



PARENT COACH
parenting with confidence, intention, and connection

TBZ talk on Inclusion
2.6.16

Shabbat Shalom. I am honored to be here this morning to share a bit of our experience with special needs and inclusion.

Several of you know my daughter, Mira. We are not here at TBZ often, however when we are here, she is quite noticeable. She gets around by wheelchair, is often eating snacks, and occasionally blurts out noises or shrieks of enjoyment as well as frustration. She is also a happy, social being enjoying engagement with almost anyone who approaches her, and who loves riding the lift that carries her from the first floor to the second. Our life with Mira has made inclusion, or the pursuit of it, a major part of our lives. I fully understand that without the issue being thrust upon you, inclusion may not be something you think about. Once you do think about it, though, it becomes clear that it is a worthy goal and a true mitzvah. But it is not necessarily easy. It is not simply having or inviting a person with special needs in the room with you. It takes thorough questioning, understanding, and creativity. With that in mind, I would like to share some thoughts with you about what inclusion means to us, what it looks like to us, and how it has, and sometimes hasn't, worked for us.

Inclusion in Public School

Mira attended a wonderful inclusive preschool for a few years in Somerville. The classroom consisted of kids who were developing along a typical timeline and several who had a variety of special needs. The teachers, knowing that Mira often needed reminders to sit up tall, would encourage the whole class to sit up tall rather than singling Mira out. Because it was very important for Mira to spend time on her belly, the teachers chose one of their morning songs to be sung while all the children got on their belly. The staff looked at the individual needs of the children and did their best to find common ground so that all could participate and feel a sense of belonging.

When we moved to Newton, Mira started public school kindergarten right behind our home mid way through the year. The local school was able to provide her a one on one aide and her peers and her teachers warmly welcomed her. She was considered to be in an inclusive classroom and school and it truly looked and felt that way for several years despite a few hiccups. There is no question that simply having Mira in a classroom with typical developing peers was a gift for everyone in

the school, not just Mira, but for all the kids in her class. For about three years, she was invited to birthday parties, older kids requested to be her reading buddy, and all the students saw and learned from Mira's needs. They saw how she used adaptive equipment ranging from a wheelchair to a special fork and cup in the classroom. The kids accepted and became familiar with these not as strange differences, but just another of many differences between kids in the classroom.

I truly believe their lives have been enhanced because of that. Many times parents of other children would comment to me how much their children were affected by their relationship with Mira; how much their children had grown from their interaction with her. It was also beneficial for Mira in feeling and knowing that she has a place in the community.

The school found ways to include Mira in potato sack races with the help of her PT as well as ways for the other kids to partner with Mira for various activities in the classroom. This type of inclusion is one example of what I will call inclusion "light". Intentions were good and she was indeed brought into the typical kid's world as best she could be.

Hiccups along the way, however, made clear the limitations of this and the difficulties we faced. I remember the morning vividly, when I walked Mira into the school and several kids in first grade were proudly carrying their animal dioramas that they had been working on for weeks. This was one of the big first grade projects. It was only when a few bright eyed and smiley friends of Mira's came up to me to ask, "What animal did Mira do for her diorama?" I stood like a deer in headlights until I started to cry. Mira had not done a diorama. She didn't have skills to assemble a diorama in a shoebox, she didn't have a way to express to me that this was an assignment that was coming up.

There may have been a paper that came home in a folder about it at some point, but without her one on one reminding me, (and my own lack of organization) Mira had no way to tell me this was happening. Let alone what she was interested in researching or how she wanted her project to look or share what other kids were doing. If we did the diorama, it would have been my diorama. Mira doesn't have much interest in animals anyway and this assignment was meaningless to her.

Could her one on one have worked with her in school on this project?

Could they have adapted the assignment so that it was meaningful and doable for Mira?

Could they have paired Mira up with another kid to perhaps do something together? If they had, this would have been a much deeper form of inclusion.

There were several other moments and events, like a parent breakfast and curriculum share that I never knew about because the notice somehow never made

it into Mira's folder that she brought home daily, and she wasn't able to mention anything about it to me.

Had they used a recording "button", Mira could actively tell me what things to look for in her folder, what was coming up, what went on in class that day, etc....A recording button is something Mira now uses daily in her new school that we and her teachers record on so that she can report to us what happened during the day and she can then share with her friends at school what she did in the afternoons and weekends.

So in her old school, while she was included in the classroom and as one definition of "include" states, she was part of a whole, she and we did not feel included. Inclusion is so much more than what meets the eye.

Doing inclusion well is not rocket science but it absolutely requires us to consciously look outside the box, shed our internal photos of what we think things should look like and think creatively on how to utilize every student's strengths.

When Mira was in the fourth grade, stark differences from the younger grades both academically and socially made themselves known like no more birthday party invites, no appropriate peer group, and no appropriate curriculum. She was still very happy to go to school and had a wonderful relationship with her one on one. Throughout a year of meetings with Newton, we were able to convince them that Mira needed to be at a school where she *felt* included, not just where she *looked* included.

Currently, Mira joyfully drives her power chair on the bus every morning to attend a school where she truly feels included. All the kids in her classroom use communication devices, she has bicycle races in the hallway during physical therapy with her friends. Mira is the only one in her class who can get around independently in a wheelchair so not only does she feel included, she is able to *be* a role model for her peers, not just *have* other peers as role models. You may be thinking, that doesn't sound inclusive. While her school is only for kids with special needs, the range is enormous and yet all the students feel included. While her current school could easily be seen by most as not an inclusive school, they are serving a huge spectrum of children who have a vast array of strengths and challenges and who likely were not feeling included in their local district. Because her sense of inclusion was only found at a school that is not titled inclusive, we make an effort to have Mira in the local community as much as possible. This means that we spend a lot of time at Starbucks and she goes shopping at Wegmans every Thursday afternoon.

One organization that our family is deeply involved with is Gateways. Gateways went about creating inclusion from a completely different way. They started by creating a Sunday school program for kids with special needs and it has grown into something so much bigger than that. They created a Jewish community for kids with special needs and then figured out how to include others. Mira attends Sunday

school every week and has two amazing, dedicated, typically-developing high school volunteers who work with her. Every child who attends the program has a teen volunteer. My son Noah is one of the volunteers who gives up sleeping in on Sunday morning to spend his time with a 10-year-old boy who has special needs. Noah loves it, not only because he enjoys the boy, but also because Gateways has created a community for the teens. Gateways has also created a youth group called Mitzvah Mentches that is made up of teens with special needs and typical teens. This program is a beautiful example of inclusion. It is about social life through social action. All participants pay a yearly membership to be a part of a group that meets bi-monthly for social events as well as philanthropy. This model of inclusion works by acknowledging that each of the kids with special needs has unique and sometimes limited interests. There is no expectation that one activity will appeal to all. For some, socializing itself is a challenge. They create philanthropic experiences where there are a variety of activities and components so that there is something for each kid and because they are all working for the common cause, teens with special needs together with typical teens, they are involved in a shared experience that they then can reflect on, talk about, and all own together.

The last thing I will say about Gateways is that almost every year they have created a Purim Carnival that is accessible to kids with a variety of special needs but also enjoyable for the siblings of those kids. It has less noise, a quiet room with games for those who need the quiet, as well as several of the games and prizes, food and music that you would find at a Purim party elsewhere. Lets face it, wouldn't many of us like a quiet room to escape to during a Purim party for a few minutes?

Mira loves her Judaism, and if you were a part of her bat mitzvah, you experienced her adoration of prayer and love of Jewish song. Mira squealed in delight as we sang Ma Tovv at the start of the service, but was also laser focused when prayers were read. Whether you were aware of it or not, you had stepped into an inclusive service. Mira led much of the service by pressing pictures representing the prayers and blessings on an I-pad. We all followed the havdallah service by reading a picture-book with images representing each word of the blessing. It felt perfectly fine when Mira vocalized her excitement during the service because it was about her and you all came to enter her world.

Let me just end by first thanking you for thinking about inclusion. Inclusion is not easy, but thinking about it, talking about it, and sharing ideas are important steps to take. In that light, if there is one thing I would like you to take away from this and consider, it is that inclusion is not just a one way street. Think not just about how others can enter our world, but also about how we can enter theirs.

Thank you.