



After the Diagnosis...

WHAT A FAMILY WITH AN AUTISTIC CHILD NEEDS

by KAREN GILAT

Karen, Zeev and Ivy Gilat, courtesy of gilat.org

THE MOMENT I LEARNED I WAS PREGNANT, I BOUGHT A BOOK, *The Jewish Parenting Book*—my first official purchase. At that time, I was a full-time cantor, living and working in Omaha, Nebraska: Everything in my life had a Jewish frame. I told myself that if I was going on a journey, I needed guidebooks. Months of pregnancy passed, and parenting books spilled from the nightstand—procreating, too, it seemed, while my husband and I slept.

Zeev—meaning radiance—was born on a blue moon late in the summer of 1993. Soon, my husband and I would learn that there weren't books yet written to prepare us for this journey. Zeev's course seemed unchartable, and books—the tools I'd always used to find my way—were inoperable here. Slowly, sometimes painfully, my husband and I stumbled forward, finding our own ways, not always in sync, negotiating, sidestepping boulders on the path. I put my half-read books on a distant shelf, and for the first time in my life set forth without them.

Zeev's first few years were a blur of melodic dissonance: Nothing adhered to anticipated scripts. Zeev refused to play with toys, but studied loose yarns in the rug intently. The ceiling fan held him rapt. If another mother on the playground laughed or sneezed, he'd scream so relentlessly that we'd have to go sit in the car. Strapped into his car seat, Mozart would abruptly soothe him. Fussy about everything, he cried all the time, until one day all crying suddenly stopped. He refused all

solid food. Patently uncomfortable in his own skin, to us he was entirely a mystery.

IN THOSE DAYS — THEY SEEM SO LONG AGO NOW — ALMOST NO ONE SAID "AUTISM," and Zeev wasn't formally tested until he was four. At age one, though, my husband and I were told that our son had a "condition"—Pervasive Developmental Disorder, Not Otherwise Specified. It meant little to us (as parents, Zeev, at some point, had simply become Zeev), but the label helped us, for the first time, find fellow travelers. It was at this point that our journey to meet Zeev halfway really began.

We moved to Seattle and I once again became pregnant, doctors having assured us that "it" wouldn't happen again. Lightning doesn't strike twice, right? Wrong. Ivy Noam was born in 1999, and she is also on the autism spectrum.

Today, bookstore shelves groan with guidebooks about autism; the disorder is now an epidemic. In relation to Jewish life, though, "autism families" often still feel the way I did during Zeev's early years. Along with my heartbreak and numbness in relation to Zeev, came a separate sense of feeling "outside" the Jewish community, of feeling crushingly alone.

It felt so painful to have friends give birth to typical children, and then effortlessly find a home in the context of synagogue holidays and rites of passage. While they joyfully accompanied their children to "Tot Shabbat" programs, enrolled them in Jewish pre-schools, and delighted in thinking about their kids' Jewish futures—a bar/bat mitzvah; a trip to Israel, perhaps; a

Jewish summer camp; the year the child would be old enough to recite the Four Questions and later, maybe, to lead the whole Seder; that day when they'd stand beneath a *chuppah*—my husband and I felt so vulnerable and forgotten.

FOR ME, IT FELT THAT JUST AS I'D LOST THE GUIDEPOSTS TO MY CHILD'S FUTURE, Judaism withdrew its guideposts, too. Would there be a place for us in Judaism if Zeev, and then later Ivy, couldn't participate in any of Judaism's developmental passages? Deeply Jewishly-identified, I would have done anything for an outstretched hand.

THOUGH MY FAMILY IS TOO FAR ALONG IN ITS JOURNEY to participate in the kind of ceremony that I limn [see below], it is not too late for families who are now finding out—or who will find out in the future—that they have children with disabilities.

First, though, I want to encourage rabbis and cantors to reach out to these parents when they hear that something's developmentally amiss—whether that be in relation to the child adopted from abroad, or to the biologically-related one born right here. Pick up the phone. Say, "I hear your child's been diagnosed. Can I visit?" The parents will feel so embraced...so embraced by Judaism. Let them feel that Judaism is there for them; not just at a bar/bat mitzvah, but at the beginning—whatever that beginning is. At the visit, just sit with them. Have a cup of tea. Sing "*Eli, Eli*" or a wordless *nig-*

gun. Share a prayer, perhaps, or a Hebrew poem. Don't worry about what to say; being speechless is also appropriate.

LET THE FAMILY KNOW THAT YOU'RE THERE TO ACCOMPANY THEM—that every parent's path through dealing with such news is different, and no one can predict how they, in particular, will find their way through so many emotions.

*Don't worry about what to say.
Being speechless is appropriate.*

Acknowledge that their path will be different, but affirm that there will be light. Hold in your mind a vision of family healing. Tell them that when they're ready, Judaism has something to give them: a ceremony. Promise them this.

Maybe they won't want it, but maybe they will. Maybe they will want it some day in the future when they feel ready to acknowledge their acceptance of their child's diagnosis. Maybe they will want it at their home with just a few people present, or with other parents of children with disabilities farther along in their journeys. Maybe they will want to have a ceremony in the synagogue. Tell them that some day—if they want it—Judaism is there to sacralize their path.

If my husband and I had had such an experience, it could have changed our world. ■



Havdalah – A New Ritual



TO WELCOME AN AUTISTIC CHILD INTO THE JEWISH COMMUNITY,
AND TO AFFIRM PARENTS' ACCEPTANCE OF THEIR CHILD'S DIFFERENCE

INSTRUCTIONS: *Turn the lights low and light the braided Havdalah candle.*

LEADER: Havdalah is the short, sweet ceremony traditionally performed at the end of the Sabbath to usher out the holy day of Shabbat and to usher in the more ordinary days of the week. Havdalah honors difference, and teaches that the world was created through difference: In *Genesis*, God separates light from darkness, then water from empty space, then Earth from water. We celebrate difference, too. Tonight, we celebrate ____, a child with autism who is different from neuro-typical children. Our tradition teaches us that difference is sacred.

PARENTS: Through this ceremony we share with all of you here our acceptance of ____'s difference as sacred.

We accept her diagnosis while knowing, at the same time, that she is much, much more than her diagnosis. We honor ____'s difference while working, at the same time, towards helping her live more fully and comfortably in the larger world. Through this ceremony, we commit to meeting ____ *where* she is—*as* she is—and we also commit to enriching who she *can be*.

ALL: Prayer cannot bring water to parched fields, nor mend a broken bridge, nor rebuild a ruined city. But prayer *can* water an arid soul, mend a broken heart, and rebuild a weakened will. Blessed are You, Creative Source in the Universe, Who helps us appreciate this difference. **AMEN.** [adapted from *Gates of Prayer*]

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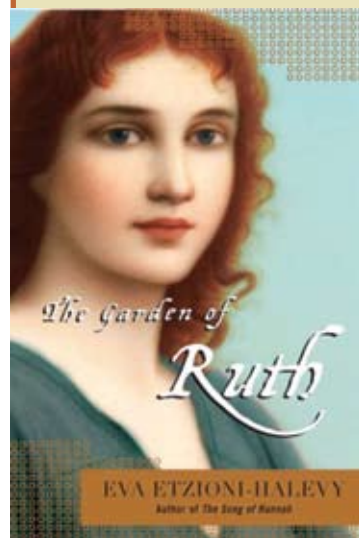


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The Garden of Ruth

Eva Etzioni-Halevy



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Plume/Penguin, 2007.
ISBN 978-0-452-28673-3.
Available through bookstores and online through the author's website:
www.evaetzionihalevy.com.

A PRAYER FOR COMMUNITY

INSTRUCTIONS: *Hand over hand, an adult helps ____ hold aloft a ceremonial cup brimming with sweet wine. All join in a wordless chant.*

Yay-bay-bay... ♪♪♪

ALL: A prayer for community: *Barukh Atah Adonai, Eloheinu Melekh ha-olam, boray pree ha-gafen.*

PARENTS: Blessed are You, Creative Source in the Universe, who bids us share, in joy, this cup of sweet sweet wine, rather than drink from it alone. May we recognize that ____'s need for connection and community is different from ours. Help us help *her* communicate more clearly, make better eye contact, and more fully read faces and emotions. May we honor and bless ____'s different understanding of relatedness, while at the same time praying for her to join all of us—her “team”—in the hard work ahead of forging connections: with herself, with her family, and with her community. **AMEN.**

ALL: May we be bound as a community of teachers to—and learners with—this child. We commit to this task of learning and adapting as we go. **AMEN.**

A PRAYER FOR THE SENSES

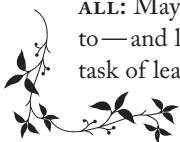
INSTRUCTIONS: *An adult helps ____ hold aloft, and then pass, ceremonial spices. All take a big whiff.*

Yay-bay-bay... ♪♪♪

ALL: A prayer for the senses: *Barukh Atah Adonai, Eloheinu Melekh ha-olam, boray meenay b'sab-mim.*

PARENTS: Blessed are You, Creative Source in the Universe, who bids us delight in our senses—smelling, tasting, seeing, touching, hearing. May we recognize that ____'s sensory experience is different from ours: Rain feels like bullets, a fly sounds like a 747, and textured food touching her lips overwhelms her. May we honor and bless ____'s different sensorium—lying on the floor with her, watching the fan overhead—but also lovingly prod her to engage with the world more fully. We pray for ____ to join all of us—her “team”—in the hard work ahead of heightening her tolerance for sensory experience.

ALL: May we be bound as a community of teachers to—and learners with—this child. We commit to this task of learning and adapting as we go. **AMEN.**



Cantor Karen Webber Gilat, a hospital chaplain, is also a poet, actress and liturgical/performance artist. Her autobiographical one-woman show, “Full House,” is about two artists raising two kids with autism. She also gives presentations about how to include families with children on the autism spectrum in synagogue life. To see the joyful Gilat family, go to Gilat.org.

A PRAYER TO HALLOW DIFFERENCE

INSTRUCTIONS: *An adult helps ____ hold aloft the braided Havdalah candle. Those gathered hold their hands to the light, noting difference: both light and shadow.*

Yay-bay-bay... ♪♪♪

ALL: A prayer to hallow difference: *Barukh Atah Adonai, Eloheinu Melekh ha-olam, boray m'oray ha-esh.*

PARENTS: Blessed are You, Creative Source in the Universe, who bids us, through the ceremony of Havdalah, to relish difference. In the light and the shadows cast by these intertwined wicks, may we celebrate what has been brought “into the light” about autism—and also recognize how much we still need to uncover. May we honor and bless those exploring autism's mysteries, and pray that their research brings us increased understanding. Speedily and in our day.

ALL: May we be bound as a community of teachers to—and learners with—this child. We commit to this task of learning and adapting as we go. **AMEN.**

A PRAYER FOR THE JOURNEY

ALL: **Yay-bay-bay...** ♪♪♪

ALL: A prayer for the journey: *Barukh Atah Adonai, Eloheinu Melekh ha-olam, ha-mav-dil ben kodesh l'chol.*

PARENTS: Blessed are You, Creative Source in the Universe, who calls us to this sacred journey, a road twisted like the Havdalah candle, filled with laughter and tears. You enable us to separate ____ from her diagnosis, and to celebrate the holy in our child.

ALL: May we be bound as a community that has committed to sensitizing itself to autism. We are grateful to ____ and her family for being our teachers. We welcome ____ and other children like her into our community. Speedily and in our day. With open arms. **AMEN.**

INSTRUCTIONS: *Pass the wine and drink, and then douse the flame in it. Turn up the lights and end by singing.*

ALL SING: *L'chi Lach*, to a land that I will show you.
Lech L'cha, to a place you do not know.
L'chi Lach, on your journey I will bless you.
And you shall be a blessing,
You shall be a blessing [2x],
L'chi Lach.

