

Home Alone

A mother's mission: that her autistic son become an independent adult.



Courtesy of

FOR most of his life, I have served my son, Nat, a buttered bagel for breakfast, but only on weekends (he checks his calendar to make sure). I never thought much of it. But now that he is 14, the breakfast has become a moment to worry.

I find myself thinking about how I have to start helping him to perfect his use of a knife or he will never be able to live by himself. He is autistic, and though so many of my dreams for him have had to change, one of my remaining wishes is that he will be an independent adult. If he can't prepare his own food, he won't be able to live alone. It's that simple.

It's not that we haven't tried to teach him these things. Before his diagnosis, when we were just a family of three, suffering in our confusion over this eccentric, silent child (who did nothing that the childhood books talked about), I spent many hours repeating simple lessons to him about how things worked, what not to touch, what to say. Repetition helped him like nothing else. He learned to talk from hearing the same books read over and over. From the time he was diagnosed at age 3, therapists have worked with him, using small steps, to develop the skills that make up the nuts and bolts of daily living: brushing teeth, tying shoelaces, taking turns, performing chores. His life's work, as a child, was broken down into doable tasks. To learn how to play with toys, you practice step by step. Push car. Put little man in car. Make car noises. Drive car to school.

He learned many things in this fashion, but most of it has not come easily. Nat has been through six different programs in 11 years of attending school — from a traditional preschool classroom to an intensive, self-contained behavior-modification classroom to inclusive settings and, finally, to prevocational training (in addition to academics, he's learning

Susan Senator is writing a book entitled "Just a Family: Finding Happiness in the Shadow of Autism" (Shambhala Publications).

how to file mail, alphabetize and order stock from a catalog). He has experienced a number of approaches: applied behavioral analysis, incidental learning, Floortime, sensory integration therapy, discrete trial training and just plain one-on-one good teaching. He has amassed a pile of skills that can be applied to many situations.

Except for the gray areas. If you start with a child who does not have an innate sense of judgment — like sometimes you open the door for people, sometimes you don't — where do you begin? If he understands the world only in discrete parts, how does it all get woven together? Educators can give him rule after rule, but there is always the exception, possibly a deadly exception when he's alone. For my son, there has ever been a missing component, the one unteachable, unifying lesson he needs to make it all work: understanding that he is a part of the world, and how to insert himself in and out of its machinery, the way we all do.

STILL, I must try. Sustaining hope is a strange and necessary thing that mothers do. One day, perhaps, it will all click into place. He will know what to do. This is what I have to believe. So I take it one task at a time, in this case cutting and toasting a bagel. I set out to master this with him, step by painstaking step. I cue him to get the bagel out of the freezer. He microwaves it. I lay my hand over his to give him the orientation of knife to bagel. ("Mommy will do it," he says. "No cut the bagel.")

But always I realize that if one thing goes wrong, he will end up with a terrible cut. How will he know if he needs a Band-Aid or if it's bad enough to warrant stitches?

O.K., I say to myself, taking a deep breath and folding away the rising despair like the breakfast napkins. Just as with the way he learns, I will defeat these problems one at a time. We can always get him a bagel slicer. But my mind races. Toaster burns, electric shocks, power failures. And what about lunch?