for

the right to exhume the body, and eventually won. When the body was exhumed, ten years after he had passed away, the body was almost *shaleim*—it was 90% whole—nearly as it was on the day of death. When I told this story at a special Shabbos for parents of special children, they were very moved. They instantly understood that there is something special, unique, and holy about these children, despite the hardships.

**What is the proper hashkafa for parents to give over to their children to accept a new sibling with Down syndrome? How should they deal with what may very possibly elicit very strong emotions and reactions?**

One should be very open with their children, immediately explaining that this is a brother or sister who is different: “Just like there are all kinds of children—there are smart children, brilliant children, silly children, thin children, and fat children—this child is also different; but we will love this child, and take care of this child, and enjoy him as part of our family.” You can tell the children that it is a *nisayon*. There is nothing wrong with that. The key is that the parents’ attitude in how they accept the *nisayon* that Hashem gives them, is the attitude that will be transmitted to the children. I want to tell you from personal experience that, yes, it is a *nisayon*.

Simultaneously, the child brings with him such love and closeness. I can unequivocally tell you that my brother Shimi, who had Down syndrome, was not an easy child, but I miss him every day! He was so near and dear to us, and we loved him so much! I talk about him all the time, and I long for him.

Yet it was not always easy! I remember when we were boys, I was once taking him for a walk on Shabbos morning and we passed a house with a magnificently manicured garden. An elderly woman was standing in the front, looking lovingly at a beautiful, perfect looking rose. Do you know what my brother Shimi did? He plucked that beautiful rose right out in front of her eyes and then stuck out his tongue at her! Of course, at that moment, I felt very awkward and uncomfortable.

I remember another story that happened on a Shabbos, when we were taking a walk with my father and the children. Suddenly, Shimi broke away and ran onto a city bus! It was Shabbos, so my father asked a non-Jew who was there, if he could please go and take the boy off the bus. The person was not accommodating, and told my father: “You do it!” What did my father, a prominent, distinguished *rov*, with a long beard, do? He went on the bus and asked the bus driver to keep the bus stationary while he went on and found Shimi. You have to understand that we were in the heart of the *Yiddishe* neighborhood, on a Shabbos morning, when everyone was in the street! Nevertheless, we approached these tasks with love, and they did not in any way embitter us or affect the deep love we had for my brother.

On the other hand, he brought such *simcha* with him wherever he went. Shimi loved to dance at *chasunas*, he loved music, and he was really so much fun to be around. Again, I think that the way my father and mother accepted him and loved him, making him an integral part of our family (even at a time when this was not at all common) played a tremendous role in our own attitudes of love and acceptance for him. Shimi was probably the best-known character in the area, and was deeply loved by Jew and non-Jew alike.

### **What would the Dayan answer if parents feel embarrassed by their special child?**

There is nothing wrong with feeling embarrassed at times; it is normal! I remember a time when Shimi adamantly insisted – while he and my brother Boruch were walking in the street – that he wanted to have Boruch's pants. He wanted Boruch to switch pants with him in the middle of the street! Of course, such a thing is embarrassing, but again, if the parents and their children understand that this is the *shelichus* that Hashem has given them, it will also have many positive side benefits. Especially when it comes to a child with Down syndrome, they will be able to look at the whole picture.

### **What do you tell people who are worried about what this can do to *shidduchim*?**

When I was learning in the Chevron Yeshiva as a *bochur*, I remember hanging pictures of my family in my dormitory room. Of course, my brother Simi was in the pictures. In those days, people sadly hid these children and they were viewed as a badge of shame. The *bochurim* told me: "You must take the pictures of Shimi down! It will hurt your *shidduchim*." I never even entertained the thought of taking them down. We loved him, we enjoyed him, and we were never ashamed that he was our brother. This was the lesson that our parents imbued in us right from the beginning. *Boruch Hashem*, I got married! As a rule, if an unwell child has been well-loved and well-cared for by his family – that very fact becomes a selling point in a *shidduch*, and it increases recommendation.

### **How much effort should be put into the child's education and development if he will never be on the level of a typically developing child?**

The *klal* in this regard, and also, in many ways, to your previous question, is that parents should look to make the child feel comfortable in *frum* society – even if he is *pottur* from *mitzvos*. That means, he should sing *zemiros* at the Shabbos table. He should come to *shul* when appropriate. We took our brother Shimi to *shul* and we even gave him *gelilah*. The *chinuch* isn't *shemiras hamitzvos* per se, but rather, making him feel content and at home in *frum* life and society.

### **Any parting thoughts?**

Parents should realize that they have a *nisayon* and a *shelichus*,

yet, in many ways, this *shelichus* will bring out the best in themselves and in their other children. It will strengthen their *emunah* and gratitude for the good in their lives. It often makes the parents and their children more empathetic and sensitive to the feelings and needs of others. Ultimately, however, as *maaminim bnei maaminim*, we know that everything Hashem does is for our good, whether we understand or not.

Let me leave you with a story that illustrates this point. We all remember the horrible terrorist attack on the Chabad House in Mumbai, India. One of the *kedoshim* who lost his life was Rav Aryeh Leibush Teitelbaum, a son-in-law of the Toldos Avrohom Yitzchok Rebbe. After the attack, no one knew definitively if he was alive or dead. They knew that he had been in the building and that he wasn't answering his phone. Logic therefore dictated that he must have been killed, but at that point, there was no *halachic eidus*. They had not gotten permission by local authorities to identify the bodies until three days after the attack. The issue, however, is that the *Gemara* in *Yeveamos* says that three days after death, the face is no longer recognizable.

The *shailah* was sent to Rav Elyashiv and Rav Elyashiv *paskened* that indeed, face recognition would not be valid, but they should look for other *simanim* or peculiarities on his body. They should go to his *rebbetzin* and ask her if there were any such things. Rav Elyashiv added that under no circumstance should they release the body for burial until they find a *siman*, because if they bury him before positive halachic identification is made, his wife might end up an *agunah* for the rest of her life. They looked, but the body was already in a state where it was difficult to find anything.

Finally, however, the *rebbetzin* remembered that, many years earlier, he had fallen and badly broken his leg. At that time, everyone was so upset. It was a bad break and he had to be off his feet for a long time, and it was very difficult. Ultimately, they obtained the x-rays of his broken leg from the hospital. Those x-rays were compared to the leg on the body and they were able to positively identify him *al pi haTorah*, thereby permitting his wife to remarry.

I am sure that years earlier, when he broke his leg, everyone was bemoaning his fate and what a difficult 'tragedy' it was. In the end, it was that difficulty that served as the *yeshuah*! From here we see that we can never know what Hashem's plan is. Sometimes things that seem difficult to us are, in the long run, the key to a *yeshuah*.

My message to all special parents of special children: If Hashem has given you both a *nisayon* and a *shelichus*, then you are capable of faithfully fulfilling it. It will not always be easy, but it is actually good. "From Hashem, no bad comes forth!"

*This interview is excerpted from an article printed in the Yaated Ne'eman. For the full version, please contact neshamalemagazine@gmail.com*

Q

Dear Shira,

## IN SESSION

I have a six year-old son with CP. He is ka”h very smart, and is of average intelligence for his age. He uses an eye gaze and always amazes us with everything he knows. He cannot talk clearly, cannot walk, nor can he yet use his hands functionally. He uses a gait trainer to get around.

He asks me questions about why he is different, and I can tell that this bothers him a lot. I am at a loss as to how to explain this to him in an age-appropriate and meaningful way.

A

Dear Parent,

Your question is a painful but courageous one, as you want to take steps to address something very difficult. Although I want to address your specific question, I will generalize my answer to be appropriate to anyone with a special need child. Before you can explain to your child, you, yourself, must be clear. How do you feel about the fact that your child is ‘different’ and is unable to do what typical children can? How do you accept it? It is not easy to accept, but get the support you need. Once you are ‘okay’ with it, then your child will also be okay.

In a previous article, I suggested taking a large piece of white paper, drawing a dot in the center, and asking your child what he sees. 99% of people respond that they see the black dot, ignoring the larger proportion of white paper. The metaphor is: don’t focus only on the small dot, but on everything—the “big picture.” Explore with your child what is contained in the ‘white’—all of his qualities, large and small, which add up to much more than his disabilities.

We have many *mashalim* explaining how an imperfection can become something beautiful. A colleague and friend of mine, Michelle Halle, introduced me to a traditional Japanese artform called *kintsugi*, which means ‘to join with gold.’ When something breaks, it is not thrown away. Rather, the pieces are put back together, joined together with sap and overlain with gold. This highlights the fractures rather than hiding them, thus transforming the previously broken and worthless pieces into a beautiful and valuable work of art.

Notice in the picture that the bigger the fracture, the more gold is used. Perhaps you would like to do this activity with your child, according to his ability. Maximize the project by breaking a piece of pottery into a lot of pieces. Put it together and cover the seams with ‘gold’ (gold marker or puff paint). When it is complete and restored, take time to notice all the details and appreciate its beauty. The metaphor is clear, but it is up to you to believe and accept it. The clearer it is to you, the easier it will be for your child to accept and appreciate his value.



Mikah, a fashion company, uses kintsugi in its clothing design. Their marketing slogan is:

**Own your struggles, and in doing so, own your strength.**

**Know you are beautiful, not despite your circumstances, but because of them.**

**Wear your scars with pride. You are one of a kind.**

Wishing you continued *nachas* and strength to persevere,

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*

# Smart & Safe

## Summer Fun

Fraydel Dickstein

As summer takes hold, the outdoors becomes our new home. I love when Yehuda, and for that matter all of my children, spend their time outdoors. The sun and exercise are so healthy for everyone. I do have this secret fear of the summer--when Yehuda spends so much more time outside our home, he tends to push his boundaries and explore new terrain. He finds more houses to visit, sometimes attempts to open car doors, etc. I don't approve of every house door he opens; for example, pets of other families can be a challenge for me. And, of course, if I don't know the occupants, I genuinely worry about my son's safety.

I need to take a moment to sincerely thank some special neighbors who not only allow Yehuda into their homes when he walks in uninvited, but welcome him and tell him how much they love when he visits. This is despite him eating all their grapes and helping himself to the contents of their fridge. He is elated for hours after being accepted in someone else's house.

This brings me to one of my pet peeves: that when bringing up a special needs child we often forget the basics. We do so very much for our special children, and the struggle is oftentimes simply to survive. I consider caring for my Yehuda to be the equivalent of parenting four or five children, depending on the day. With our typical children, we know the value of complimenting and telling them how good they are. Yet, when it comes to our special children, we often forget to tell them how good they are and how happy we are to have them in our families. We need to let them know that they light up our days, even if it's sometimes hard to feel this way. We try to talk about the *Shechina* that rests on Yehuda, and not only about the messes and havoc he often creates. I watch him glow and grow taller from the compliments, and I find that each day my positive feelings become more and more genuine. It's unbelievably special when a neighbor does this as well. (Incidentally, these neighbors and others who show kindness to our children often, themselves, have a special needs child or sibling.)

Back to the summer issue of Yehuda pushing his boundaries, exploring unknown territory, and wandering away. As much as we try to stay on top of our dear children, and as hard as we try, I find that doors get left open in the summer. Here are some solutions toward providing a safer summer experience:

**Medical ID bracelets** (\$24.95 on [www.AmericanMedical-ID.com](http://www.AmericanMedical-ID.com))

This seems to me like a basic safety precaution for Yehuda. I chose this specific company as they said it would be very difficult for the child to remove the bracelet by himself, which is a huge priority for us. It's important include a cell phone number so that you can be easily reached.



### GPS Trackers

There are various GPS systems we can attach to our children. Angel Senses is one of the popular ones.

**Angel Sense GPS Tracker (\$69 on [Angelsense.com](http://Angelsense.com) or 646-770-2950)**

The Angel Sense GPS tracker's motto is: "Maximum safety for your child. Peace of mind for you." That sounds good to me. A summer camp required it for Yehuda so we bought it, although we never ended up using it. It has many options and capabilities, such as 2-way voice, an alarm that you can activate, runner mode, and ETA feature.



The device itself is not very expensive, and they often have coupons and special deals. The monthly subscription ranges from \$33-\$52. One problem with the device is keeping it on your child, especially if you have one who likes to strip. They have some solutions, such as a special sleeve that attaches to the child's clothing with magnetic fasteners. It can only be removed with a special magnetic key.

Amazon carries other options for trackers which are less expensive and sound like they can be quite helpful. Please let us know if you have used any trackers that you were satisfied with. Many of us are fortunate to be able to send our children to sleep-away camp in the summer. Even so, we generally still have some unstructured time and need ideas for things to do with our children and families that are enjoyable and physically practical. For us personally, as Yehuda gets older and bigger, it becomes more challenging, as he won't go where he doesn't

want to. A dear friend gave us permission to bring Yehuda to their pool. It is the perfect pool, a round, above-ground pool less than four feet deep, so I am not worried he will drown. The whole swimming activity takes a few hours and all my kids are ecstatic to go, so it is great entertainment on a long summer day. Sometimes Yehuda won't get out of the car, so everyone else is disappointed. On such occasions, I have done drive-through Slurpees to sweeten the mood.

As far as trips go, I have to admit they are really hard. On rainy days, it's super hard to find appropriate indoors trips. Here are a few ideas that have potential:

**We Rock the Spectrum Kid's Gym** ([www.wrtsfranchise.com](http://www.wrtsfranchise.com) or 818-996-6620) is a new chain that has 24 locations throughout the USA. Their philosophy is to provide a place for children of all ability levels to play together. All children can benefit from their uniquely designed sensory equipment that aids children with sensory processing disorders.



We had a great time when we went there. The equipment was great and there were no flashing lights or loud music, so Yehuda really enjoyed it. They are wheelchair accessible as well. My other children, who were then ages ten and under, really enjoyed it as well. It was a winner of a trip for everyone.

**Chuck E Cheese** ([chuckecheese.com](http://chuckecheese.com))



Although this is a regular mainstream trip, we have found them to be so nice and understanding to Yehuda. **Not all locations are wheelchair accessible.** Some locations have sensory friendly Sundays—two hours on the first Sunday of the month—devoted to special needs children. Call your local branch for more information.

**Trampoline Parks**

[urbanairtrampolinepark.com](http://urbanairtrampolinepark.com)      [rebounderz.com](http://rebounderz.com)  
[skyzone.com](http://skyzone.com)      [getairsports.com](http://getairsports.com)  
[hangartrampolineparks.com](http://hangartrampolineparks.com)

I asked a few friends, and trampoline parks were high on their

lists of great places to go with your special needs child. Some locations offer sensory friendly hours for a quieter, toned-down jumping experience for those with special needs. Call your local branch for more information.



**Outdoor Parks**

Recently a friend told me that her son tries to escape from parks. This can make a park outing very stressful and not too doable. This may be a solution for her:

**Jake's Place Playground**, located in Cherry Hill, NJ. *Jake's Place is an all-inclusive playground that is designed to provide a fun and safe play area for special needs children and adults. This cushioned play area has wide ramps that can accommodate wheelchairs, sensory-friendly activities, rock walls, and structures to help children develop better coordination and balance. For parents who need a little peace of mind, this playground also features a security fence.*



Other parks that have similar features include Westchester Recreation Center in Los Angeles, Dream Come True Playground in Harrisonburg, Virginia, Hadley's Park in Potomac, Maryland, Friendship Park in Ra'anana, Israel, and Jacob's Park in Boynton Beach, FL.



**Jiminy Peak Mountain Resort** ([www.jiminypeak.com](http://www.jiminypeak.com) or 413-738-5500), in Hancock, MA, is a ski resort and hotel. Their list of services is too long to write here! They are wheelchair accessible and also offer an adaptive program, which provides ski and snowboard lessons to individuals of all ages with physical, cognitive or developmental disabilities. Jiminy Peak partners with STRIDE Adaptive Sports, a nonprofit adaptive skiing and recreation organization for individuals with disabilities.

I would love to hear stories of successful trips or great places to go that you have personally experienced with your special needs child(ren). It would be wonderful to share this information with our readers.

*Please feel free to send any questions or topics you would like covered to: [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com). I look forward to hearing from you soon!*

# SPECIAL PARENTS

# of SPECIAL CHILDREN:

Chayala Tawil

## *A Candid Conversation about Mainstreaming*

**Neshamale: What made you decide to send your daughter with Down syndrome to a mainstream yeshiva program?**

**Leah Jacobs:** We live out of town and there are no special programs for *frum* boys or girls, so there was simply no choice. There are public school programs, of course, but both my husband and I felt strongly against sending our daughter into a secular environment. She would surely pick up undesirable values, language, and behaviors there. To us, the risk of the potential damage outweighed the possible benefits of a “special” program.

We did speak with *da’as Torah* to make sure that we were making the right decision. The *gadol* told us that as long as she will gain something in a regular yeshiva class, there is no reason to send her elsewhere. *Baruch Hashem*, this enabled us to feel secure about our choice. *Chasdei Hashem*, Shevy, now in eighth grade, benefits and learns quite a lot in a regular class.

**Neshamale: Did you do anything special to facilitate her success in Pre-1-A and beyond?**

**Leah Jacobs:** Since Shevy is already in eighth grade, it’s hard to recall everything that transpired in the earlier grades. One thing is certain – we took her learning and school responsibilities seriously! She had a full-day shadow with her (beginning in playgroup until the present day). When the learning was over her head (which was quite often the case), a competent shadow took her out for one-on-one tutoring. We did homework each night, modified to her level. We held her accountable for what she could learn, and she took modified tests. Shevy learned to read Hebrew in Pre-1-A. During the summer she had a *Kriyah Morah* to review and solidify the harder areas, to ready her for first grade.

**Neshamale: Does Shevy have real friends?**

**Leah Jacobs:** This is a hard question to answer. If you were to ask Shevy, she would give an unequivocal resounding “Yes!” All of the girls are so good to her! They are always ready to give her a hand with anything she may need, and they are patient with her sometimes “immature behavior.”

Yet, I realize that she doesn’t have the real friendships that girls her age enjoy. She can’t really schmooze and review her day with a friend at night. She isn’t invited on Shabbos afternoons to play at her peers’ homes. I certainly understand, and bear no resentment. On the contrary, I am grateful for the girls’ beautiful *midos*, and the warmth they shower her with each school day.

Shevy also enjoys being popular among the many high school girls who extend their warmth, attention, and time to her. Some take her out once a week, or are involved with her on Sunday through a *chesed* program. She feels loved wherever she goes, because everyone knows Shevy and make her feel like they are her best friend!

**Neshamale: What do you see as the main benefit of mainstreaming?**

**Leah Jacobs:** A tremendous benefit is that Shevy appreciates and enjoys the *Yomim Tovim*. She learns about them in depth, does arts and crafts, and sings about them. She really absorbs the excitement in the air of the classroom before each *Yom Tov*.

The fact that she can read and translate *Chumash*, read a *Rashi*, etc., is very important to me, as I feel it connects her to

*Yiddishekeit*. Some people might say: “Who cares? How will this help her in life?” but I do feel that it’s meaningful. And she is very proud of herself, too!

Another benefit is that Shevy learns normal behaviors by being around normal kids all the time. She constantly hears articulate people using high vocabulary and normal speech patterns. The topics her peers discuss are probably more typical than those she would hear if she were only among other special children. I feel that this makes her conversations and interests in life more mature. In terms of *ruchniyos*, she hears so much *hashkafa* in school. Even if she doesn’t understand all of it, whatever she picks up means a lot to me.

**Neshamale: Are there any negatives or challenges in mainstreaming?**

**Leah Jacobs:** Definitely! The hardest part for me is watching my daughter on the sidelines of the social scene. As I mentioned, Shevy is well-liked, and the girls are very nice to her. However, as a mother, it is still painful to watch her trying so hard to keep up with the girls’ conversations; they are just too fast for her to follow. If she went to a special school from the beginning, then maybe, at this point, she would have actual friends on her level to talk to and play with.

Another very challenging part of mainstreaming is finding the right shadows (and paying them!). A good shadow is very hard to come by, and sometimes even a good one is just not the right fit. Even when it’s not a great match, we can be stuck, because it’s hard to fire someone and it’s even harder to find someone else. It can be very stressful.

As Shevy gets older and the lessons get harder, we spend a lot of time modifying the school work and adjusting her academic goals.

People might say that we are missing out on having a specialized program with built-in therapy, etc. In my limited experience, I haven’t been so impressed with the few programs that I looked into, so I don’t really feel that this is the case. In Shevy’s younger years, we did some after-school therapy and speech therapy now and then.

Another challenging aspect for me is filling in the gaps at night. Her classmates come home and have two hours of homework to do, and a few hours to socialize. Shevy can only handle 15

minutes of homework, after which she expects Mommy to be her director of recreational activities and entertainment.

**Neshamale: If someone had both options open to them, would you recommend that they send their child to a special program or mainstream the child in a yeshiva?**

To decide between the two options, I would first look very carefully into the special program to see how good it is. If they offer an excellent program, and you feel that your child won’t pick up too many bizarre behaviors or be affected negatively in his/her *ruchniyos*, then it can be the better option. But if it looks like you are sacrificing *ruchniyos*, whether in *tznius* or *kashrus*—for me, it just wouldn’t be an option. However, it goes without saying, that you should be realistic and only consider mainstreaming if you think your child is high-functioning enough to be able to keep up and to benefit from such a set-up. At the end of the day, it’s a very individual decision.

**Neshamale: Do you have any nice stories to relate?**

There have been so many heartwarming moments. One aspect that comes to mind is how everyone has always been so careful to include Shevy. Shevy is on a gluten-free diet, and has other allergies as well. When she was in Pre-1-A, her *morah* baked cupcakes for the class for a special occasion. She called the night before to ask me how to make gluten-free cupcakes. I offered to make them myself, but she insisted that she wanted to do it, and she made Shevy’s cupcake look the same as the others!

Whenever her class has a pizza party, they always order French fries for her, or something else that she can eat.

Every year, before Purim, a girl in her grade calls to ask which foods Shevy can eat. I tell her not to worry about it, but she insists that she wants to prepare a *shalach manos* that Shevy will be able to enjoy. Last year, she brought Shevy a huge *shalach manos* with 10 different gluten-free snacks! It is just so beautiful to see how others, especially young children, are so loving and accommodating.

**Neshamale: Thank you so much for sharing your experiences with us! Much continued hatzlacha!**

*Leah Jacobs is using a pen name. She can be contacted through Neshamale Magazine.*

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***However, it goes without saying, that you should be realistic and only consider mainstreaming if you think your child is high-functioning enough to be able to keep up and to benefit from such a set-up. At the end of the day, it’s a very individual decision.***

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# Lets Get Educated

## Aqua Therapy

Tzivy Szmidt, MAT

*With appreciation to Aviva Fishman OTR/L, who took time to share her knowledge of this specialty with us. Aviva works at Achievement in Motion, a New Jersey OT practice specializing in Aqua Therapy,*

### What is Aqua Therapy?

As with conventional “Land Therapy,” Aqua Therapy helps children obtain skills needed to function in their environment, but uses water as the medium. The therapy session takes place in a pool, with the child and a licensed OT or PT specially trained in Aqua Therapy.

### Why would someone choose Aqua Therapy over other therapies?

It is easier for a child to learn new skills in the non-restrictive environment of the water rather than on land. Water provides more deep-pressure to the body than air, and gives the body a full sensory experience at all times. This enhanced sensory input aids in the child’s body awareness and helps develop his motor learning.

Due to the buoyancy of water, it is easier for children to perform skills in the gravity-lessened environment. This helps children focus more on the balance and coordination of the movement than the strength it takes to complete it.

The warm water in a heated pool allows the muscles to relax and exercise more freely, without placing undue stress on the musculoskeletal system.

### How does Aqua Therapy differ from swimming lessons?

Aqua Therapy is skilled treatment in the water; swimming lessons are recreational. Every Aqua Therapy session is fine-tuned to the child’s goal. For example, with a child who is still bed wetting, the goal would be to create activities to target that goal. In this case, we would work on integrating the reflexes, promoting improved body awareness, and working from a behavioral and social/emotional angle.

### Who are the best candidates for Aqua Therapy?

Everyone can benefit! Aviva has a pediatric practice, so her clientele focuses on newborn through age 21. The youngest child she treated was a ten month-old girl with Cerebral Palsy. Children with physical disabilities, ASD, social/emotional, ADD, and children exhibiting anxiety, are among those who have been treated by Achievement in Motion.

Aviva runs a family-centered practice. At the start of the child’s plan of care, goals are created with the parents and therapist. The parents are encouraged to observe the sessions. Time is dedicated weekly to train the parents in activities to do at home to assist their child in meeting his/her goals. Frequent contact between Aviva and the parent enables the parent to know when goals are reached and when clients are ready for discharge.

Aviva believes parents should learn to understand their child better and the child should learn to understand himself better, in order to create a lasting effect that will enhance the child’s quality of life. If a parent can learn to understand the root of their child’s needs and which activities or tools are required to assist their child, the need for therapy is reduced. When a parent calls saying: “My child is always having meltdowns...” often the parent doesn’t understand the root of the issue. By educating the parent about the root of the problem, focus shifts toward an attainable goal.

### Aqua Therapy in Action:

*A client came to Achievement in Motion to address balance issues. This twelve year-old girl couldn’t go down steps without holding on to the banister with both hands. She was even nervous she would trip when helping her mother bring food from the kitchen to the Shabbos table. By the time she was discharged, this girl was able to go down steps without holding on, while carrying food, with no difficulty at all!*

*Another client was a 7th grader who had difficulty sitting still in class and was missing social skills. She reached the goals we set up and was discharged in the summer. During PTA in the fall, the teacher told the girl’s mother: “Thank you for sharing your daughter with me; she is doing beautifully and is so well liked.”*

## Pediatric AqQuatic Therapy

Our specialized therapy services include but are not limited to children who may have the following needs:

- Sensory Deficits
- Autism Spectrum Disorder
- ADD/ADHD
- Difficulties with Social/Emotional Interactions
- Physical Disabilities

All sessions will be given by Aviva Fishman MS OTR/L, a certified and trained occupational therapist licensed in NJ & NY.

Please call 718-614-1734 to find out how aqua therapy can benefit your child.

Services will be provided year round in an indoor pool located in Lakewood

## GLOSSARY OF HEBREW TERMINOLOGY

Note: All words are in Ashkenasic (Eastern European) pronunciation. (Y)=Yiddish, (A)=Aramaic

Acharis ha'yamim – the end of days  
 Al kanfei nesharim – on the wings of eagles  
 Av – 11th Hebrew month  
 B'nai Yisroel – the Children of Israel (the Jewish People)  
 Bais haMikdash – the Holy Temple  
 Baruch HaShem – Praise G-d!  
 Bain ha'zemanim – Yeshiva intersession  
 Bentshing – blessing (v), usually ref to reciting the Grace after meals (Yinglish!)  
 Bim'hayra v'yamaynu, Amen – May it be speedily, in our days, Amen.  
 Bracha – blessing  
 Chasdei Hashem – idiom: God's kindness  
 Chazal – our Sages, of blessed memory (acronym: Chachamim Zichronom Lvracha)  
 Chesed – acts of kindness  
 Cholent – beef bean stew, popular Shabbos dish (Y)  
 Chumash – the Five Books of Moses  
 D'var Torah – Torah oration  
 Daas Torah – advice of Torah sages  
 Divrei chizuk – inspirational words  
 Doros – generations  
 Eibeshter – G-d (Y)  
 Emunah – faith  
 Fleishig – of meat (adj) (Y)  
 Frum – religiously observant (Y)  
 Gadol – revered, eminent rabbi  
 Galus – Exile  
 Galus Mitzrayim – the Exile in Egypt  
 Gemara – Talmud (A)  
 Geulah – the Redemption  
 HaKadosh Boruch Hu – The Holy One, Blessed Be He (G-d)  
 Hanhala – Principal/School Directors  
 Hashgacha – supervision  
 Hashkafa – outlook  
 Hatavah – improvement  
 Hatzlacha – success  
 Heilige – holy (Y)  
 Ka'h – “Kayn Ayin HaRa” – Warding away the evil eye (Y)  
 Kashrus – in accordance with Torah dietary laws  
 Klal – the Jewish community  
 haKosel haMa'aravi – the Western Wall  
 Kriyah morah – Hebrew reading teacher  
 Kriyas Yam Suf – splitting of the Reed Sea  
 Limudei Kodesh – Torah study; lit: Holy studies  
 Mah Nishtana – “Why is it different?” a section of Passover Haggadah recited by the youngest child at the Seder  
 Midos – character traits  
 Morah – teacher  
 Moshiach – Messiah  
 M'shalaym – pay  
 M'shalaym s'charam – pay their reward  
 Nachas – pride and joy (usually from children)

Nebach (noun) – unfortunate one  
 Negel vasser – morning hand washing; lit: nail water (Y)  
 Neilah – concluding prayer service of Yom Kippur  
 Neshama/os – soul/s  
 Nisayon – test  
 Nisayon ha'chaim – test of life  
 Parasha – weekly Torah section  
 Rashi – foremost commentator on the Torah/Talmud  
 Rofoi kol basar – Healer of all flesh (ie: G-d)  
 Ruachniyos – spirituality  
 Seudah – meal  
 Shalach manos – gifts of food sent on Purim  
 Shalosh seudos – third Shabbos meal  
 Shechina – the Divine Presence  
 Shidduchim – marital matches  
 Shira – song  
 Shul – Synagogue  
 Shver – Father in law (Y)  
 Siyata d'Shmaya – help from Heaven (A)  
 Tafkid – purpose  
 Tamuz – 10th month of the Hebrew year  
 Tante – Aunt (Y)  
 Tefillos – prayers  
 Tekufa – period of time  
 Tikkun – repair, rectification  
 Tisha b'Av – 9th day of Hebrew month Av, a fast day to mourn the destruction of the Holy Temple  
 Tzadikim – Righteous ones  
 Tznius – modesty  
 Upsherin – Boy's first haircut at 3 yrs old (Y)  
 Vort (D'var Torah) – a short Torah oration (Y)  
 Yetzias Mitzrayim – Exodus from Egypt  
 Yidden – Jews (Y)  
 Yiddishkeit – Judaism (Y)  
 Yingel – little boy (Y)  
 Yisurim – suffering, punishment  
 Yomim Tovim – Jewish holidays  
 Zaid, Zayde – Grandfather (Y)  
 Z'man – time  
 Zoche – worthy, merit  
 Agunah – woman unable to remarry  
 Al pi haTorah – according to the Torah  
 Bais haK'varos --cemetery  
 Bochur – young man  
 Bracha – blessing  
 Chasunah – wedding  
 Chelek – portion  
 Cheshbon – calculation  
 Chinuch – education  
 Davka – specifically  
 Frum – religious (Y)  
 Gelilah – rolling up the Torah scroll

Guf naki – clean body  
 Halachic eidus – testimony according to Jewish law  
 Halachos – Torah laws  
 Hanhaga – a way of conducting oneself  
 Inyan – topic  
 Kedoshim – Holy ones  
 Klal – 1) general rule 2) entirety of the Jewish people  
 Maaminim b'nei maaminim – believers who are the sons of believers  
 Me'chalel Shabbos – desecrating Sabbath  
 Meisim – the dead  
 M'kabel – accept  
 Moreh ha'raah – guiding rabbi  
 Pasken – adjudicate  
 Posek – adjudicator  
 Possul – nullified/invalid  
 Pottur – exempt  
 Rebbetzin – Rabbi's wife (Y)  
 Rov – revered Rabbi  
 Shailah – question  
 Shaleim – complete  
 Shelichus – being sent, ie: to a remote city (usually to spread Jewish teachings)  
 Shimush – use of  
 Shmiras haMitzvos – Keeping the commandments  
 Simanim – signs  
 Simcha – joy, joyous event  
 Sugya – topic (A)  
 Tanach – the entire written Torah; acronym: Torah, Nevi'im, Kesuvim (Torah, Prophets, Writings)  
 Tefillin – phylacteries (a particular ritual prayer object)  
 Treife – not Kosher  
 Yeshuah – salvation  
 Yid – Jew (Y)  
 Yorshim – heirs  
 Zemiros – songs (usually referring to those sung at Shabbos meals)

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In the upcoming Tishrei issue we plan to print a section on the topic of “**Back to School**”. We are looking for your input to help cover this theme from all angles. Please submit your articles, stories, poems, thoughts, concerns and advice that may be of interest. Your anonymity will be protected if requested.



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

Deadline for submissions: **July 22**  
 Email: [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com)  
 Mail: 112 6th St. Lakewood, NJ 08701



*“The wings of transformation  
are born of patience and struggle”*

