



# נשמהלה Neshamale magazine

*Sharing Our Special Experiences: Chizuk & Inspiration*

**NEW COLUMN!**

**WALKING WITH NOACH / 14**

**EXPLORING:**  
**APPRECIATING THE**  
**VIEW OF THE VISUALLY**  
**IMPAIRED / 19**

**IN SESSION**  
**I DIDN'T BOND WITH**  
**MY BABY AT BIRTH / 16**

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In the upcoming Summer Issue we plan to focus on the topic of  
**Shabbos! Spending the holiest day of the week with our special  
neshamos can feel truly sublime or downright impossible! Please share  
your feelings, experiences, and tips!**

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

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Dear Readers,

When Avrumi was born, we had no idea that he was anything but a typical, healthy, normal baby. One of the first things I noticed and worried about was his vision. Even as a tiny newborn, I felt that something was off in the way his eyes moved. The eye doctor who tested him agreed, and diagnosed him with a list of visual problems. We were very concerned, and immediately did all we could to try to improve his eyesight. Many of these problems did improve with time, but we went on to discover delays and diagnoses that affected his life much more significantly than the original vision issues.

To this day, his teachers and therapists ask: “What’s the story with Avrumi’s vision? What can he see easily? What’s out of his range?” Understanding Avrumi’s visual abilities helps them set up the classroom, his iPad, and his activities appropriately. While it’s obvious that Avrumi can basically see, Baruch Hashem, it’s also clear that he has vision issues. Despite all of our efforts and consults with doctors and experts, we still don’t know what the world looks like through his eyes.

I think that this reality is a perfect parable for our son’s life—we can’t fully understand his perception of the world around him. As family members of those with special needs, it’s important for us to realize that, as much as we learn about our loved one’s challenges, we do not live with those challenges ourselves. Appreciating this truth can help us be more empathetic and tolerant.

I want to tell you about an experience I had with Avrumi that really helped me acquire this perspective. Feeding my special son has always been very tedious and frustrating. He is an extremely picky eater (about every detail: the texture, the temperature, the type of spoon, the person feeding him, etc.). He makes a huge mess out of even the simplest foods, and has a lot of trouble chewing and maneuvering food around in his mouth (Baruch Hashem, these issues have improved greatly over the past few years, and we continue in our efforts to help him progress until IY”H he will become a “natural” eater!).

About two years ago, I had a very frustrating, though not unusual, experience trying to feed Avrumi his breakfast. I prepared his oatmeal just the way he likes it, not too hot, not too cold, not too thick, and not too thin (If this sounds like Goldilocks, Avrumi does have gorgeous blond hair!). I woke up early enough to have him dressed and ready in his comfortable Rifton chair, with plenty of time to feed him calmly. But his behavior was anything but calm. Avrumi was acting agitated for no apparent reason, and stubbornly refused to open his mouth for a single bite.

At first I was patient and gave him some time, trying again every few minutes. But with the clock ticking toward our departure time, I started getting edgy and frustrated. I knew he didn’t eat well in school, and it was very important to me that he get in at least one decent meal at the beginning of his day. I felt he was being unreasonable, and could see no reason why he wouldn’t eat his simple bowl of oatmeal. I’m embarrassed to say that I lost my patience and tried to force-feed Avrumi. He started crying and trying to spit it out, which only made me more upset, as I obstinately continued spooning the stuff into his mouth. After a few difficult minutes, we were left with a hysterically crying little boy, covered in globs of oatmeal; one very frustrated mother, overcome with both anger and guilt; and half a bowl of uneaten oatmeal. I gave up, washed him down, and drove him to school.

I then went to work, still tense and upset. Needing to vent and garner some sympathy, I unloaded the whole episode onto my co-worker, Leah. As I came to the end of my tirade, the first words out of her mouth were: “Poor Avrumi! It must be really tough to have such a hard time doing something as simple as eating breakfast.”

Her comment stopped me in my tracks. My first reaction was: “What? Poor Avrumi? What about me?!” But I let her words sink in, and suddenly my whole perspective turned around. It was like I had been looking at the scene using a mirror, seeing only myself. Leah had lifted the backing and turned it into a window. Now I could see Avrumi, with his own frustrations from his sensory sensitivities and motor planning difficulties. I could sense his weariness with his inability to express his needs. I could appreciate the pain he must have felt when his mother force-fed him something that he really didn’t want to eat.

It wasn’t a pretty scene, but the perspective it gave me was life-changing. Since that memorable morning, I’ve tried really hard to see events from Avrumi’s perspective. When I find myself getting frustrated with his behaviors, I try to remember that this is not only about me, but also about him. When I take the time and effort to try to understand his feelings, sometimes I can actually figure out what is bothering him. And at other times, just knowing that I have never seen the situation through his eyes, is enough to help me stay calm and caring.

Here’s hoping that we can all learn to look into our special children’s windows, and envelop them with love and understanding.

*Chayala*



# From the Doctor's Desk

## | *Some Visual Background*

Yehudis Blavin, PA-C

### **Q: Who are the different specialists involved in eye care?**

An **ophthalmologist** is a doctor (MD or DO) who went through medical school and then did a residency in ophthalmology, specializing in eye care and ocular disease. An ophthalmologist can diagnose and treat complex eye problems, prescribe glasses or contacts, and perform surgical procedures on the eye.

An **optometrist** is a doctor of optometry (OD) and is also titled “doctor.” An optometrist trains in a four-year post-bachelor optometry school. Optometrists can diagnose and treat eye disorders and prescribe glasses or contact lenses. Some optometrists undergo a subsequent fellowship to obtain additional training in a specific area of eye care.

An **optician** specializes in making and fitting glasses and contact lenses.

An **orthoptist** diagnoses and treats alignment disorders and problems with eye movement or binocular vision (how the eyes work together). They primarily work with patients who have strabismus (crossed eyes), amblyopia (lazy eye), or accommodative dysfunction (difficulty with visual focusing). They may use eye exercises, prisms, or patches to strengthen eye muscles and help patients use both eyes together effectively.

### **Q: What is vision therapy and why is it a debated subject?**

Vision therapy builds on orthoptics to treat a variety of visual or behavioral issues. Vision therapy is usually done by a developmental or behavioral optometrist who trained in vision therapy after completing optometry school. The developmental optometrist creates an individualized treatment plan for each patient, although the actual vision therapy may be carried out by other (non-optometrist) staff members.

Like traditional orthoptics, vision therapy uses eye exercises and specialized equipment, including prisms, lenses, filters, occluders, and sometimes computer-based programs, to strengthen eye muscles and improve visual focus. Vision therapy is generally accepted as a treatment for binocular vision disorders that affect the way the two eyes work together. These include strabismus, amblyopia, and accommodative disorders, including issues with focusing or tracking. Vision therapy can also be helpful for improving hand-eye coordination, depth perception, and visual processing.

Vision therapy becomes more controversial when it is used for learning-related or behavioral purposes. Vision therapy is frequently suggested for poor reading, spelling, or handwriting skills, for example writing letters backward or mixing up similar letters, such as p, b and d. It is also considered for behavioral difficulties such as hyperactivity or difficulty maintaining attention. The thought is that an affected child may have an undiagnosed underlying vision problem that affects his learning or behavior. Via vision therapy, the child can develop better eye coordination and is then better able to process visual information. Over time, the brain-vision system can learn new patterns and decrease the learning or behavioral challenges.

The American Academy of Ophthalmology and the American Academy of Pediatrics both denounce vision therapy as “scientifically unsupported.” Their position is that scientific studies on the effects of vision therapy do not show enough benefit to support its use for behavioral or learning issues. Their main concern is that investing time and money into vision therapy wastes resources and delays proper intervention, which can lead to even further learning delays for affected children. They are also concerned that people will consider



vision therapy as an alternative to glasses or eye surgery that may be necessary to properly treat a patient's visual issue.

Like many things in life, balance is key. We need not set our eyes (no pun intended!) on one treatment modality to the exclusion of all others. Parents who want to pursue vision therapy for their child should do their homework first. Make sure the person administering the therapy is qualified and properly trained. Consult with a trusted ophthalmologist or optometrist (preferably one who does not do vision therapy himself and therefore is less biased) to see if s/he thinks vision therapy would be a worthwhile investment for the particular situation. Decide how long the vision therapy trial should be and what specific goals treatment should address. If vision therapy does not prove effective after the specified amount of time, a more traditional intervention approach can be considered for treatment.

*Yehudis Blavin is a Physician Assistant who specializes in internal medicine and surgery.*

*Please note: The Information expressed in this column is for educational purposes-only and should not substitute for the advice of your personal medical professional.*

**Do you have a medical question that you would like answered? Send in your question to Neshamale and we may feature it in a future article.**



## Chizuk Boost #6

Rabbi Baruch Rabinowitz

### Sipur Yetzias Mitzrayim

On *Seder* night, we gather around the table with our families and we're *m'kayem* the *mitzvah* of *Sipur Yetzias Mitzrayim*, telling over the story of the Exodus from Egypt. We impart to our children the foundations of *emunah*, of *hashgacha pratis*, of *neis* and *teva*. We even use props – *matzah* and *marror* and the *k'arah* – to make it tactile and visual, so that we can properly provide a special experience for each of our children, at his level.

Indeed, we are told to tell the story to our children in full detail. The more we speak about it, the more praiseworthy we are. Reading the *Haggadah* with all its many details of our history bolsters our *emunah*, our absolute faith that everything that happens to us is exactly what is supposed to happen. *Bitachon*, our sense of security and trust in the *Ribono shel Olam*, is built on *Seder* night.

As we speak at great length about everything Hashem did for *Klal Yisroel*, we recognize that He is there for us all the time, in each event, and in each *Makkah* (plague), as well. Everything we went through – to bring us to *Mitzrayim*, through *Mitzrayim*, and out of *Mitzrayim* – was orchestrated by the *Ribono shel Olam*. Each part of the story was part of His *cheshbon*; it had a purpose, a rhyme, a reason.

When we hold up the *matzah* at the beginning of the *seder*, we recognize its symbolism as both *lechem oni* (the bread of affliction), that we ate as slaves, and as the *matzah* of freedom. We split and hide half of the *matzah* during *Yachatz*, but we say the whole *Hagaddah* in all its detail on that first smaller half of *matzah*. We recount our entire story to build up our *bitachon*, our knowledge that *Hakadosh Boruch Hu* is taking care of us all the way through.

And the bigger half of *matzah* that's *tzafun*, hidden away? That *matzah* is the *afikoman*. It represents the future *Geulah*, the bigger things that will ultimately be revealed. We hide and search for that piece of *matzah*, knowing full well that we *will* find it. We have *bitachon* that all that is hidden will be revealed in the future.

כנגד ארבע בנים דברה תורה (The Torah speaks of Four Sons). Yes, the *Ribono shel Olam* says, you may wish you had only *בנים חכמים* (wise sons) around your table. But some of Hashem's children are *chachamim*, wise, and some are *tam*, simple, and some are *she'aino yodea l'shol*, who don't know how to ask. Some of them have more that is hidden – *tzafun* – than is revealed; some of them... maybe you don't understand why Hashem created them or gave them to you. But they are all *Hakadosh Boruch Hu's* children and He put them around your *Seder* table. On the night of the *Seder* we sit with *all* of our children, and develop that sense of *bitachon* that there is a purpose to all of this.

May we be *zoche* this *Pesach* to appreciate all that is "*tzafun*" and to *daven* to the *Ribono shel Olam* that He should reveal the meaning behind all that is hidden in our lives so that we can sing *Hallel Shalem* – ונאמר לפניו שירה חדשה הללוקה – (We will say before Him a new song, Halleluka!).

*This Chizuk Boost is excerpted and adapted from one of Rabbi Baruch Rabinowitz's weekly 10 minute Chizuk shiurim for parents of children with special needs. There are now over 130 recordings, which can be accessed on Kol HaLashon (718-906-6400, press 1, 4, 97, 2).*



# Pokeiach Ivrim: *Revealing the World to My Vision Impaired Child*

L.B. Kohn

I often wondered why the *bracha* that thanks Hashem for our vision uses the word *pokeiach*. Isn't a *pikeiach* a wise person? Why don't we say "*poseyach einayim*?" Why aren't we just thanking Hashem that we have eyes? What does wisdom, or brains, have to do with it? As we learn from our son, we realize that *Chazal* knew just what we should say.

Pesach of 2008 was like any other. We traveled to our parents, split *sedarim* and *Chol haMoed* trips, and enjoyed time with our children, aged three months to six. Returning home, my husband went to his new job (he had just begun working), I went to my teaching job out of Lakewood, and my kids went to their respective *morahs*.

About a week after Pesach, I was driving home from school after lunch. I generally did not have a phone, but my brother had recently upgraded and given me his old one, so I was now the proud owner of a black flip phone with basic texting.

And that phone was ringing. It was my infant's babysitter.

"Mrs. Kohn? Your baby wasn't breathing. But I did CPR. And I called 911."

It was too much for me to take in all at once. I didn't absorb much of what she said, except that she had called 911.

I gave her the number to Hatzalah and told her to call them. I didn't take it that seriously – babies stop breathing for a moment or two here or there. But I had just received a brochure from *Kupat Ha'ir*, so I pledged some money for my son's safety.

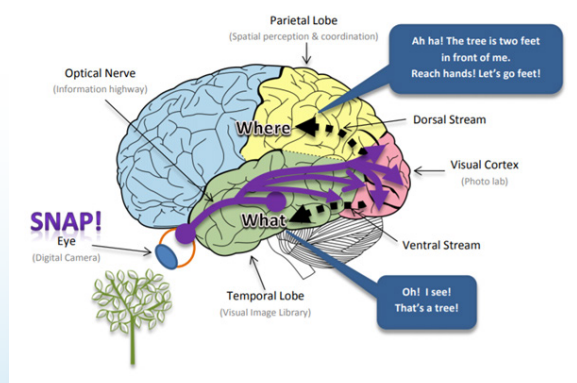
I called her back, to be sure Hatzalah was coming, and asked for the full story as I drove. She sounded quite rattled.

"He was sleeping – on his back – in the crib upstairs. I didn't hear him crying for his bottle, so I went upstairs to check on him. He was BLUE – totally blue! Not breathing! I had just taken a CPR course, so I ran downstairs and got the instruction book. I put your baby on the floor, opened the book, and did exactly what it said. And he started breathing! But I don't know...."

I pledged a lot more money to *Kupat Ha'ir*, and raced home as fast as I could.

I feel like I've been racing ever since. But I have yet to win the race.

The lack of oxygen left Elazar with a brain injury, epilepsy, word recall issues, and predominantly CVI (Cortical Visual Impairment). Despite its last letter (I), CVI has nothing to do with the actual eye. It is the brain's inability to recognize the visual signals received. When our eyes take in a scene, the signals travel through our right and left eyes to the optic nerve, the highway that carries visual information. The signals cross pathways along the optic tracts, and then travel through the brain to the Visual Cortex ("photo lab") at the back of the brain.





What this means is that an awful lot of real estate in the brain is involved in seeing. In fact, 60% of the brain is visual, and helps us to understand all our other senses.<sup>1</sup>

You touch something? Your brain visualizes what you are feeling. You hear rumbling in the sky? Your mind displays the image of an airplane. It smells like pizza? The vision center in your brain conjectures an image related to that smell, maybe the slice, or the brick oven. You taste something sweet? Try it – your vision center is humming along with your taste buds.

Imagine if that visual highway was closed for construction. Or closed forever. How could you possibly acquire the information you need to understand the world?

To compound matters, the physical eye works. It's still sending signals to the brain. But because the highway is full of roadblocks, only parts of the signal reach the processing area and the brain reaches funny conclusions. So the person *thinks* he sees, but doesn't realize how many incorrect or missing pieces there are in the scene. The way people describe it is like looking into a kaleidoscope: You can see everything in there. But nothing has any meaning to you – you can't identify it. The only "shapes" in the kaleidoscope that you notice are shapes you've been taught to identify manually (ie: that rounded red thing with a small stem is an apple), and then *those familiar objects may be the only things you see in any scene you experience*. You would miss a lot of information in life.



And adult with CVI wrote: "This sums up how I see when I'm in a new place"

We didn't understand all of this right away. It's been, and still is, a life-long learning process. To complicate matters, at nine months, Elazar started having occasional seizures that were quite frightening, and sometimes required hospital stays, oxygen, or even intubation. The fuzzy knowledge that he had some vision processing problem moved to our back burner.

By the time Elazar was two, the problem had moved to the front. He was speaking – but only in verbs (run, eat, more...). He couldn't name anything in the room. We started tracking and charting the things that didn't make sense: He could see food, but when the color matched his high chair tray, he couldn't find it. He threw his brother's *yarmulkas* off their heads (and

<sup>1</sup> EllenMazel, Lofti Merabet 2018

to this day can't stand anything on people's heads, including babies with hairbands). He liked therapy, but if they took out flashcards he crumpled them and threw them away. He was happy to listen to stories, but wouldn't look into a book.

We took our chart to a Neuro Ophthalmologist in CHOP who read it, looked at our child for a second, and said: "Visual Agnosia. Prosopagnosia. Cortical vision."

Sure thing!

He gave us a brief explanation of the concept – the eye sees, but the brain doesn't understand. He told us he has rarely seen such a high functioning child with this condition, and could he study our child to write a paper? And then: "There is no therapy for this condition. Therapists don't understand it. Educators don't understand it. Just take him home and treat him like a blind child."

My husband and I looked at him incredulously.

"Sir, we don't believe in just throwing in the towel. Therapists don't get it? We'll teach them. Teachers don't get it? We'll train them. We will NOT just treat him like a blind child, we will do whatever we can to help him utilize whatever vision he has."

And so began the hard work...

To go through all the modifications we've made to make Elazar's life functional would take more than a book (which is why I haven't written one yet!), but since I'm well aware that CVI is growing more rampant by the year (as more and more brain injured children survive), I will highlight some of the important discoveries and changes we've made over the years.

## FLASHCARDS

When Elazar was about 4, and still refusing to look at books or anything 2D, we realized that he just couldn't identify the images as real-life things. Late one night, in a fit of frustration (or *siyata di'Shmaya*?) I ran around the house collecting objects that were familiar to him: sippy cup, bottle, fork, spoon, plate, soda bottle, tissue box, shirt, pants, etc. I photographed each one on a clear background (which I later learned should have been black). Then I developed 2 of each photo in large size, and laminated them with hard laminate (less glare, more durable).

I placed his real sippy cup and the photo in front of him and showed him. "Look – cuppy, cuppy!" We did this a few times with a few objects until suddenly I saw his eyes light up – he *chapped!* These pictures represented real things! He *knew* those things!





## INSPIRING

At that point, it became a game.

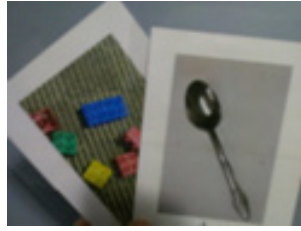
Level 1: Match the photo to the real object.

Level 2: Match the photo to its identical partner (remember, I'd made two).

Level 3: I say the name of an object, you find the photo.

We played for hours.

What I learned years later is that we had loosely accomplished the basic levels of CVI visual learning: A. Discriminate (This object is not that object), B. Recognize (You tell me its name, I now can find it), C. Identify (On my own, I see something and know its name).



### PARSHA PLAY

Before Elazar graduated Early Intervention, we knew that he would not be in a regular *yeshiva* that teaches Judaic studies, and that hurt. How could we instill in our child the lessons that every little Jewish kid knows?

Hashem sent us an incredible *chesed* that we hadn't anticipated, and it set the tone for years of productive learning.

A former student of mine, just home from seminary, was complaining to me that she was bored in the evenings and looking for a *chesed* job. Somehow it popped into my head to ask if she would come play *Parsha* with my two year old Elazar. He couldn't look at books, didn't understand pictures, and had no use for crayons and markers. Our idea was to play out the story of each *parsha* using *mentchies* and props.

She loved the idea.

And so, this 19 year old with no special ed training spent two years coming, week after week, to sit on the floor with my son and play the *parsha*. It worked wonders! He really got the story, and loved the experience! And the helper, thrilled with her own success, branched out during the *Vayikra* weeks and began teaching him *Brachos* and other major *yedios*.

### KRIAH

Kriah was a very hard goal, one we were told may never happen, especially in two languages! I started with textured letters: using Velcro and felt, I cut out three letters and glued them on a black background, highlighting the letter shape in yellow highlighter.

It was a very slow process. He just didn't get it.

Fast forward a few months, when relatives of ours won an iPad in a Chinese auction and gifted it to our son. We added a simple Israeli app that involved tracing each letter with his finger, and the program then announced the letter and its sound.

Bingo! In two months, Elazar had mastered the *Alef Bais*. (*Kriah* is a different story, not for the scope of this article. But if anyone needs to teach a CVI child to read Hebrew, you are welcome to contact me through this publication; I'm happy to walk you through our journey and tell you what did and didn't work).

We also learned from this that the iPad is a very valuable learning resource for kids with CVI. The backlighting, dimension, and movement it offers, combined with the incredible amount of repetition available (the iPad has way more patience than we do!) trained his brain to see and identify many things.

### EXPERIENCE STORIES

We realized that Elazar has very limited visual memory. This means that whatever he experiences teaches him very little, since he hardly retains any memory of the experience. Think about it. You come back from a fantastic *Misameach* trip to Nickolodeon Amusement Park, and someone asks you: "How was it?"

Immediately, your visual brain brings up image after image: the bright green "moving slime" on the screen outside the park, blue T-shirts labeled *Misameach*, tables laden with soda cans of every color, endless pans of food, a giant green track that sends a cart roaring over your head every few minutes, etc.

He gets none of that. It just doesn't store. So his memory may look like this: Flashing green. Lots of confusing noise. The taste of bubbly Coke. The whoosh of the escalator going down. A pounding heart every time there's a roar. Uncle Moishy's voice. And a hodgepodge of color crowding his brainview, although it's hard to recall just which colors.

Building on the success of the *parsha* games, our initial solution to this problem was the Story Creator App.

It was a very simple app on Elazar's iPad that enabled us to create a storybook of a recent experience (*Yom Tov*, a trip, a hospital stay, etc.) – and eventually we used it for upcoming experiences as well. We used our own photos for the pages of the books, and recorded audio on each page. He loved reading the stories and remembering the fun times we'd had.

He did NOT love looking at unfamiliar stories of upcoming



events, that to him just looked like more noise, confusion, and blur.

If you peered into my playroom window at midnight one September, you'd see me alone in the room building with Magnatiles. Oh! Is that what Mommies do when they're bored?

I wish! I'm never bored.

I was building a *shul* that looked just like ours. With men's and ladies' sections, an *Aron Kodesh*, two *sifrei Torah* (rolled up tissues), tables, *shtenders*, *bimah*, and lots of men, women, and children. Then, all by myself, I played out the *hakafos* and *aliyos* of *Simchas Torah*, and snapped pictures of the whole story. The next day, together with my children, we recorded what it would sound like.

And Elazar absolutely refused to look at it.

Until *Isru Chag*. At that point, having already experienced *Simchas Torah*, he delighted in watching it over and over—and the next *Simchas Torah* he did much better!

The Story Creator app served as our initial platform for any message we wanted to teach him. We started recording ourselves reading books to him, snapping photos of the pages, and moved on to social stories and *midos* messages. We even have a story called "How to make Playdough" and another about making cholent. These were recorded by Elazar and his siblings together, a really fun activity!

The problem was, as Elazar got a bit more confident with the iPad, he began editing my stories. The app was very basic and we couldn't lock in our final version. It was time for a more sophisticated platform.

### POWER POINT SEFORIM

As Elazar began recognizing Hebrew letters and *nekudos* (although not together), we really wanted to include typed Hebrew words and *shoroshim* in his stories, but Story Creator was too simple. I tried a few more storybook apps but they didn't have what we needed. Finally, we veered away from Apple and recorded a long *Megillas Esther* show in Power Point. Elazar himself did a lot of the recording with me, as we acted out the story with *mentchies* and accessories, snapping pictures while we played.

It was a great success! In fact, Elazar still watches that show every year as Adar approaches. And we now had a new tool. But

we needed a computer for him to use that wasn't the family's.

At this point, we bought a small Acer tablet (like an iPad but with Windows). It became his *SEFER*. The world was now open to us, as we began experimenting with Power Point.

We now had the ability to tailor the view more appropriately to CVI: black background, spaces between letters, moving images and effects, and background music or vocals in just the right timing.

It also allowed us to insert small video clips that enhanced the presentation.

And, best of all, *he couldn't edit my shows*, as I transferred them to his tablet only in "finished" mode, so they played automatically without stopping.

Before moving on, I want to explain that the iPad and tablet were just about Elazar's only window to the world. People with CVI find new experiences, faces, and places terrifying and dizzying. My son is happiest to stay at home, watch the same video over and over, listening to the same story repeated, and playing with one or two toys forever. He hates guests, often yelling at "intruders" to leave our house (especially if they are there to play with his siblings), although he's fine with respite volunteers there to entertain HIM. He detests going anywhere, complaining that it makes him dizzy or sick, and will at times throw a royal tantrum when he is compelled to join a trip (such as the family leaving town together, or a *Chol haMoed* outing). Most of our family's daily schedule revolves around Elazar's preferences and needs, and his siblings have all learned to be *mevater* to him by the time they were two years old.

With this severe dearth of life experience, Elazar really has no clue how the world functions outside of his house and classrooms. The videos and shows we created for him are often the only way we can teach him anything.

*(For those in similar situations, the old collection of Mr. Rogers videos is uncomplicated, clearly explained, and contain a treasure trove of informational tours geared to preschoolers, such as "How Crayons are Made," "What Happens in the Post Office," "Learning to Play a Musical Instrument," "Saying I'm Sorry," and many, many more. Getting my son to watch a new series is a business in and of itself – we have siblings watch it casually nearby his own familiar video, and talk about it until he slowly absorbs and agrees to watch the new series. This can take weeks!)*

Once he accepted the *Megillas Esther* show (after *Purim*, of course!), we were on a roll. *Gemara* stories like *Nachum Ish Gamzu* and Rabbi Akiva were next in line. Finally, we decided it was time for Elazar to have his own *siddur*.





This was quite a project. *Baruch Hashem*, Rabbi Nachum Lehmann of CSB Cares in Brooklyn was able to supply the complete text of *Tefillas Shacharis* with *nekudos*. Our job was to modify it so Elazar could read it; hence, *The Talking Siddur*. The CSB team designed a specific highlight color that was very attractive to my son. Our initial Power Point *Siddur* was set up so that whichever line he touched would be highlighted with his purple glow, as the narration played for that line (narrated by my older son, or Elazar himself when he was willing).

He was still young, so this *siddur* consisted of *Birchas haTorah* and *Birchos haShachar*. But Elazar was so proud to take his *siddur* to school and play it out loud as his self-contained class *davened*. We also printed and bound a large, cardstock hardcopy of the *siddur* to be used on Shabbos, even though he really couldn't read it too well.

### EDUCATIONAL CARD GAMES

Elazar's first grade Rebbi ((he was in a special education school but went to a self-contained cheder every morning for two hours) introduced the boys to the *Shoroshim* Pack – numerous sets of flash cards with pictures depicting each *shoresh*. Of course, these were not designed for the Visually Impaired – they were black and white with the *shoresh* printed in crude outlined letters. But our motto is to try working with whatever we can.

The family had fun coloring in three copies of each *shoresh* card printed in 4x6 size. We then printed the actual 3-letter word in Elazar's preferred colors and fonts on a black background and taped it over the *shoresh* on the card. We now had a game – “Go Fish!” – except that it was “Go *Shoresh*!” By the end of the year, Elazar knew and recognized about 100 *shoroshim* with their meanings.



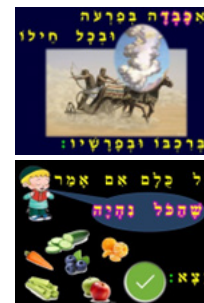
### CHUMASH, MISHNAYOS

As Elazar grew older and left the in-district Special Ed system, he started learning *Chumash* and *Mishnayos* in a self-contained class. The boys all had *seforim*—what could Elazar use?

We tried and tried explaining to various 1:1 aids how to create

CVI friendly *seforim* in Power Point, but they just weren't coming out right. The developer had to be able to “see with a CVI view” to understand how to set up each page. The school didn't know anyone who could “see” like that, other than Elazar's own parents. And thus, I got a new job. The school appointed me to create Elazar's *seforim*, which were then transferred by USB to the *Rebbi's* extra-large screen for the whole class to enjoy.

It was a win-win situation. Elazar was so super proud that his mother designed these shows, that he became one of the best participants in *Chumash* and *Mishnayos* classes. And we no longer faced the immense frustration of seeing ineffective modifications; his new programs were laid out the way he needed, had sound, and contained many motion effects to help him see.



### ENGLISH READING PROGRAM

Teaching a CVI child to read English actually has a documented method, developed about 15 years ago by Dr. Christine Roman-Lantzy. The basic gist of it is to teach every word as a single unit (sight words), since the child with CVI has a hard time identifying multiple letters together. The designer outlines each word closely to depict the shape in a bright color. Then the child is shown the outlined word, together with an identical outline *missing the letters inside*. They eventually learn to “read” the shape of the word. This takes years, but it actually does work.



### PLOTAGON

Around 5 years ago I was on *Zoom* with a man in England who develops digital Judaic learning programs, and he introduced me to the Plotagon program. This app enables the user to create a real animated video using pre-designed 3D backgrounds and characters. It gives the choice of using digital voices to read the user's script, or recording people's own voices.

This was a gold mine for us, as the Power Points were very time-consuming to design. These videos (if not requiring moving text on the screen), were far easier to design and looked more interesting to the viewer. For a long time, we had been pining to teach Elazar *Shemoneh Esrei*, but even with *kriah* skills, a person with CVI hardly ever reads fluently for content. Reading takes so long; it's used more for reference, or identifying objects. *Shemoneh Esrei* has too many words for him to hope to read without tiring.



And so began The Project.

We started with an introduction and the first *bracha*. We created two little characters that played out a skit before each *bracha* that explained the contents of the *tefilla* in English. This was followed by a character dressed like my son who stood at a tree and *shuckled* while the recorded voice *davened Shmoneh Esrei* in the same *nigun* used in *shul* for *Chazoras haShatz*. We knew that with a tune, Elazar was far more likely to be able to memorize the *tefilla*.

It was slow going, but the kids were all involved and excited. Slowly, we made our way through most of the *brachos* until *Shema Koleinu*. And then life happened, and The Project sort of sat on the back burner.

Then COVID arrived. My husband and I were among the first hit, and we were relatively pretty sick. He was in bed with double pneumonia and I was breathless with an endless bronchitis and many other lovely side effects of COVID 19. We needed a *zechus*. At some point during another sleepless, breathless night, I pledged to finish the *Shemoneh Esrei* video by the end of *Pesach*. How? I had no clue. But it just had to happen.

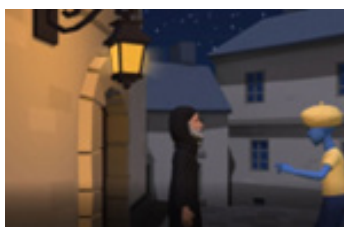
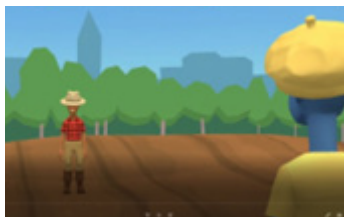
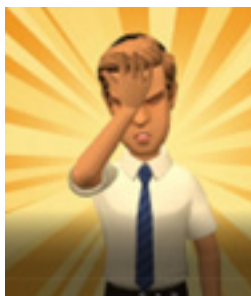
And it did.

With tremendous *Siyata diShmaya* and many airless moments at the computer, the entire *Shemoneh Esrei*, divided into five short videos, was complete by the end of *Chol haMoed*. And our son pretty much learned *Shemoneh Esrei* by heart.

### GOING FORWARD

Don't think for a moment that thus ended the *nisyonos* of having a brain-injured child. As the teenage years set in, our son's rigidity increased, and attending an underfunded, understaffed school didn't help. If he was too difficult for the *Rebbi*, he was sent to "chill" with his aide. While she did teach him a lot, he also learned that he is not part of "the system," and that rules don't really apply to him. Together with a frontal brain injury that makes it nearly impossible for him to tolerate discomfort or notice other people's needs, Elazar's autistic behaviors began increasing until he could no longer handle school (and it was mutual).

So, while we are the happy owners of numerous videos of *Tefillos* and *Yomim Tovim*, *Shoroshim* and *Yedios Klalios* cards, printed



and animated *Siddurim*, and more, we are also the loving hosts of a teenage boy who's been out of school for almost a year. He is quite happy staying home all day doing very little with the in-house ABA's available, but it doesn't do much for his long-term ability to function in society.

Although we certainly wish he were in school, that's not to say he isn't growing. We're loosely working on family goals which we couldn't do while Elazar was under the stress of attending schools—things like time limits on screentime, helping at home a bit, taking care of the baby (he's so gentle with her!), sharing, *davening*, *bentching*, getting dressed every day regardless of schedule, and expanding his horizons by going further than the front door. We recently took the whole family, including Elazar, on a real vacation for the first time ever (for all of 2.5 days)! We rented a private house with a pool and other amenities, even ordering all our groceries in, so that we wouldn't have to leave the house. But he did it! And we are so proud!

As our journey continues, we try to take one day at a time and focus on the positive. Despite the challenges, with Hashem's help, we will continue to celebrate the victories and appreciate our special son Elazar and all that he has to offer.

*Author's note: Aside from the programs and modifications we make on our own, it's imperative for the parents of a CVI child to educate every teacher, therapist, and shadow, because CVI affects every discipline. For example, a Speech therapist wanted to work with Social Stories – but he can't see stick figures that she draws in a rush, so we asked her to use mentchies. She wanted to use flash cards – he can't understand the images. So we had to find a work-around. The OT was working on holding a fork – but he kept missing the food because he couldn't SEE it! She should have put the food on a solid color plate that would make the food show up clearly. A teacher showed up in a different sheitel one day and he couldn't look at her or talk to her all day. And so on. It's critical for the parent to have a solid understanding of CVI and how it affects every part of the child's day (read Dr. Roman's revised book on CVI), and know how to guide and troubleshoot with the entire team (very diplomatically, of course!) in order for the child to succeed.*

*The author is writing under a pen name. She would be happy to share her educational materials and help anyone dealing with CVI and can be contacted through Neshamale magazine.*





## Quality ABA:

What It Means to Your Child

Sara Miriam Pitterman

*ABA, or Applied Behavior Analysis, is a mode of therapy used for clients with Autism. This column will explain ABA by providing a sample session to illustrate how the therapy is used.*

### Sample Session #4: A focus on functional living skills, leisure skills, and communication skills in the natural environment.

*Dear Reader,*

*When Neshamale magazine asked me to feature Binyomin's profile, I knew I was in for a challenge. I wished I could wave a magic wand and solve all the struggles, but the road is a long one, filled with love, laughter, and elbow grease. I have tried to portray the immediate session, together with longer-term goals and what ABA would offer him. I hope you learn something new.*

### Meet Binyomin:

Binyomin is an 8 year old, super-active, gorgeous boy who is non-verbal. Binyomin gets frustrated easily, which leads to mild aggressive behaviors toward whomever is closest to him. Although he generally does not actually hurt anyone, it is scary for those around him. He often plays with water in the sink, and seeks out items to chew, such as the straps of his knapsack. Binyomin has limited leisure activities and has a hard time occupying himself, although he can be structured and can complete simple tasks.

To properly address Binyomin's needs, the following concepts would be included in Binyomin's programming: communication, sensory needs/active movement throughout the day, aggression behavior plan, leisure skills, long stretches of productive stimulating activities, functional life skills, religious/cultural goals that are important to his family, engagement and connection.

The session highlighted today is a 3-5pm session in the home setting. Binyomin comes home from a full school day, so we assume that he has had OT/PT and/or gym/outdoor play, as well as language and academic programming. Our session will focus on functional living skills, leisure skills, and communication skills.

### Toby Diskin, ABA Therapist

Working with Binyomin is challenging, yet rewarding. What's really nice about his program is that, because the session is at home, we work on his skills in the place in which they happen. This makes it much more likely to see carryover. Although progress is slow, it's so meaningful to Binyomin and his family. It's also a balance to work in someone else's home. I never want to step on anyone's toes or interfere with the family dynamics, but I also need to be around to accomplish what we are aiming to do. I only work on Tuesdays and Thursdays, with another therapist coming Mondays and Wednesdays, so I come to every session fresh and energetic. This is important, because burnout rates are high when working with kids like Binyomin.

## GOALS

### Aggression Behavior Plan:

Binyomin's aggressive behavior is rooted in poor frustration tolerance ("automatically reinforcing" in ABA terminology). He must build the ability to:

- Ask for help
- Accept a "no,"
- Wait and self-soothe

We set up many visual reminders around the house, such as help signs on the freezer door, the door to the backyard, and the snack bag box.

The plan is to look for specific triggers and preempt the aggression with a request for help.

(If mom feels it's important for the siblings to see a response to the aggression, a brief "safe hands" time-out might be used. However, if his frustration tolerance is not built up, the time-out is unlikely to be effective, or the aggression will just be replaced by something else.)

Self-soothing: With insight from Binyomin's OT, we have determined that teaching him to give himself a hug would be a good alternative sensory input to help redirect his aggression.

This is being practiced directly, teaching him to squeeze himself when told: "Give yourself a hug." Once it's a more automatic reaction, we will start using it when we anticipate aggression.

## INSIGHTS

## GOALS

## INSIGHTS

### Preparing a snack using a visual schedule:

- Cheese and crackers, yogurt and cereal, or fruit smoothie.
- Asking for items he can't find using a PECS communication book. We stage some missing items to encourage communication practice.
- Expanding communication by using adjectives
- As Binyomin has mastered asking for basic desired items, we are now working on adjectives. When asking for cheese, we will offer sliced cheese or grated cheese, teaching Binyomin to request more specific items.

Each step towards using a visual schedule had to be taught individually, such as finding items based on a picture 'shopping list.' We are now putting it together into a sequence of activities.

PECS (Picture Exchange Communication System) uses specific pictures to teach children how to communicate. Learners must select the correct picture, approach an adult, and make a request. This method of communication differs from a device used by some learners, who keep pushing the desired picture, even if no one is around.

### Leisure Goal: Expanding interests

- Sticker books: matching stickers to outlines/black and white pictures
- Duplo imitation: following a block design on a picture

**Asking for help:** This major goal runs throughout Binyomin's session. As Binyomin often engages in aggression towards others when frustrated, teaching him to ask for help is imperative.

These goals are to increase the number of activities Binyomin can do independently. Sticker books are very mobile, so they can come along to doctor appointments for use in waiting rooms. The plan with the Duplo is to transfer to smaller Legos once Binyomin's skills improve. Lego has endless variety and has a long age appropriate time span

**Asking for help:** The therapist must be extremely attentive, catch Binyomin as soon as he shows the slightest bit of frustration, and direct him to use the large HELP symbol on his PECS book.

### Social connection with therapist and siblings.

Toby uses this time to connect with Binyomin in a low-pressure manner. She uses Binyomin's interests, and works to integrate herself with them. If any of Binyomin's sibling are available, they join as well.

During this 15+ minute unstructured time, Binyomin leads the way. It's a chance for the therapist to connect, and a chance for Binyomin to relax. He often engages in much more of self-stimulating behavior (such as chewing on Velcro and hand washing), but also enjoys music and dancing.

### Leisure goals: expanding time and moving from one activity to the next.

- Stringing beads, simple block imitation, color by number, matching items, etc.
- Binyomin has a picture schedule on a clipboard, with an envelope on the bottom for finished activities. He also has a set of 3 drawers which include all necessary materials.

**The aim is to complete 6 consecutive activities, with a goal of 15 minutes of self-entertainment. In order for this to be successful, Binyomin must learn to follow all instructions from the picture schedule; otherwise he will always need a prompter. The last picture is access to a music mat, which is extremely reinforcing. To obtain it, he needs to bring the picture to his mother.**

Over the last few years, Binyomin has learned many simple tasks in school. Unfortunately, his attention and motivation are fleeting. This results in his mother having to constantly structure him if he is to engage in any functional activities.

During this time the therapist acts as a physical prompter only. If Binyomin goes off task, she hand-over-hand prompts him back to the correct step.

In order to ensure this skill can be done when the therapist is not there we designed from the start to have Mom play in integral role. Eventually, we'd like Binyomin to do this on his own whenever his mother gives him the clipboard. This way, she can have a few minutes to prepare supper, help his siblings with homework, etc.

As Binyomin improves, we will need to program in for his frustrations, using a HELP picture when there are struggles.

### Family participation/setting the table:


This is another visual schedule activity. In the kitchen, Binyomin sets the table for dinner. He must follow the visuals that indicate what is needed that night (ie: bowls, spoons).

It's important for the child who struggles to be able to be a giver in some way, if he is capable. Once a week we have Binyomin put something sweet at everyone's seat, such as a chocolate for dessert. This is especially important for younger siblings, to be able to see Binyomin as the conduit of positivity.

Binyomin's goals are designed for a home session, so they don't include much "table time"/ direct teaching of new skills. If properly followed, they can effect real change, and can be much more than just respite support. It's important for parents to be involved in the planning and decision-making, since they are the ones to best prioritize what means the most to their family unit and its functioning.

*Sara Miriam Pitterman is a BCBA, working in Lakewood, NJ for Brainbuilders LLC, an insurance-based ABA company. You can contact her at: [smpitterman@brainbuildersnj.org](mailto:smpitterman@brainbuildersnj.org)*





# Walking with Noach

## Walking to School

Chaya Shain

I would like to invite you, Dear Readers, to come along on a walk with me in my neighborhood of Lakewood, New Jersey, accompanied by my bright, charming, special son, Noach. You may observe his excitement when he passes certain people and tries to touch them, uninhibited and delightedly trying to connect with them. You may listen as he talks to me about the people occupying his thoughts, and the houses and rooms in certain people's houses that he craves to visit. You may watch as he rubs my hands and makes his special "Noach noises." You will certainly notice how different he is.

My Noach was always special. He was the cutest, happiest baby who seemed to be typically developing. At about 18 months old, we started noticing atypical behaviors such as sitting down on the sidewalk and rocking back and forth, excessive rocking while standing and holding on to his crib bar (for two hours straight), and obsessions with different objects, such as empty milk bottles. We were concerned about his language development and response. The doctor tried reassuring us that all this was within the normal range of behaviors. After all, he had good eye contact. With his adorable dark curls and deep brown eyes, he was the picture of sweet innocence, and you would melt looking at him.

"Test his hearing," we were told. The results were inconclusive of course, due to his behavior. Early Intervention eventually came up after we were away for the summer, trying to keep track of Noach, who could easily run away, seemingly to the end of the earth. We had another baby and kept on trucking. Noach's services morphed into twenty hours a week. We arrived at a diagnosis of ASD, and kept it under wraps. We felt Hashem leading us along what became a very intense journey, filled with tremendous *siyatta dishmaya* and many wonderful *shiluchim*.

So here I am today, walking my post-Bar Mitzvah son to school. Today I can say that I am proud of the treasure at my side. I am proud of this precious boy and the mountains he has climbed. I am proud of his sense of purpose, of his acceptance of himself. I am proud that he knows where he is going, and that he embraces each day, and his life as a whole.

I try to teach him and direct him as to what is appropriate and

what is not, so that he has the best chances of advancement in his social life. But regardless, I love him fiercely and truly accept him for who he is – and he knows it.

After a few minutes, we come to the edge of my neighborhood and face a road that has become a thoroughfare of sorts. With a green fence on one side, it borders one of the most *heilige* establishments existing today – The School for Children with Hidden Intelligence, otherwise known as SCHI. Yes, I am walking my son to his school, which Hashem in His great kindness, placed in such close proximity to our home. Together we cross the road, Noach's briefcase on his back, his frame now almost as tall as mine. We pass the green fence and see the school's side entrance up ahead.

It is here that parents drop off their precious charges, handing them over to the dedicated and loving staff members. Vans pull up, some of them sleek and shiny, others dilapidated and worn. We see the parents lovingly extracting their special children, some of them having an easier time than others. Please stay here with me to observe the scene.

There are children with all sorts of disabilities and deformities, with parents from all walks and stages of life. To me, the most touching are the children who cannot function independently in any way, and spend their days strapped into chairs, some without muscle function or neurological abilities. But when you look into their faces, you may be struck by their *p'nim*, the shining light radiating from within. There may be a beautiful smile, perhaps not displayed at the mouth, but from their twinkling eyes. Just the sight of it can take your breath away.

Glance back at the father or mother whose love is so evident and notice the same shine on their faces as they say their goodbyes. The changing of the guards between parents and teachers is laced with incredible feelings that are hard to put into words. As much as you want to move on with your day, the scene is truly riveting.

Different feelings bubble up to the surface as we confront these painful, yet uplifting sights. I look at my handsome, strapping Noach, and his deficiencies suddenly seem to pale in

comparison to the more severe handicaps that we just witnessed. How lucky I am that this is the child I am bringing to SCHI. A beautiful boy who can walk and run on his own two feet, and even talk and learn. A boy who possesses such *chein* that his special behaviors can be easily forgiven.

Surely you can join me in my sense of wonderment at the purpose that such deficient children have. How can we understand the severe handicaps that a human being has to live with day in and day out? But then, remember the glow that shines from their faces. The glow tells you that they are definitely serving a very special purpose. If that's the case, then clearly every single person in the world is here to serve his own unique purpose, with whatever capabilities and capacities he was given.

After experiencing this special trip, your perspective on life surely changes. As we walk back toward the green gate, let us take a moment to embrace the challenges that face us each day with greater insight into the unique purpose created for each of us. It's also an opportunity to focus on feeling grateful for whatever our own *pekel* may be, after seeing the special challenges that other parents face. As we let these ideas sink in, let's take it a bit further and start to view every person we encounter in life as someone with a unique task, an individual purpose, and yes, their own set of challenges, capacities, capabilities, and deficiencies to accomplish their unique mission in life.

If we truly view each person as unique and purposefully created and endowed, then we will realize that our every interaction with others is also part of the master plan. It is intended for us to perfect ourselves, by developing our *middos* and our patience, broadening the potential of who we can become, and bringing tremendous *nachas* to Hashem. Truly, we should view every individual as special, for indeed every one of us is! Let us not be oblivious to the struggles of those around us. Let us be ever so grateful for what we have—and let us not forget to express that appreciation!



# Let's Get Educated

AAC

Leah Tawil, SLP

## What is AAC?

AAC stands for Augmentative Alternative Communication. **Augmentative** means to add to someone's speech. **Alternative** refers to communication that takes the place of speech.

## Who uses AAC?

Many different types of people could benefit from AAC. Some may be born with a diagnosis that affects their speech and/or receptive/expressive language: Autism, cerebral palsy, Down syndrome, Angelman syndrome, and Fragile X syndrome are some common congenital (from birth) conditions that may cause a severe communication disorder. There are also many people that acquire a condition, including Traumatic Brain Injury (TBI), Huntington's disease, and Parkinson's disease.

Any age person can use AAC techniques, even younger than 3-years-old!

## When is AAC used?

Some people use AAC their whole life, while others use it only for a short time, like after a surgery, when they cannot talk.

## How does it work?

There are many different types of AAC. They are classified into two main categories: No/Low-tech and High-tech.

**No/Low-tech includes:** gestures, facial expressions, writing/drawing, picture, word, or letter boards which can be pointed to.

**High-tech includes** an app on an iPad/tablet, or a speech-generating device (a computer that produces a "voice").

Many AAC devices can be used in other ways than touching it. Even people who have trouble moving their arms and legs can use an AAC device.

## AAC in Action:

*Adina, age 7, is severely limited in her expressive language skills. Her comprehension is also delayed, but is far more advanced than her expressive language. She currently uses a low-tech communication board, called a 'core board', which has 16 pictures. The speech therapist models simple sentences, while verbalizing, as they play simple games.*

*"My turn," the speech therapist says. She points to the squares with the Boardmaker symbol for "Me," while putting the car on the top of the track and watching it with Adina, as it zooms down. She points and says: "Down," and this time Adina points as well. Then the speech therapist points at the "You" symbol, and says: "Your turn." She waits a few seconds, then takes Adina's hand and points together with her, at "Me," before allowing her to take a turn with the car.*

*The information in the article was taken from ASHA <https://www.asha.org/public/speech/disorders/aac/> and the International Society for Augmentative and Alternative Communication <https://isaac-online.org/english/what-is-aac/what-is-communication/communication-aids/>.*



Q

## IN SESSION

Dear Shira,

**My special needs child was in the hospital for many months after birth. Because we have a large family, we stayed at home and visited her daily in the NICU. She's now been home a few months, and I feel that I am still not well connected with her. Her needs are tremendous, and I constantly get upset and frustrated with caring for her, instead of feeling compassionate and loving her. I think I feel this way because I was unable to experience the natural bond that a mother gains by taking care of her child's needs when she is born. How do I work on loving my child more, and building that mother-child bond?**

**Thank you,  
Anonymous**

A

Dear Anonymous,

I feel sad that you signed your name Anonymous, because your feelings are very common and natural, and you don't have to feel ashamed or "less than." You are not anonymous at all, but just a regular mother who didn't have an opportunity to connect with her baby. Bonding after the birth of a child is important, but there are many circumstances that do not allow the typical bonding to occur. The relationship can be restored when the time will allow.

Please allow me to read between the lines and address your feelings. You wrote that you feel so "frustrated." Anger and frustration are often synonymous. Art therapy is a very effective form of therapy that allows a person to express him/herself without having to speak. One exercise that is used is to design the "mask of anger." When someone wears a mask, it covers up and hides what is going on inside. For example, suppose a mother allows her teenager to go out with her friends, but gives her a curfew of 11:00 PM. When her daughter comes in at 2:00 AM, the mother greets her at the door and screams at her to show how angry she is that her daughter came home three hours late. Her "mask" shows her anger, but what are her true inner feelings? She was petrified, scared out of her wits with worry about her daughter! However, it is easier to show anger than to reveal her true feeling.

Let's examine your frustration: if we peel away your mask, what are your true inner feelings? I wonder if you are feeling overwhelmed with all your daughter's needs, along with the needs of everyone else in the family. Are you feeling drained? Do you feel guilty for having these feelings? These

are extremely common feelings, and I hope you can find the support and validation that will help you, your baby, and your family. In my very first article in *Neshamale* magazine, a mother wrote that she doesn't like to ask for help, as she likes to do everything herself. However, as her child's needs increase, she finds that she needs help, after all. I responded that for every time there is a "no," there is also a "yes." If someone says "no" to help, then their being overwhelmed will increase, or someone/something will be ignored. Parents of special needs children must give themselves permission to get necessary help and support.

I am writing this on *Tu B'shvat*, and I saw a quote that I hope you will find meaningful: "The next time you start feeling impatient with your progress, remember that the last thing to grow on a fruit tree is the fruit."

Attending to a child who has a lot of needs, whose progress is not so obvious and/or very slow, can be very frustrating. Take one minute, hour, day at a time, and pace yourself. Get the support you need and praise yourself for every accomplishment, even if you think it is miniscule!

Wishing you much *hatzlacha* and continued *nachas* from your family.

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*

Regarding the shades:

1) Cordless shades may break more easily from general use, but they can be lifted into place, out of reach, when applicable.

2) For daytime, I tinted my house windows so that others cannot see in (while raising the cordless blinds out of reach).

3) While being a very expensive option, blinds-in-windows (by Pele) have the actual shade between window panes, with a lever for up and down. This may or may not be less attractive to your children!

*Hatzlacha!*

M.E.

We attach Velcro to the border of the window frame, then sew the other side of the Velcro to the curtain or blind. You can stick the curtain up, and if the children pull it down, it can easily be put up again. I use the Command brand, as I find it works well. See the picture of our blind and window frame with the Velcro attached.



I too encountered a similar problem, and frosted the window in my son's work-time room with frosted contact paper. It's cheap, easy to put on, allows for sunlight, and it works!

B. R.



## Tips From The Experts

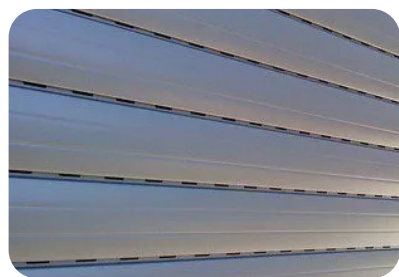
*hey! that's us!*

**What does everyone do about shades and curtains in their home? My two special needs children are attracted to the up-and-down motion and are constantly breaking them. Thank you!**

I live in Eretz Yisroel, and here we have *trissim*.

The *tris* is made of completely opaque plastic or metal. It opens and closes behind the closed window, so it's away from active hands. I think you can get them in America as well.

They do not really provide privacy together with a little light, because they are completely opaque.



We have faux wood blinds. When my son pulls hard on the blinds, they can crack. There is a relatively easy and simple way to fix this, if you have extra blinds on the bottom. Open the bottom of the blind and loosen the threads. Remove the broken piece and move the ones underneath it up into position, moving the individual slats up until they are all back in place. Close up the bottom until the next one breaks! (We usually wait until a few are cracked to do this job, otherwise we'd be doing it too often!)

R.T.

Window shades are a loaded subject! We lost invitations to family members as they were afraid he would break their window shades. At the time I was hurt, but today I understand 100%, as window shades are expensive. My last resort has been to jam a disposable window shade or even a sheet or a towel in the top of the window. Today we are doing well with a simple plastic shade with the chain screwed onto a plastic anchor. Bli ayin hara, it is durable, washable, and hard to play with.

I find that using a stronger cordless shade that has to be pushed up and down is not as much fun for the children, and can withstand the pushing and pulling more. I have a roller shade that stays all the way up, so it can't be pulled, and an accordion shade that's been through a lot and still is working. These are not the cheap ones—they run \$100 and up.

T.S.

Question for the next issue:

**My seven year old son doesn't play by himself and always needs to be entertained one on one. I'm looking for ideas of toys or activities that others have found to be exciting and engaging, yet simple enough, for kids to play with on their own. Thank you!**

Please send us your answers to: [neshamalemagazine@gmail.com](mailto:neshamalemagazine@gmail.com) or text your answers to: 848-299-2908



# Illuminations

## CHILDREN OF ETERNITY

During the bitter slavery in *Mitzrayim*, Pharaoh decreed death upon any newborn Jewish baby boy. At that time, the *Gadol HaDor*, Amram, made a decision to stop having children. But then his young daughter Miriam convinced him otherwise. One of the things she told him was that even if the *Mitzrim* would fulfill this decree, the baby would still live on forever in *Olam HaBa*. It did not matter how long the infant would actually survive—once the *neshama* was brought down into this world, it would live on in eternity.

The job of every Jewish parent is to be the guardian of the holy *neshama* Hashem brings down into this world and places into their care. They are to ensure that the *neshama* stays pure and eventually is *zocheh* to live on forever. Some children live for 120 years and some live for just a day. The amount of life they need to reach *Olam HaBa* is determined by Hashem. Some children are brilliant and some are not; some have handicaps and some don't. Every child is different, but the goal for every one of them is the same.

The *sefer Divreh Yeshua v'Nechama* tells a story that took place many years ago in Gateshead, England. A man had a baby born to him with Down Syndrome. He and his wife raised the child and loved him very much. They had, Baruch Hashem, many other children who were all strong and healthy. When the Down Syndrome child was turning 13, his parents decided to make him a small Bar Mitzvah celebration. The father invited a *minyan* of men to a *seuda* at his home, one of whom was the author of the story. During the meal, the Rosh Yeshiva of Gateshead, Rav Leib Gurwicz, got up to speak. This is what he said:

*"At this time in history, we are all gilgulim, which means we have all already lived in this world before, but had to come back to fix*

*something we didn't accomplish the first time. If there is a person who is born with a tremendous amount of potential, for example he is wise and strong-minded and has charisma, that means that he has a lot to accomplish here that he did not do the first time. But if there is a person who has very little potential, his body doesn't really develop or he doesn't have the mental capacities to do that much—that means he is a gilgul of a very great tzaddik who almost finished his job already. He came back to do some minor corrections, perhaps to say some brachos, or to do acts of kindness, or perhaps just to be the vehicle through which others can perform kindness. Surely, this type of person needs to do much less than others to be able to live on forever in Olam HaBa. The less capabilities a person is born with, the better his neshama is already."*

The Rabbi then concluded his speech by saying: *"Fortunate are you, the parents of such a lofty neshama. You were chosen to be the guardian of this great tzaddik, which means he will be in your family amongst your children not only here, but in the World to Come as well, and there you will see how great he really is."*

The parents were noticeably emotional from these words of the Rabbi and they thanked him very much for coming and for his heartwarming words of *chizuk*. The father then took his Bar Mitzvah boy to Israel to get *brachos* from *Gedolei HaDor*. When he returned, he said that when he went with his son to the *Chazon Ish* to get a *bracha*, the *Chazon Ish* immediately stood up fully from his sitting position. The man was astounded and turned around to see if there were any other great rabbis behind him. When he saw no one there, he assumed that the *Chazon Ish* had stood up for him, so he said: "Rabbi, you don't need to get up for me."

The *Chazon Ish* told him: "I'm standing up for your son. This boy has one of the greatest *neshamos* in our entire generation. He is deserving of my honor."

We have no idea how great people really are. A parent who may feel broken over his child's lack of development or lack of ability must know that he is raising a very holy *tzaddik* and that he will be *zoche* to have that child in his family *l'netzach netzachim* (forever).

*This is reprinted with permission from Rabbi Dovid Ashear of Living Emunah.*





## CVI: Cortical Visual Impairment

### Cortical Visual Impairment: What Families Need to Know

By Chris Russell, MS. Ed., TVI, CVI Specialist

*Do you have concerns about your child's vision?*

*Have you observed any unusual visual behaviors from your child that cannot be explained by what you know about his eyes and eye health?*

*Does your child have a history of medical experiences or conditions possibly affecting his brain?*

#### What is CVI?

Cortical Visual Impairment (CVI) is a neurological form of visual impairment caused by “damage or atypical structures in the visual pathways and/or visual processing centers of the brain” (Roman Lantzy, 2018). CVI is the leading cause of visual impairment affecting children in countries or regions with access to quality neonatal health care.

#### How is CVI different from other types of visual impairments?

Individuals with CVI often have healthy eyes and obtain normal results on an eye exam, because it is the processing of vision in the brain that is atypical, not the physical health of the eyes. CVI does not have an impact on visual acuity, contrast sensitivity, or many of the other symptoms of ocular visual impairments. CVI cannot be corrected with glasses.

Importantly, children and youth with CVI can be expected to make progress in their use of vision over time, if provided

with appropriate assessment and intervention. CVI requires a very different approach to instructional supports and environmental/material adaptations, as compared with eye-related (ocular) visual impairments.

#### Some medical history that could be significant for CVI:

- History of premature birth, especially if the child experienced a lack of oxygen (anoxic brain injury) or too much oxygen (hypoxic brain injury), such as hypoxic ischemic encephalopathy (HIE) or periventricular leukomalacia (PVL)
- Seizure disorder or history of seizures or infantile spasms
- Stroke or cerebrovascular accident (CVA)
- Intraventricular hemorrhage (IVH)
- Cerebral palsy (not a cause of CVI, but could be a coexisting condition)
- Chromosomal disorder or syndrome
- Neurological condition or structural abnormality in the brain
- Traumatic brain injury at any age



**Some things to look out for (visual “red flags” for CVI):**

- Staring at ceiling lights or windows
- Does not make eye contact or look at people
- Looking indirectly at people or objects; seems to be “looking past” or “looking through” a person or object, rather than looking directly at it
- Only looking at objects that have bright colors (red, yellow, neons)
- Only looking at objects that have movement or light-up qualities
- Does not look while touching or reaching for objects or toys (or looks away)
- Turns or tilts head at an angle while looking, or appears to only look from the corners of his eyes or peripheral visual fields (from the right or left side)
- Shows a processing delay in looking at or turning toward objects
- Has difficulty using vision in more complex or busy environments, or with more visually busy or cluttered materials
- Has difficulty looking at new or unfamiliar objects or people

**What should you do if you have observed any of these behaviors?**

1. **Obtain a thorough clinical vision assessment from a qualified clinical eye specialist (ophthalmologist, optometrist, or neuro-ophthalmologist):**

The first step you should take is to make sure that the abnormal visual behaviors you are observing cannot be explained by an eye-related (ocular) visual impairment. Take your child to a pediatric ophthalmologist or neuro-ophthalmologist.

**It is important that you take your child to an eye doctor who has an understanding of CVI, and is familiar with this condition and comfortable diagnosing CVI. DO NOT assume that all eye doctors are familiar with CVI.** Some eye doctors are not comfortable diagnosing CVI, or may give inaccurate information about CVI, such as stating that “CVI is not a real diagnosable condition,” or that “there is nothing you can do to support vision and development for a child with CVI,” and that “the child will not benefit from vision supports or

services.” This is inaccurate information, and may be the perspective of an eye doctor who has specialization in understanding the eyes but not with conditions that affect visual processing in the brain.

**When making an appointment with an eye doctor, first ask the office or doctor’s assistant:**

- “Is this doctor familiar with CVI and will this doctor diagnose CVI if appropriate?”
- If not, seek out an eye doctor who is familiar and comfortable discussing and diagnosing CVI, if appropriate.

During the appointment, ask for a thorough and comprehensive ocular exam to make sure that there are no significant conditions affecting the eyes that could explain the abnormal visual behaviors you are observing. If there are not, ask for a diagnosis of CVI if appropriate.

2. **Obtain a quality functional vision assessment to support your child’s educational or early intervention program:**

If you have a diagnosis of CVI from the clinical vision specialist, the next step is to obtain a functional vision assessment (FVA) from a teacher of students with visual impairments (TVI). This can be provided independently or through the educational system/school process. A FVA will provide important information about how your child is using his vision, and what visual goals and supports are needed to promote his progress and growth over time.

3. **Support the team to implement the recommendations of the functional vision assessment:**

Once you have a functional vision assessment and detailed information about your child’s visual functioning and the goals and supports he needs, make sure that your child’s early intervention or educational team has this information, and understands how to incorporate these recommendations throughout your child’s program.

For additional resources or with questions, please contact: \_\_\_\_\_  
christopher.russell2013@gmail.com



# Infantile Spasms & CVI

Raizy Sander

Faiga Malky is my fifth child, born with Down syndrome. Since birth, she developed nicely, reaching milestones even sooner than expected. At two weeks old, she held up her head when on her tummy; at five months old, she rolled over. At ten months, Faiga Malky started having a startle reflex, or so we thought. Any time she was startled by noise or touch, her head dropped for half of a second. If she was lying on the floor and I picked her up unexpectedly, her head automatically dropped for a very short time. It didn't dawn on me that this could be a neurological issue, since it occurred mostly when she was startled. I was able to initiate it; I could touch her unexpectedly and she would drop her head. These head drops became more frequent, yet I was unaware that it was an urgent matter.

When we were under lock-up during the Coronavirus onset, we had a Zoom session with Lynn Walker, one of Faiga Malky's therapists. Faiga Malky had a head drop during the session, and Lynn was very concerned about it. She gently told me that the matter required urgent attention, and should be checked out by a neurologist right away. However, we were unable to get an appointment with a neurologist for months.

I spoke to a woman whose daughter had infantile spasms, and she described the same head drops that Faiga Malky was having. She told me that Chaim Medical told her to rush her child to the emergency room for an immediate EEG. Realizing that this was serious, I contacted Chaim Medical. They urged me to take Faiga Malky to the emergency room for an EEG for seizures.

We called an ambulance and rushed to Columbia Hospital. They put an EEG device on her head and admitted her to the hospital. I told the doctor that I could initiate the head drops by startling her, and they told me to do so, so that they could check her brain activity. A neurologist came in the morning and told me that the EEG was picking up seizure-like activity. They started Faiga Malky on the lowest dosage of Vigabatrin powder, intending to gradually triple the dose. *Baruch Hashem*, as soon as Faiga Malky started the medication, her head drops stopped completely.

I went for a second opinion to Dr. Orin Devinsky, an expert neurologist at NYU. He said that since the head drops stopped completely after starting on the lowest dosage, then we could stay at that dosage. He also told us that, in his 30 years of

experience, most children with Down syndrome outgrew infantile spasms rather soon, whereas other typical children may have more severe cases.

We are fortunate that Faiga Malky's Occupational Therapist, Lynn, was trained and experienced in many other areas. She realized that Faiga Malky had developed CVI (Cortical Visual Impairment) from her infantile spasms. CVI is caused by a brain problem rather than an eye problem, and is often overlooked by ophthalmologists because the eye looks perfect—the issue is that the brain doesn't properly interpret what the eye sees.

The therapies done for my daughter's CVI are meant to stimulate her brain so that she can see properly. Thankfully, with her early diagnosis, we were able to work on her CVI, and she has made tremendous progress, B"H from barely seeing to really seeing.



We got in touch with Chris Russell, an expert in the CVI field. After giving Faiga Malky a functional visual assessment, he was able to tell us exactly where she was in the CVI range, and what we could do to help improve her vision. Aside from his expertise, Russell was very supportive, and his positivity put me at ease. When Faiga Malky was first diagnosed with CVI, I was devastated, picturing her life without vision. B"H, two years later you cannot tell that she has any vision issues.

Infantile spasms can be easily missed, but it is extremely important for parents to be educated and aware of what to look for. Spasms and seizures need to be addressed right away in order to avoid brain damage. If your child is having head drops or any other abnormal head movement, have it checked out immediately. *B'ezras Hashem*, with the right treatment, your child will be just fine.

Unfortunately, many doctors, ophthalmologists, and therapists are not aware of CVI. If you think your child is showing symptoms of CVI, reach out to a professional who can do a functional vision assessment. You can then learn what to do to help your child improve his vision.

*Raizy has become a sort of liaison for children with CVI. If anyone wants to connect with Chris Russell, contact Raizy at 718-607-2784.*

*This article was originally printed in the Down Syndrome Amongst Us magazine.*



# Tips for the Blind & Visually Impaired

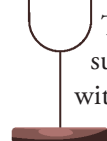
N.M.



**Determine the Visual Ability:** The first step is to determine to what extent and in what manner the child's vision is impaired. Not all visual impairments are the same. A child may have no vision at all, or just light perception. He may have reduced visual fields (meaning that he doesn't see to the sides, or above/below). A child may have reduced acuity, meaning that things may be blurry, even if he wears eyeglasses. Your child may also have a brain-based visual impairment, also known as CVI (Cortical Visual Impairment or Cerebral Visual Impairment). This means that he may have normal eyes, but his brain is not able to interpret what he sees in the usual way. Gaining clarity in understanding the impairment is extremely important, and will help you know which of the following tips will be most helpful in your particular situation.

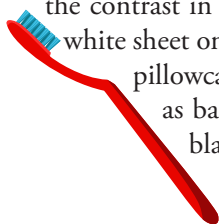


**Use Lighting:** Use lots of light, both natural and artificial, to make things easier to see. Install task lighting where the most important activities take place, such as eating and reading, and point the lights at the items being used, not at the eyes. Use floor lamps, table lamps, or movable clip-on lamps for flexibility.

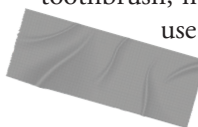


Try to eliminate glare (on screens, books, table surfaces, etc.) as much as possible by experimenting with placement of the lamps/lights. Using adjustable window coverings and dark placemats on high-gloss surfaces can be helpful in reducing glare. A slant board can also be helpful. If you don't have one, just use a two-inch binder. Prop up toys or books on it for a better view.

**Use Color and Contrast:** You may find that the child has a color preference, such as red or metallic silver. If that is the case, try to use that color to call attention to his belongings, such as his toothbrush, drinking cup, etc. You can also keep things organized by using different brightly colored containers for storing clothing, toys, etc. High contrast between an object and the background against which it is seen, is often helpful to children who are visually impaired. Look for ways to increase the contrast in your home. A bright blue pillowcase against a white sheet on a bed will be easier for your child to see than a pillowcase and sheet of the same color. Use black paper as background for projects. Using white chalk on a blackboard provides a great contrast.



**Make it Tactile:** There are endless ways to use a tactile approach around the home and classroom. One teacher shared that she always keeps a hot glue gun handy--she uses it to outline papers, pictures, and letters, providing tactile guides for writing, coloring, cutting, etc. One mother uses rubber bands to mark her daughter's belongings, such as her own hairbrush, toothbrush, medicine bottle, water bottle, etc. You can also use pieces of duct tape to mark things (duct tape is stickier and more noticeable than the classic round stick-on-labels).



**Take a Multi-Sensory Approach:** Children with visual impairment, who do not have the benefit of learning through visual observation, need direct exposure to understand the world around them. For example, teaching about animals by showing large print pictures in a book/iPad, or even using small plastic figures, will not be very meaningful. However, taking children to a farm to feel each animal, hear their sounds, and smell their odors, will leave a vivid impression on their minds. Once they appreciate what the different animals are, then the small plastic figures or pictures will have better association and understanding.



Learning letters is another example. Always create, rather than draw. Use tactile manipulatives, such as clay, to shape the letters, rather than doing coloring sheets.

Basic household activities, such as cooking, washing dishes, doing laundry, cleaning, etc. offer lots of opportunities for learning about everyday concepts such as wet/dry, hot/cold, big/little, heavy/light. These activities can be set up to include enhanced sensory awareness and important motor skills, such as when pouring water, measuring rice, digging in sand, etc.

**Placement of Items:** It is helpful to keep items in predictable locations so that the child can find them more easily. Clothing, toys, books, eating utensils and bath items should always be stored in the same place. Mark their locations with braille or large print, as well as a tactile symbol. Help your child locate and put away toys by marking bins with tactile symbols, for example, hot-glue a Magna-tile or a Lego piece to the outside of their respective bins.

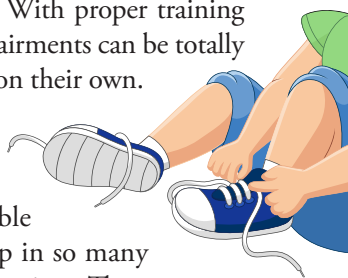


**Keep things Safe:** It's especially important to have a clean and neat environment when there are children with visual disability. Keep doors of rooms and closets closed. Try to keep the floors free of toys, shoes, backpacks, and anything else that can be tripped over. Tape down the edges of small rugs so they don't slip or slide. Avoid keeping low furniture, such as coffee tables, in the middle of a room. At mealtimes, use knives with rounded tips, and use short, wide cups (tumblers) to avoid spillage.

**Respect their Needs:** Children with CVI and other visual disabilities find life in general, and especially new experiences, overwhelming. Before attending a simcha or going to a new location, it's helpful to give plenty of advance warning and descriptions of what to expect. Make every effort to have the child well-rested and fed before arriving. Try to arrive early, or at a quieter time, and settle down in a quiet corner. It is completely normal for the child to need breaks from new and noisy environments. Read their cues, and know when to allow them a "time-away" to fend off a melt-down. Offering this "time-away" when at a simcha, the mall, or even at your own Shabbos table, may be necessary for your child, giving him the space he needs to rebuild his ability to come back again.

**Foster Independence:** Adults tend to have rachmanus on a visually impaired child and try to do as much as possible to smooth the way for him. In reality, this could very well be misplaced pity. Teaching our children independence may be the kindest thing we can possibly do for them, as we want to set them up for the most successful life possible. Start with basic daily activities, such as getting themselves a drink, taking a shower, and getting ready to leave the house. Although it's faster and easier to just "do it for them," how will they ever learn? Believe in your child's ability, and teach him step-by-step processes until they become ingrained habits. At the appropriate age, get the child a braille or talking watch and the responsibility to be on time. With proper training and support, children with visual impairments can be totally functional, even navigating outdoors on their own.

Recent technological advancements offer many opportunities to the visually impaired that weren't available in the past. Apps are available to help in so many areas, including education and navigation. These can be especially helpful for mainstreamed students. Be sure to stay up to date on the latest developments.



*Thank you to Miriam Cohen and other parents and teachers who wish to remain anonymous for sharing their ideas and suggestions for this article.*

## JEWISH RESOURCES FOR THE BLIND AND VISUALLY IMPAIRED

### Insight Beyond Eyesight

**InsightbeyondEyesight@gmail.com**

A support group that provides educational fun-filled activities, parties, and events, appropriate for frum blind girls and boys up to 9 years old, and occasional separate programs for older boys. They also have a monthly conference-line support group for the parents of blind children, where different speakers talk about their lives and their accomplishments as blind people.

### CSB Care

**www.computersciences.org**

Jewish Resources, Technology, and Technical Support Computer Services for the Blind distributes custom braille siddurim, Chumashim, Gemaras, Jewish magazines, and books.

### Jewish Braille International

**Jbilibrary.org**

### Jewish Heritage for the Blind

**jewishheritage.org**

**1-800-995-1888**

Provides Siddur, Machzorim, Megillas Esther, Haggadah, Tehillim, Jewish calendar, and more in large print and braille, free of charge. They also publish children's books in Braille in English, Hebrew, French, and Spanish.

### Kol HaLashon

**718-906-6400**

Listen to recordings on Torah topics, leisure reading, lectures, audio books.

### Bookshare

**www.bookshare.org/cms/**

Prepares books in any format needed.



# A New Perspective



N.S.

I've always had the feeling that, just because I have been granted the presence of a child with special needs in our family, it doesn't make ME special. I am still the same "me" who has challenges and deals with the daily goings-on. No magic button switched on when my child was born. Because of this child, I am working, not to be that 'special mom' in the world's eyes, but to be that 'special person' in Hashem's eyes. To me, that's what is important.

It is very nice to hear someone say: "Woow! Such a *heilige neshama* that you have the *zechus* to have! You are sooo lucky and special! The *Aibeshter* really loves you! You were handpicked for this *neshama*. Your family is the perfect home for him. Hashem only chooses the special people whom He knows can handle it." That compliment, given sincerely, is very appreciated, validating, and reassuring.

Nevertheless, living with this special *neshama* daily, comes with its set of challenges.

It's not easy for my son not to be able to read at 15, or being the only one sitting during *Shimoneh Esrei/Kedusha* while the whole *shul* is standing, looking at him awkwardly.

Being stopped by strangers while my son is having a meltdown on the street and having to listen to them tell me off for not being *mechanech* my child correctly makes me want to burst into tears. Or feeling that dagger-in-the heart from people not wanting to sit next to my son because he eats sloppily.

I'm worn out from running around all over to specialists, trying to get a diagnosis to be able to help him. Or having to reschedule appointments in order to accommodate a much harder-to-obtain appointment that was scheduled without our knowing in advance when it would be.

It's challenging to spend a full month's salary to try and re-try every therapy and treatment, conventional and unconventional, that there is out there. Not to mention not knowing what the result will be, but only doing our *hishtadlus* to know that we did all that we felt we could to help our child (and still feeling guilty for maybe not doing enough...).

It's hard for the siblings to agree to take their big brother in his hat and *bekishev* to the park on Shabbos and have him ride down the slide, squealing and giggling like a little kid. And then having to comfort them for how other people are looking at them.

It's frustrating to hear at the Shabbos morning *seuda*: "Mommy, when is Shabbos over? I want to hear music already." And it's exhausting never being able to take a break to re-charge ourselves (so we can be there further for him), because the people we were hoping would watch him for a while were afraid to take it upon themselves (and just as well, as we were concerned whether they would be able to understand him...).


Yes, we are told that our children have special *neshamos*. But really, do they? Like, ok, they are special. But I never fully grasped to what extent, because I am too busy living it with all the struggles. And the dashed dreams of what I thought would be. And awaiting and yearning for my *tefillos* to be answered.

And then.

And then I went for our yearly checkup at the pediatric neurologist—that same neurologist with whom, each time we schedule an appointment, has over a year's wait (Wink, wink, to all of you nodding your heads in understanding). And, when we finally booked the appointment, it turned out to be right when we had a very important trip out of the country, so said appointment had to wait until the next earliest cancellation—in another four months.

So here we finally were, sitting at the appointment and discussing some of the behaviors that concerned us. Some of them led to autistic qualities, even though that was not the diagnosis.

One of the issues we were troubled and confused about was our son's obsessive behavior. For example, if he does anything to hurt or bother someone, he immediately asks for *mechilah*. If he accidentally does something to the baby, he asks me: "Mommy, is the baby *moichel* me?" And every night before he goes to sleep, he calls out from his bed: "Mommy, are you *moichel* me?" My usual answer is: "What did you do wrong that you are asking for *mechilah*?" Sometimes he answers: "Nothing,"



and sometimes he tells me what he felt he did wrong (*Halevai* that I would make such a daily *cheshton hanefesh!*). I tell him: “Yes, I am *moichel*, but really there is no reason to ask; of *course* I am *moichel* you!”

I was concerned about this behavior, but the doctor explained it in an extraordinary way: “You think this child is being obsessive and just has anxiety about that? NOT AT ALL! He is on such a high level that he will never manage to rest if there is someone or something that he has slighted. He needs to make sure that he always has a clean slate. His *neshama* is clean and wants to stay clean.”

Then the doctor looked at us excitedly and said: “You have to hear this! Just last week I had parents come in with their severely autistic 18 year old son. He was standing to the side during the visit, while I was looking forward, speaking to the parents. At one point I said to the parents: “I am going to tell you a joke.” They jumped and said: “NO WAY! You may NOT say a joke in our son’s presence. He cannot deal with jokes and gets very agitated and distressed when he hears a joke.” I told them that was ok, but that I would say it anyway. They again adamantly begged me not to say the joke, but I did anyway. I spoke facing them and asked: “To which person will a Rav,

we do. They know the truth and no joke can take its place.”

I was so taken aback and awed at how this highly acclaimed professional viewed his patients; I was in total shock over what I heard.

And do you know what? Now everything made sense.

The more I see my son for who he really is (since the doctor made the real truth so clear to me), the more I see how correct the doctor was.

It’s only been two months since that appointment, yet if I tell you that my life has been totally changed in regard to this child, it would be an understatement. Sometimes I think I just want to start all over again from the beginning with this new reality, but I know that this time and place and stage is JUST where the *Aibishter* wants me to be. So, I will just take my newfound gift of knowledge and not just be *moichel* my child when he asks for *mechilah* (what I thought was an obsession), but I now truly treasure where that pure question stems from. I also answer his unasked questions that he cannot express well, and take him to shul when he asks to go, knowing that, even though he cannot follow along, his *neshama* needs to be there.

***They jumped and said: “NO WAY! You may NOT say a joke in our son’s presence. He cannot deal with jokes and gets very agitated and distressed when he hears a joke.”***

President, or Rosh Kollel take off their hats?” I gave them a minute to think and then I answered: “To the barber!”

Now, my patient BURST out laughing. He couldn’t stop rolling! And his parents were so shocked that they almost started crying. They said: “You don’t understand. He *NEVER* lets us say any jokes. He goes wild every time someone jokes.”

The doctor explained to them: “Do you know why he can’t take a joke? Because most times, a joke is on someone in particular or at a whole group’s expense, or makes fun of someone, or it’s just not the truth. And these kids are so pure that they cannot stomach such talk.”

He continued: “It’s not because the child has autistic qualities and are too literal, it’s because the child has such a special *neshama* that when someone says *sheker*, their *neshama* just doesn’t process it. It’s not that their brain isn’t ‘getting’ it; it’s that their purity cannot deal with it. Their *heiligkeit* doesn’t let such talk go into them, because of their absolute wholeness and trueness. They can’t take anything but the truth. They know so much more than

I now understand why, during Succos my son basically stays in the succah 24 hours a day. And why he likes babies and their purity. Now I honor him when he says he also wants to learn, even though he can’t.

I abide by the lesson he taught me, to *never* make fun of people and say it’s only a joke - because it’s never funny when it’s at the expense of anyone or anything. And I now know that being near him is a gift and a privilege that not everyone is *zoche* to be able to deal with.

My husband, our children, and I now realize that our son was handcrafted for us. Not only did we receive just what was perfectly tailored for us, we now see that we got something so much more than what meets the eye. What we originally thought brought pain, problems, embarrassment, and challenge, we now understand. We feel closer and more secure when we are around him. I can say with full confidence that we finally appreciate the *heilige* and oh so special *neshama* that has been gifted to us.



# Smart & Safe

Fraydel Dickstein

MARVELOUS MEMBERSHIPS

Every time I bring pen to paper to write for *Neshamale* Magazine, the same words go through my mind: *Hineni Hauni Mimash, Nirash V'n'fchad*. (These are the words the *Chazzan* uses before beginning *davening* on Yom Kippur, to convey how unworthy he feels to beseech Hashem for mercy on *Klal Yisroel's* behalf.) I feel it's insolent for me to address this audience of parents with special needs children. How can I give my cute little ideas to such great people when I stand in awe of every single one of you? I just spoke to a friend whose child is experiencing a medical crisis, and today was a down day. She said to me that her husband told her: "Our moods cannot revolve around the well-being of our child."

I was so humbled. It affects my mood when my supper burns, and they are dealing with a crisis for which there are no simple answers. Yet they understand that their child's well-being is solely in Hashem's hands, so it should not affect their mood. They need to go on in their beautiful service of Hashem, even if there's a crisis. The *emunah* and *bitachon* that lie behind such words is mind-boggling. This is an incredibly high level of acceptance!

To be honest, I find many parents of special children to be on a spiritual level that is inconceivable. Years ago, Yehuda had a physical therapist who serviced special needs children. She told me that she feels jealous of all the parents who sit in her waiting room, because they know exactly why they are here in this world, while she often grapples.

In this column, I would like to share ideas of how to keep our children busy outside our homes. Dealing with our children's boredom is an uphill battle, and keeping them happy and busy can be a tremendous challenge. I hope these ideas will work for you, or spark other ideas that may work for you and your child.

**Sky Zone**  
(609) 398-4759  
1001 New Hampshire Ave  
Suite A, Lakewood, NJ  
08701

In a previous *Smart & Safe* article, I mentioned trampoline parks as being special needs-friendly



places. Little did I know then, that they would become one of my favorite places. Yehuda goes to Sky Zone two or three times a week, and sometimes even more. This is not because I struck it rich, but rather because I took out a membership.

Here are the rates:

Basic Membership - \$24.99 per month

90 minutes of play

Toddler Time & Glow (1x per month)

20% off purchases

1 pair of socks included

Elite Membership - \$28.99 per month

Unlimited time to play Monday – Friday

120 minutes of play Saturday – Sunday

25% off purchases

1 pair of socks included

These rates may vary according to location. Our local Sky Zone required a minimum 12 month sign-up, which made it very costly for the whole family, but so worthwhile for Yehuda!

With Yehuda going at least ten times per month, it comes to literally three dollars a time, which is phenomenal! I took out the Elite Membership, which allows his caregiver to jump with him, and gives him much more jumping time.

It's the perfect thing for us, as Yehuda, at thirteen, is too big to sit in a room with a therapist and play Bingo. He needs to be able to do his own thing. I doubt there would be many therapists who would be willing to do this with him anyway.

My husband once took Yehuda there, and was so happy to see what a great environment it is for him. Yehuda was so proud to show off Sky Zone to his father and brother—it was his domain. It is beautiful to see how comfortable he is there.

**Urban Air**  
(732) 659-9060  
1256 Indian Head Rd,  
Toms River, NJ 08755

Urban Air is also a trampoline park, but



there's a lot of different fun things to do as well. We had a membership there too, as they were open until 9 pm. With a big boy, the later a place is open, the better. Once they shortened their hours to 8 pm, it made more sense to stick with Sky Zone, especially because of its close proximity to our house.

Urban Air rates fluctuate, but overall, they are very reasonable, at times less than \$20 a month.

Because both Sky Zone and Urban Air are both so affordable, for a while we had a membership to both of them simultaneously. This allowed us to have two great options to vary between, costing less than \$50 per month total.

There are many other trampoline parks, such as Get Air, Climb Zone, and others. We have found most of these types of places to be friendly to special needs kids. A good idea would be to go once before purchasing a membership, to be sure that you are satisfied with the activities, environment, attitude of staff, etc. If your child gets overwhelmed by crowds or noise, try to find out when there is a quiet time to schedule visits. We have seen that it's usually quiet on weekday evenings, and Yehuda enjoys it much more then. Now that he has become so comfortable there, he will sometimes still enjoy a visit even at busier times.

**Billy Beez, Palisades Mall**  
(845) 535-9277  
1282 Palisades Center Dr,  
West Nyack, NY 10994

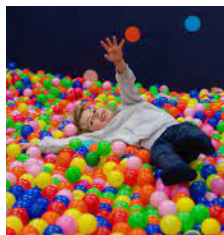


This is a really fun indoor playground In Palisades Mall. They have passes that cost \$210 for 10 times and it includes a free adult admission with the child.

The world tallest indoor ropes course is also at the Palisades Mall. For the right child, this can be a great activity.

**House of Fun 718-360-4662**  
1630 E 15th Street Brooklyn,  
New York 11229

House Of Fun is an indoor kids venue and is packed with a variety of bounce houses (including slides, play grounds and obstacle courses), a coloring center and arcade games. During the weekends, the open play includes face painting and live entertainment, such as a magician and balloon twisting!



A mother told me she was able to get the price of this covered by her self-direction budget (feel free to

reach out if you need help with this).

**Six Flags Amusement Park**  
661-255-4100

There are over 27 Six Flags theme parks in North America.



At the Jackson location, you can buy a Gold Pass, which will give you unlimited access to the park for only \$74.99. My friend bought it one year and was very happy about it. Her son only went twice, but it was a four hour trip each time, which meant eight hours of fun respite. Which works out to about ten dollars an hour; not bad!

My friend felt the same way that I did, that when therapists have to keep our children busy, there is a limit to how long they can last, and what they can do. Most of our home therapists are either young, or work really hard in their day jobs. Honestly, how long can we expect them to keep our child busy *Erev Shabbos*, or *Chol HaMoed*, or even just a long Sunday? I also want their interaction to be positive for everyone, and trips are fun— therapy toys just don't compare to Sky Zone or Six Flags! Volunteers really enjoy taking children to these places. It's entertaining for the child, and exciting for the therapist/volunteer, too.

**Field of Dreams**  
1511 North Bay Avenue, Toms  
River, NJ

Membership is free for special needs families. You can get a membership on their website or by visiting the park in person.



Field of Dreams is not far from our house, and we started going every Friday until Shabbos got too early. It is a really special place to visit. When we left the first time, my daughter said to me: "It's not only that no one stares at Yehuda, but we wouldn't even be able to go if we didn't have him!"



The park is a magnificent playground, all wheelchair-accessible. There is a miniature golf course, a variety of swings, and a basketball court with an option for wheelchair-bound or any other special children. There are game pavilions, books, places to sit, an unbelievably safe trampoline (Yehuda is on it in the picture) which also appears to be





wheelchair-accessible, and a zip line. There is so much attention to detail throughout. You truly feel privileged to have a special child/sib when going there.

They say that you need a smartphone to enter, but as of now, that requirement is not in effect, and you can go without it. In any case, your initial visit does not require one. Please note that they are closed until April 1st.

I went to a speech tonight, and the incredible speaker, Rifka Herman, shared a small anecdote that puts this all into perspective. She works in a kindergarten to help children with challenges. She once had a real drama queen under her care, and everything was simply earth-shattering with her. In that class, they celebrated birthdays without the mothers, so they took tons of pictures to send home. When it was this little girl's birthday, she came in her tutu and the whole get-up—she was absolutely shining. Everything was going great, and they were about to snap a stunning class picture, when the birthday girl realized that she was being squished by some of the other children. She completely fell apart, and the whole birthday party and happy atmosphere were at risk of a hard belly flop. The teacher looked at her and asked: “Are you the birthday girl?” to which she immediately perked up and said: “Yes!” with the greatest pride. The teacher said: “Well, birthday girls are supposed to be squished!” and magically, she cheered up and was just so delighted, because birthday girls are *supposed to be squished*.

This story screamed out to me loudly: Yehuda is supposed to be the way he is! I am supposed to buy endless bath mats to protect my floors. I am supposed to need to lock doors constantly and listen to siblings who are embarrassed.

The sweetness of it is *supposed* to be this way—giving up resistance and just accepting—I can feel the peace coursing through me. Hashem, it's just how it's supposed to be.

(If anyone knows just how many floods will decay wood floors and can predict when we are in danger of ceiling collapse, please let me know!)

I wish you all much success in finding things to keep your special *Neshmalach* busy, and your own sanity intact! May we all be *zoche* to recognize that this is how it's *supposed* to be, and may our lack of resistance create an opening to allow Hashem's *brachos* to flood our very essence!



## Right in Our Backyard

Yitti Berkovic

When we bought our house a few years ago, the realtor went on and on about our home's many added benefits – a great neighborhood, nearby transportation, and easy access to shopping (I'm not sure my husband saw that last one as a benefit).

The realtor made the sale, and we have been happy ever since, but he missed telling us about another sweet bonus, hidden from view behind the long rows of trees in our yard. We discovered that if you follow the path down the road until you can't go any further, and cut through the trees that snake uphill, you will find yourself smack in middle of a cemetery where several Chasidic *rebbe*s and *rebbezins* are buried.

I guess the realtor didn't think a cemetery was a selling point, and at first, I didn't think so either. If anything, it was an aggravation—there's extra traffic when there is a *yahrtzeit*, and, too often, visitors confuse my street for the cemetery's parking lot. But when I started meeting the people who had traveled from near and far to daven at these *kevarim*, I began to appreciate that maybe there is a not-so-hidden treasure right in my backyard.

I am not *Chasidish* and was not *zoche* to meet any of the luminaries while they were alive, but when I am feeling overwhelmed, when I am feeling anxious, when I am feeling like I need to just throw my burden up to Hashem, I can grab my *siddur*, walk my way down the block and through the trees, and add my *tefillos* to the vortex of prayer just steps from my home. It has become an incredible source of comfort.

The cemetery is never empty. I have gone in the early morning, and I have gone just moments before sunset, and there is always a hubbub of activity, with many women standing side-by-side, lost in their own worlds, lost in their own prayers, lost in their private gratitude or private pain.

Last week, it was even more crowded than usual when I stopped off on my way home from work. As I took my spot in front of the Ribnitzer Rebbe *ztz"l's* *kever*, I caught sight of a woman I know, leaning up against the *kever's* supporting wall. Really, I heard her before I saw her.

She was crying – no, she was *sobbing*. I don't know if she noticed

me, and I quickly pretended I hadn't seen her. To protect her? To protect me? I'm not sure. Either way, she seemed oblivious to my presence. She held her siddur high, covering her face, but doing nothing to muffle her sobs. Her cries were loud, aching, raw – *brutally raw*. And it gutted me – right through to my core.

I know her. She is a proud woman – beloved by so many for her warmth, her sunny disposition, her easy and loud laugh. How broken must she feel if she can cry like this so publicly? How badly must she be suffering to lose herself so completely? It was stunning; it was heart-wrenching—though I wasn't completely surprised.

I'd heard through the grapevine that she was going through *something*. I had clucked my tongue and sighed sadly, but I had moved on. Really, I had forgotten all about it – all about *her*. But now, the tiny room echoed with her sobs, and I felt so *stupid*. Why hadn't I thought about the depth of her pain? Why had I been so able to move on?

*Why?* Because it was her pain—not my pain. And I know, from my own experience, how difficult it can be to truly understand someone else's heartache.

A few years ago, our son Naftali, who has autism, went through a very difficult stage. For medical reasons, he needed to take a new medication, but the side effects were devastating: almost overnight, he became angry, aggressive, and even violent.

Suddenly, he went from being our baby-faced child to a grown boy (almost man?) who was stronger than I was, who was now scary and even destructive. He punched holes in walls and he shattered windows, rattled by a strength he didn't know how to contain.

In the throes of it all, Yossi and I didn't advertise what we were going through. We didn't want to scare our friends or our families; more than anything, we wanted everyone in our lives to feel comfortable around Naftali. But our secrecy was isolating, and it was an incredibly lonely time for our family.

At the end of a long day, my husband and I would fall onto the

couch, stare up at the ceiling, and as he listened, I lamented. “How can they expect us to get to that wedding if we cannot leave Naftali?” “How can they expect me to prepare a meal for that new mother if I can barely find the time to cook for our own family?” “Why don't people understand how hard this is for us?”

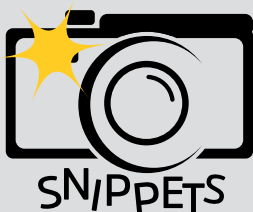
But of course they couldn't understand. Even the people we told, those who clucked their tongues the way I had clucked my tongue, didn't really get it. How could they? They weren't *here*, they weren't living this with me. They didn't feel my frustration, my helplessness, my anger, my hurt. They saw me with my fixed smile, with the makeup covering the bags under my eyes, with my fierce desire to continue like everything was normal. Even if they listened to my heartache, they didn't *live* my heartache, and that created a barrier between my experience and theirs.

Baruch Hashem, Naftali's aggressive stage eventually passed, and he is now back to his (mostly) adorable self. But that loneliness has stayed with me. That loneliness should have been the impetus for me to be a little more thoughtful, a little more empathic, a little more *pained* when I first heard about the sorrows of this woman standing beside me. It shouldn't have taken me to *hear* her heartrending cries for me to cry alongside her, for me to cry along *with* her.

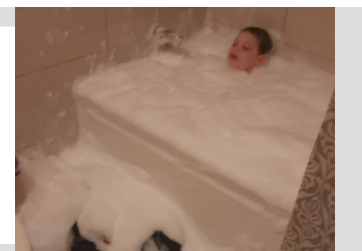
Rabbi Akiva taught us the commandment of *v'ahavta l'rei'echa kamocha* – and its message has been distilled into the sweet songs we teach our children this time of year, as *sefira* draws near. Sometimes, though, even as we sing it, we forget to *live* it. Sometimes we forget that it might just be the hardest commandment of them all.

*Sefira* is a time when the wedding bands go silent and we turn off our own music. Maybe we can use this quiet time to listen a little bit harder. To listen for the stories that aren't spoken aloud. To listen for the heartache that gets drowned out in the noise of the everyday. To listen for the suffering happening right in our backyards. This way, when we daven, it's not just for our own pain – but also for the pain of those standing alongside us.

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



**Attention Yehuda Dickstein:  
Don't think you're the only one who  
knows how to take a good bath!!!**





## RESOURCE GUIDE - Part IV

*Helpful resources you may not know about*

E. Hazzan and D. Wadiche

### EQUIPMENT/THERAPY GRANTS:

#### 1. The Special Children's Foundation

[Grants@ffsni.org](mailto:Grants@ffsni.org)

Email for application. For items/equipment not covered by insurance.

#### 2. Special Angels Foundation

[www.specialangelsfoundation.org](http://www.specialangelsfoundation.org)

[specialangelsfoundation@gmail.com](mailto:specialangelsfoundation@gmail.com) | 888-835-3919

4195 Chiano Hills Parkway #373

Chiano Hills, CA 91709

Grants for children ages 0-18 with all types of special needs, including autism.

Up to \$2500 in assistive equipment, essentials that will help the child learn or grow: wheelchairs, iPads, etc.

Also \$1500 toward therapy, including "out of the box" therapies (ie: horse therapy).

Money is paid directly to the provider, or the Foundation will buy the item for you.

Apply online; expect an answer within the month.

For a paper copy, call: 848-326-1512, then email or mail it back directly to them.

#### 3. Small Steps in Speech

[Info@smallstepsinspeech.org](mailto:Info@smallstepsinspeech.org) | 1-888-577-3256

Helps pay for speech therapy. Paid directly to therapist.

Requires a letter from the speech therapist indicating how often sessions are held and the charge.

You will need to prove that insurance does not cover the therapy and they will ask if you ever received a speech grant from another organization.

You will need a biography on the child, and they may also ask for the IEP if you have one.

Funds must be used within a certain amount of time, so only apply when you're ready to start.

#### 4. The Orange Effect

[www.theorangeeffect.org](http://www.theorangeeffect.org) | [info@theorangeeffect.org](mailto:info@theorangeeffect.org)

Helps pay for speech therapy. Paid directly to therapist.

Requires a letter from the speech therapist with how often sessions will be and the charge.

You will need to prove that insurance does not cover the therapy, and they will ask if you ever received a speech grant from another organization.

You will need a biography on the child, and they may also ask for the IEP if you have one.

Funds must be used within a certain amount of time, so only apply when you're ready to start. They require the therapist to send in summaries of the sessions.

*(Ed. Note: If you are looking for a speech grant, the application process for Small Steps and The Orange Effect are very similar, and it is a lot easier to apply for both of them at the same time, rather than trying one and then, later on, the other.)*

### FINANCIAL ASSISTANCE/GRANTS:

#### 1. Fred's Footsteps

[www.fredsfootsteps.org](http://www.fredsfootsteps.org) | 484-368-3602

Support for sick or disabled children.

They help with home modifications, vans (as well as car repairs if you need to travel back and forth to the hospital), and equipment. They also help cover household bills that are piling up due to medical expenses, and lost wages of parents who are forced to leave work or reduce their hours to provide round-the-clock care of a child.

Vendors are paid directly.

One-time acceptance to the program – up to \$10,000 during a one-year period.

Ex: If you require a ramp, they ask you to get three estimates from local vendors and have your hospital social worker upload it on the website. If approved, they chose one of the vendors to pay.

One or both parents must be employed, or on temporary leave due to their child's illness.

A hospital social worker needs to apply for you.

Social workers at CHOP (Children's Hospital of Philadelphia) are familiar with this program and are happy to assist you.

You can request a social worker from your hospital if you weren't assigned one.

#### 2. MyGOAL Autism Grant

[www.mygoalinc.com](http://www.mygoalinc.com) | 877-886-9462

Applications are open from January to April each year.

\$1000 grant for families with an autistic child of any age.

There is an income limit.

Funds can be used at parents' discretion. You will be required to send in a picture and testimonial video if awarded the grant.

Apply online. You can reapply yearly.

#### 3. Kelly and Dolan Memorial Fund

[www.dolanfund.org](http://www.dolanfund.org) | 215-643-0763

Offers financial assistance of up to \$500 yearly. They pay bills directly for car, phone, electricity, water, etc. if there is financial difficulty due to a child's illness/disability.

Assists families in NJ, Pennsylvania, and Delaware.

Referrals to the program must be made by a healthcare provider or social worker.

#### 4. Autism Care Today

[www.act-today.org](http://www.act-today.org) | 805-506-5235

Assistance for children with Autism

See website for FAQs or go directly to <https://app.smarterselect.com/programs/82733-Autism-Care-Today> to apply. Have your tax return (you can block out SS#) and proof of diagnosis ready to upload.

Grant payments will be made directly for pre-approved treatment. You will be asked to fill in the provider's information. You can choose only one item to apply for up to \$5000 in any of these categories:



compiled by Fraydel Dickstein

One night I took my son Shaya, who has Down syndrome, to *Eyes on the Nine* to get eyeglasses. There was a large Lego table out in the waiting room for kids to play with. Another boy was building on it, and I was worried that Shaya would ruin his tower, or worse. The boy's father saw that Shaya wanted to play, albeit his son was none too pleased to share. The father sat down at the table next to his son and said: "Of course Shaya could play. Shaya is our new friend!" Shaya was thrilled!

When his wife came out, Shaya ran over and said to her: "You have a paper!" in his adorable voice, while nearly grabbing her prescription out of her hands. She said: "I am so happy to see you—of course you can see my paper!" The way this man and his wife treated Shaya, with so much respect and friendliness, had me on a high the whole week. How I wish there would be many more couples like them!

Yossi, my sweet, sensitive, fun-loving 9 year old, loves to play with Zevi, his special needs 5 year old brother. They roll around together, laughing, and riding bikes around the dining room. One afternoon, Zevi happily went out for a few hours with a wonderful volunteer. I was enjoying tending to my other children with more focus, when Yossi said: "Mommy, when is Zevi coming home already? It's too boring without him!" I did a double take and thanked Hashem for both of my special boys!

Deena is basically non-verbal. One day I told her that I was going to make supper for her soon. She took a children's book out of her bag, flipped a few pages, and pointed to a picture of kids having pizza.

"You want pizza for super?" I asked. She said: "YEAH!"

Of course, I gave her pizza. I had already put a package of pasta on the counter. After I gave her the pizza, I noticed that the pasta was back in the pantry!

Noach wanted mustard desperately, but he could not get it open. In desperation, he threw it on the floor and it exploded all over! After he enjoyed his mustard, he tried to find the cover to put it away. Noach said: "Please Hashem, help me find the cover to the mustard! We need to *daven* to Hashem. We need a *siddur*!" He took a *bentcher* from the Shabbos table and started to *daven* with it. My husband came by and said maybe I had thrown the mustard top in the garbage. And there it was—Noach's precious *tefilos* were answered! I was so grateful to Hashem that Noach, my child who is so limited, got it that we need to *daven* to Hashem and was able to communicate this. *Hodu L'Hashem*—how great are Your ways!

One Friday night I was complaining out loud that I wouldn't be able to sleep because my son Chaim had turned on my bedroom light. My five-year-old daughter overheard and said: "Mommy, just *daven* that he should be regular!" Then, after thinking a minute she continued: "But I won't! Hashem made him like this, and I love him just how he is!" Somehow, after hearing her cute *mussar*, my annoyance melted away!

This Shabbos we had over my married nephew, his wife, and their precious baby boy.

In the afternoon, the mother went to take a nap and my kids got to enjoy the baby. When my daughter Yehudis (age 9 with special needs) woke up from her Shabbos nap, I brought her into the playroom so she could "play" with the other children, AKA fall all over their creations and mess up their games. When she came, Esty (3), piped up in her squeaky voice and said: "We're so lucky that we have our yummy Yehudis—and a yummy baby too. Right, Mommy?"

Right, indeed!

Applied Behavior Analysis (ABA) Therapy, Assistive Technology, Legal Assistance, Medical Premiums and Co-pay, Medical Testing, Occupational or Speech Therapy, Safety

Equipment (ie: Fencing, GPS Tracking Device), Sensory Equipment, Social Skills Program, Tuition Assistance, or enter your own—although they may not consider other requests.



## 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!

# Perfectly Calculated

T.S.

*Hashem knows just how much we can take. I see time and time again how Hashem sends along the perfect helpers, the perfect “pick-me-ups” .. all at the perfect time and in the perfect place.*

Sundays are not easy days for me, what with trying to take care of everything with all the kids home. Thank Hashem for Lakewood’s Special Children’s Center, which offers a wonderful Sunday program for our son Yossi. The only issue is that the day is over quite early, with Yossi coming home at around 3:15. I was talking to a friend, another “special” mom, telling her how Sunday dismissal is way too early, and how I really felt that I needed someone to take him straight after Center. A little later that very day(!), I got a call from a previous Center *morah*, asking permission to take Yossi for the floor time hours she needed for college. Since he comes home quite late the other days, the only time that would work was Sundays straight from Center. Not only didn’t I have to ask, but instead of me thanking her (Don’t worry, I did!), she was thanking me! After about an hour of quality time spent with a *morah* he adores, she would even bring him home. I realized that I needed to stop worrying, as Hashem really takes care of our special children!

We had an appointment at CHOP with a new doctor, back in the beginning of our journey. We brought along some videos of Yossi’s seizures, since he often had unusual seizures along with a clean EEG, so it wasn’t clear what was going on - to us or the doctor. We were in the waiting room and Yossi was playing nicely when he suddenly had a seizure. This was very unusual because Yossi *never* had seizures out of the house and was also usually sick beforehand. The doctor came and checked him out on the spot. She was able to see exactly what was going on. Interestingly enough, it was a short seizure, and he was fine by the time we came home. We felt Hashem gave him that seizure just to give us all clarity. Even the doctor

was amazed by this clear *hashgacha*!

Yossi is on a very restricted diet and is only allowed to eat what we give him and nothing else. Of course, I always warn the bus drivers that it’s dangerous for him to eat anything. I recently got a call from a mother of a child on his bus who “happens” to once have been on the same diet. She wanted to let me know that the driver asked her for a banana (which is full of carbs and dangerous for Yossi) because the driver forgot to bring one for Yossi that day. This mother told the driver off, and I did as well, and the driver apologized and B”H all’s well. But what are the odds that the driver asked for a banana from the one person who knows Yossi and his diet? Hashem is looking out for our children! (That also solved the puzzle of why Yossi’s numbers were so low *and* why he was excitedly running onto the bus every morning!)

One Friday I got a knock on my door. A *frum* lady I didn’t know was standing there with Yossi. But wasn’t Yossi playing upstairs with his older sibling? Apparently not! We are not sure what and how it happened, but evidently he got tired of playing and decided to walk to his volunteer. *Shomer p’saim Hashem!* The mother of a different volunteer passed by Yossi a few blocks away (just a half block before a very busy intersection!). Her daughter had taken Yossi out only once or twice, but the mother remembered him and brought him home safely. I must also acknowledge that Hashem even saved me from the panic of realizing that my son wasn’t home and from the stress of looking for him. This reminded me that every ounce of pain and worry is measured out and accounted for!

One Friday I went with Yossi’s brother to the shoe

store. I only realized when I got there that I had left my phone at home. This was a first, but my husband was home with my kids and I figured they could manage without my availability for a bit. We ended up needing to go to another store, and it took longer than expected. We came home (with shoes, B”H) to see a bunch of *Hatzalah* ambulances in front of our house. While we were gone, Yossi had a really serious, long seizure. It had taken place a while earlier, and by the time I walked in, he was sleeping peacefully and *Hatzalah* was packing up and leaving. My husband said it was the scariest seizure he’s ever seen. Hashem knows exactly how much I could handle, and selfish as it sounds, I’m not sorry it took so long or that I left my phone at home!



Yossi had a very severe long seizure that would not stop so they were transferring him via helicopter to CHOP. The plan was that my husband would fly with him and I would go home to our other children and join him the next morning. I was very distraught and had no energy to even tell anyone, so I figured I would just manage on my own. It was Sunday and the kids were just hanging around while I said *Tehilim* in my room. My sister in law was calling but I ignored it, but then I heard her message on the answering machine and couldn’t ignore it! “Hi, I hope I’m not being nosy but I happened to be leaving the dentist earlier and saw Yehuda going into a helicopter with Yossi. I am coming to pick up your kids.” It was the sweetest spices and I suddenly felt like I received a hug from Hashem! My kids came home later that night ready for bed, supper eaten, and a great time had by all. I was able to daven and relax, proof again that Hashem knows exactly how much we need to go through, and is with us every step of the way!



It was *bein hazmanim* and I felt like I really needed a getaway with my husband, but with Yossi, even going away for one night gets complicated. I tried a responsible older niece and another older girl who knows Yossi, but for different reasons they were unable to help. “Oh well,” I thought, “maybe it’s just not bashert.” Little did I know that Hashem had a better plan than I could have ever imagined. The next day I bumped into my younger sister-in-law and she asked me if I have any plans. I told her that I had wanted to go away but it wasn’t working out. Very naturally, she said: “Binyomin (my brother/ her husband) is home now and I’m not working. Why don’t we come sleep by you? It’ll be a little vacation for us!” And so, without me even having to ask, Hashem sent my sister-in-law (whom my kids adore and who is super responsible) to babysit. She did not even let me call home, and begged us to stay away a little longer! Hashem made sure we would have a relaxing

vacation, with every detail taken care of!



I had a baby on Thursday and my husband very kindly and firmly had me stay in the hospital for Shabbos. It would be hectic at home with the kids home and my parents there for the *kiddush*, and I needed my rest. What my husband neglected to mention (for fear I would run home), was that Yossi was having a hard time, having seizures and throwing up. Somehow my husband got through it, but at one point he said he couldn’t anymore. He had to go to *Mincha* and simply needed a break to learn and relax. As he walked downstairs, he was surprised to see a girl playing with Yossi in the playroom. He thought *Eliyahu HaNavi* had arrived! When asked where she came from, she said that she was passing by and figured she would come see if it was a good time to play with Yossi. She didn’t know I was in the hospital and she wasn’t sent by anyone... aside from Hashem!



We had my extended family Chanukah party on *motzai Shabbos* in Brooklyn. I made a few half-hearted attempts to get a babysitter, but I knew it would be almost impossible to find someone available all night on *motzai Shabbos* Chanukah. I decided that in the worst-case scenario, my husband would stay home with Yossi and I’d drive in with the rest of the kids; a difficult feat for me but, oh well. Early on *motzai Shabbos*, before I’d had a chance to make a single call, my niece called to say that her Chanukah party was canceled at the last minute and that she’d be happy to come with her friend for as long as we needed. (I know one reason why her party was canceled!)



Yossi’s seizures were generally early morning. I have always been anxious that my other children shouldn’t feel the trauma as I do because of their brother’s seizures. Baruch Hashem, my children would somehow miraculously sleep through countless *Hatzalah* members trekking through the house, coming in with their beepers, machinery, and all. The children rarely ever saw Yossi experience a seizure. In the morning, they would say some *Tehilim* and go off to school, blissfully unaware. I once heard one of them comment: “Big deal, he always comes back home at the end.” (BH!) One time, my baby needed stitches and *Hatzalah* came. I overheard my kids saying that this is much scarier than when Yossi has a seizure (Just for the record, Yossi looks very scary during his seizures—white face, blue lips, rolling eyes, etc.). I realized that, because they never witnessed the seizures, they were not traumatized by the idea of them. I once again felt the *chesed* of Hashem and appreciated how every part of this *nisyaon* is measured out to the smallest detail.



Shifra Kaufman

# *Dear Neighbor*

I see it in your eyes every day. That immense pain, but also that vast love. We don't stand together physically, but our hearts unite with our similar feelings. You are a small woman, but I know that inside you are as strong as a rock. As you take your little boy, thrashing and fighting, off his bus, I know you feel pain from the hardship you were given, but also a fiercely strong love for the child who is called your own.

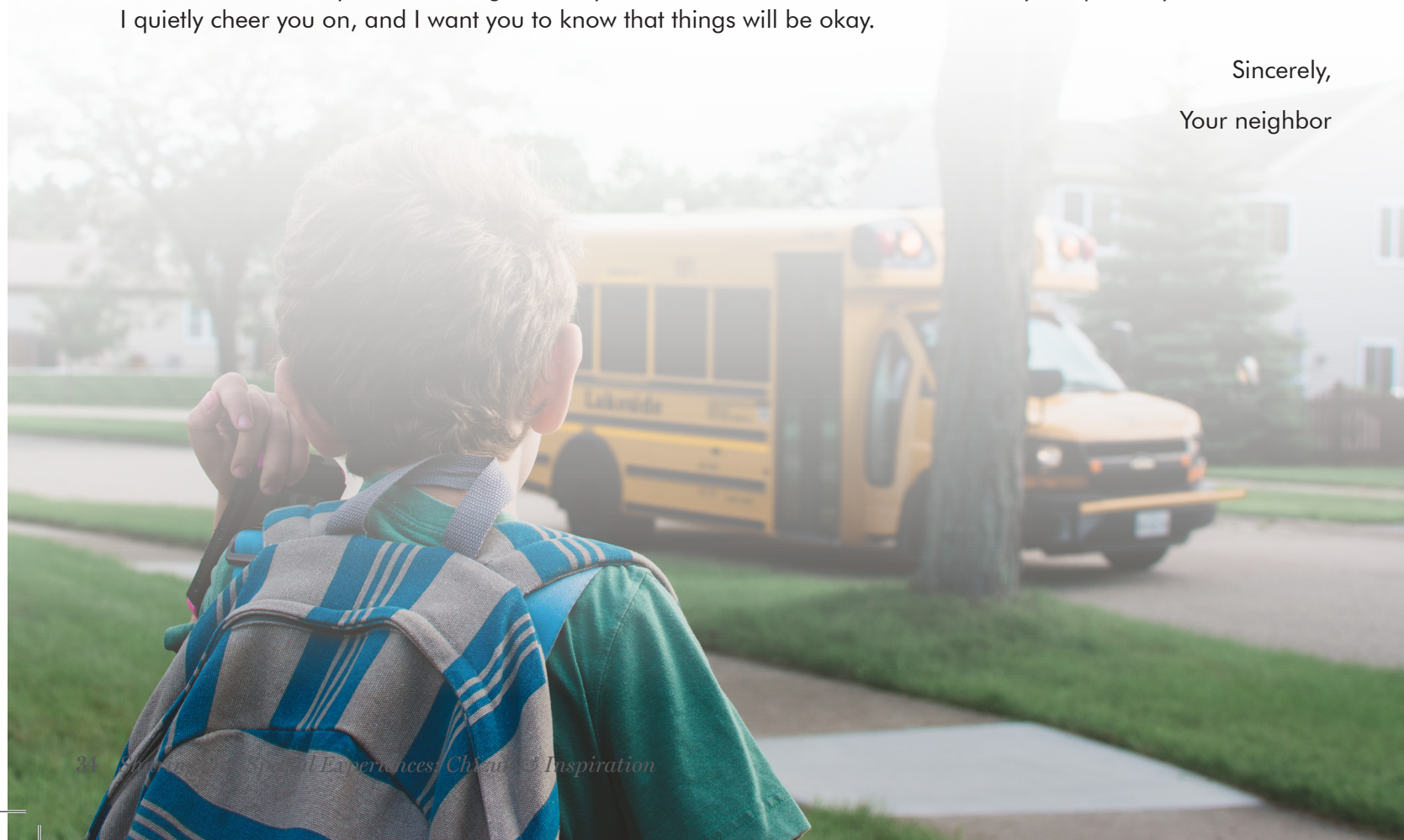
My daughter is not the same as your son. My daughter can't see Hashem's beautiful world like your son can. My daughter can't speak, so she doesn't say the harsh words that your son does. But both of our children have special needs – both different, and both challenging.

Every day when I pass you getting your son from the bus, while I get my daughter from her van, I feel united with you in feelings of pain, love, and the wonder of how we will do it all over again tomorrow. As you and I both dress, feed, and bathe our children again and again, we love them more and more, until our hearts are bursting with a motherly pride that no one can ever take away.

I am just as proud of my special daughter as I am of the rest of my children. Proud of her small and steady improvements. Proud of how hard she is trying to be normal in her abnormal body and environment. And I'm proud of myself, for pushing forward even when I have a bad day. When it's feeding time and she's screaming and I patiently (or not so patiently) get her to eat a little more—that's courage.

While the pain of knowing that life will always be different for us still stings, there are so many parts to love and hug and never let go. So, my dear neighbor, although we are different from one another in so many ways, just know that I am with you. And though we may seem to inhabit different worlds, I really am part of your world, too. I quietly cheer you on, and I want you to know that things will be okay.

Sincerely,  
Your neighbor



## GLOSSARY OF HEBREW TERMS APPEARING IN NESHAMALE MAGAZINE

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

**Afikoman** – Matzah hidden at the Passover Seder (A)  
**Aibeshter** – The Creator (Y)  
**Aleph Bais** – Hebrew alphabet  
**Aliyos** – Being called up to the Torah  
**Aron Kodesh** – Holy Ark in synagogue  
**B'Ezras Hashem** – With the help of G-d  
**Bein haZ'manim** – Yeshiva vacation break  
**Bekishe** – Long Chassidic-style coat (Y)  
**Bentcher** – Booklet containing the Grace after Meals (Y)  
**Bentching** – Reciting the Grace after Meals (Y)  
**B'vi'yas Mashiach Tzidkeinu, bi'm'heira v'yameinu** – With the timely coming of our righteous Messiah  
**Bimah** – Elevated stand or table  
**Birchas haTorah** – Blessing over the Torah  
**Birchas Hedyot** – Blessing from a non-Cohen  
**Birchas HaShachar** – Morning Blessings  
**Bitachon** – Trust in G-d  
**Baruch Hashem** – Blessed is G-d; Thank G-d  
**Bracha/Brachos** – Blessing/s  
**Chasidish** – Hassidic Jews who adhere to the teachings of certain Rabbis (Y)  
**Chazoras haShatz** – Repetition of the Shmonah Esrei prayer  
**Chein** – Grace, charm  
**Cheshbon** – Calculation  
**Cheshbon haNefesh** – Taking account of one's actions  
**Chizuk** – Strength, encouragement  
**Chol HaMoed** – Intermediate days of the holidays of Passover and Succos  
**Chumash** – Five Books of Moses  
**Daven** – Pray (Y)  
**Eemunah** – Faith in G-d  
**Fleishig** – Meat (Y)  
**Gadol haDor** – Great rabbi of the generation  
**Gemara** – Talmud (A)  
**Geulah** – The Redemption  
**Hagaddah** – Guidebook to the Passover Seder  
**HaKadosh Boruch Hu** – The Holy One, Blessed is He  
**Hakafos** – Dancing in circles—with the Torah on Simchas Torah; with Lulav and Esrog on Succos  
**Hashgacha Pratis** – Divine Providence  
**Hatzlacha** – Wish for Success  
**Heilige** – Holy (Y)  
**Hishtadlus** – Effort  
**Isru Chag** – The day following a Jewish holiday  
**Kever/Kevarim** – Grave/s  
**Kiddush** – Blessing to sanctify Shabbos or Yom Tov, made over wine

**Kriyah** – Tearing one's garment as a sign of mourning  
**L'netzach netzachim** – For all eternity  
**M'kayem** – To fulfil  
**Machenech** – Educator  
**Mechilah** – Forgiveness  
**Megillas Esther** – The Scroll/Book of Esther  
**Mentchies** – Little toy people (Y)  
**Middos** – Character traits  
**Mincha** – Afternoon prayer service  
**Mishnayos** – Teachings of the Oral Torah  
**Mitzrayim** – Egypt  
**Moichel** – Forgive  
**Morahs** – Teachers  
**Motzei Shabbos** – Post-Shabbos  
**Mussar** – Ethical teachings  
**Neis** – Miracle  
**Nekudos** – Points, Hebrew vowel/accent symbols  
**Neshama** – Soul  
**Nigun** – Tune  
**Nisyonos** – Tests  
**Olam haBa** – The World to Come  
**P'nim** – Internal  
**Pareve** – Neutral in Kashrus, neither milk nor meat  
**Parasha** – Weekly section of Torah  
**Pekel** – package, also burden (Y)  
**Pokei'ach Ivrim** – He (G-d) opens the eyes of the blind  
**Rachmanus** – Mercy  
**Rebbe/Rebbs** – Chassidic Rabbinical leaders; also Elementary school Torah teachers  
**Rebbetzin** – Rabbi's wife (Y)  
**Ribono Shel Olam** – Master of the World (G-d)  
**Sedarim** – Torah learning sessions; also Passover Seders  
**Seder** – Ritual Passover dinner  
**Seforim** – Books  
**Seuda** – Festive meal  
**Sheker** – Lie, falsehood  
**Shemoneh Esrei** – the Amidah, main Hebrew prayer  
**Shiluchim** – Emissaries

**Kedusha** – Holiness  
**Shores/shorashim** – Root/s  
**Shtenders** – Tall book stands (Y)  
**Shuckle** – Rocking back and forth while praying (Y)  
**Siddur** – Hebrew prayer book  
**Sifrei Torah** – Torah scrolls  
**Simchas Torah** – Holiday of Rejoicing with the Torah  
**Siyata d'Shmaya** – With the help of Heaven (A)  
**Tefilla** – Prayer  
**Tefillas Shacharis** – Morning prayer service  
**Tefillos** – Prayers  
**Tehillim** – Psalms  
**Teva** – Nature  
**Tu b'Shevat** – Jewish Arbor Day  
**Tzadik** – Righteous person  
**Yachatz** – Ritual of breaking the matzah at the Pesach Seder  
**Yahrtzeit** – Anniversary of someone's death (Y)  
**Yarmulkas** – Skullcaps (Y)  
**Yedios** – Jewish concepts  
**Yom Tov** – Jewish holiday  
**Zechus** – Merit  
**Zeeskeit** – Sweetie pie (Y)

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A close-up photograph of a bouquet of tulips. The bouquet includes several white tulips at the top, transitioning into a dense cluster of pink and red tulips, with some orange and yellow ones at the bottom. The flowers are covered in water droplets, suggesting they are fresh or have been misted. The background is a dark, out-of-focus green, likely foliage. A quote is overlaid in the upper left quadrant in a yellow, cursive font, flanked by two yellow double-slash symbols.

*// When you change the way you  
look at things, the things you  
look at change. //*