

## Our Journey

Delivered by Marc Reich

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In recognition of

Jewish Disabilities Awareness and Inclusion Month

I'm the luckiest guy in the world. You might ask me why? Today I get to stand before you and kvell about my family and the community we live in. I'm excited! Let me start by introducing my family. For those who don't know me, my name is Marc Reich. My wife is Rebecca Reich and we have 3 amazing daughters Sammie 14, Carly 9 and Maci 9. We belong to Temple Beth El where Becca serves on the Inclusion Committee and the Youth Committee. I work at Excellus BCBS as a Director of IT, a soccer coach, on the Jewish Federation Board and currently serve as the President of the Board at Jewish Family Service.

February was Jewish Disabilities Awareness and Inclusion Month, JDAIM for short. A time where we raise awareness and support efforts to foster inclusion of individuals with disabilities and their families in Jewish communities. Today in particular I'm going to share with you a little bit about our family's journey with our daughter Carly who at an early age was diagnosed with autism and low muscle tone. I'm also going to share how this journey has intersected with Jewish Rochester. Although our journey may be different from many of yours, I'm here to share that ours although challenging is also incredible at the same time.

Did you know the Torah teaches us about supporting those with disabilities? In Bereshit we are reminded that each of us is created in the image of God אֶת־הָאָדָם

אֱלֹהִים בְּצַלְמֵוּ. We are all created equal. The Torah goes on to further support those with disabilities. In Vayikra chapter 19 - תִּתֵּן לֹא, עֵוֶר וְלִפְנֵי-חַרֵּשׁ תִּקְלֵל-לֹא - The Torah states you should not insult the deaf or put a stumbling block before the blind. Even today's parsha Tetzaveh teaches us about the Kohen Gadol and their importance. Although not everyone can be a Kohen Gadol, the parsha goes on to speak about how there are roles for everyone in our religion. Inclusion is much like this. All that we ask for is that those with special needs be given a chance to learn and to participate, and fill the many roles in our religion and community. Carly is not going to be the Kohen Gadol, but there are many other roles that she has and will some day fill. Perhaps it is "Rabbi Carly" as she identifies herself every time she enters Temple Beth El.

As I speak about inclusion I believe it is important to first understand what it means to be excluded. Tonight we celebrate Purim. The Megillah reminds us that the Jewish people were the targets of Haman's goal to eliminate all Jews. Today we are experiencing a new wave of Anti-Semitism in our country, which was felt right here in Rochester. Last week headstones were overturned at Waad Hakolel Cemetery on Stonewood Avenue. And again, this week with the bomb threat at the Rochester JCC. Why should we as Jews be treated differently? What did we do? Are we that different from others? Why are we being excluded? There are parallels from this feeling of exclusion to how individuals and families with special needs sometimes feel. Do people understand that if Carly yells out, she's excited, but isn't trying to offend anyone? Even though Carly and may act a little different are people willing to spend time with her to learn how amazing of a person she is? Shouldn't Carly and others be given the same opportunities as everyone else? Inclusion isn't just about those with

disabilities. It's making sure that all of those no matter size, color or preference have the ability to participate and be a part of us all.

I can stand before you and explain Autism and other disabilities based on medical findings and research. Instead, I want to share a short poem called Welcome To Holland written by Emily Perl Kingsley who wrote for Sesame Street, and has a son with Down Syndrome. I believe it truly humanizes what it is like dealing with disabilities as a family.

### Welcome to Holland

"I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills..and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

As parents, there was no thought in our minds that we would travel the road to Holland.

Experts tell you as parents you should never compare your children's intellectual and physical growth to one another because each child grows and matures differently.

However, we saw that Carly was struggling to hit key milestones. She was unable to sit up, eat and hold her head up due to low muscle tone. She was showing delays in crawling, walking and talking. We had no idea what was going on, and we did not know who to reach out to for support. Where do we go from here? It felt as if each road led to another dead end. After many phone calls and hours of research, Becca and I decided to have Carly evaluated, and at 6 months old we learned about her diagnosis of hypotonia and Autism. And so our journey began, however not in Holland but in Rochester, NY.

Early Intervention started at 6 months and continued for 3 years with In-Home therapy. Our front door was revolving with therapists in and out sometimes up to 4 hours a day. For a smaller city we have incredibly dedicated, knowledgeable and caring resources. Our pediatric specialists and programs are top notch. Through their support Carly although delayed, began to reach key milestones.

As Carly grows up we push for her to have the same opportunities that anyone her age has but with support. When Carly became school age we not only wanted to make sure she was in the best class to support her needs, but we also wanted her to attend Hebrew School. Jewish religion and traditions are important to our family, and we wanted to make sure Carly was exposed to this not just at home but also at Temple and in Rochester. We know that Rochester offers amazing programs to help children and adults with special needs, but we were not sure what the Jewish Community could provide. So our journey continues.

So our question, how would Carly and others be included in Jewish Rochester? In order for Carly to attend Hebrew School, she would need an aide for safety and extra support in the classroom. Knowing this we began speaking to Temple Beth El Hebrew School staff. They were nothing but supportive. Through working together with Temple Beth El and our Jewish Community, we were able to give her the support needed so she could attend Hebrew School.

Carly loves Hebrew school. So much so that when she gets off the bus Wednesday afternoons, her first question is “can I go to Hebrew School today?” She’s learned so much already. One of her favorite songs is Hatikvah. She can show you all the Moses pictures, menorahs on display and Jewish flags at Temple. In fact Carly loves Moses so much that we bought her a Moses figurine for her birthday that she plays with at home (yes, Amazon sells everything). Just this week her teacher asked each student to pick a topic to write about. Carly could pick any topic she likes. You know what she chose? Temple. She said, “I want to write about Temple.” One of our goals for Carly is to participate in her B’Not Mitzvah with her twin sister Maci. None of this would have been possible without the support of TBE.

Yet our journey continues. Today there are examples of what Rochester Jewish Organizations are doing to make inclusion a reality. Temple Beth El for example has been leading the way for inclusion services and programs. Our temple has been recognized by the Ruderman Family Foundation for our focus on inclusion. We have made a number of changes in our temple to accommodate support to all. Last year Rabbi Artsan joined us for a weekend where he shared his personal stories, and reminded us that inclusion is not just about children, or adults with special needs, but includes everyone in our community from individuals with mental illnesses to LGBTQ

to hard-of-hearing to our elderly. The Jewish Federation has been focusing on making sure that we build out our educational opportunities for those with special needs and train our teachers on how to support them. Jewish Family Service currently is exploring ways to help individuals and families with special needs.

This is just the beginning of our journey however. We have come a long way but there are still so many needs families are dealing with. As our political world changes, decisions are made impacting families with special needs. Many services and grants are no longer being funded. The state has greatly reduced the number of group homes instead opting for a managed support model. These changes have put a tremendous amount of stress on families forcing many people to quit jobs, to support their loved ones. Many of our friends are struggling to find programs during the daytime where their adult children can attend and be safe. Family members look for group homes so as they become older, their children will have safe places to live when they can no longer care for them. Respite or sitter services are available so family members can have a brief break from the daily care. These are just a few examples of the many needs that exist. How can we as a Jewish community help to support?

What's important to know is that many programs, services, and even group homes, are not associated with Jewish Organizations. Many people turn to agencies such as Heritage Christian Services, Mary Cariola or the ARC of Monroe for help. Although these organizations provide tremendous support there is a need for a strong Jewish presence in this space. Again what can we do in our Jewish Rochester to change this? Our Jewish community is so giving; we need to continue to find ways to support everyone regardless of abilities. Yes we should think strategically about how to

provide support, but we can also continue to build our support service by service. Can we make sure our Jewish Schools and Camps have all that they need to help support special needs children and adults? Can we start programs such as day-habs with Jewish content where adults have places to go to so family members don't have to quit their jobs? Can we provide work programs with support but give back to our community? Lastly, can we find appropriate and safe places for those with disabilities to live? As I mention examples, many of you might say I'm dealing with the same issues for the young and elderly. I don't disagree. Can we look at some of the great programs we have in place and expand those to special needs? Jewish Rochester has the ability to lead and become a community that others will look to. I believe that we can do this through support and collaboration amongst our Jewish Organizations and Temples. Welcome to our journey.

So how is our Carly doing today? She's incredible. Every day she amazes us. Anyone who spends time with her falls in love with her. She is so intelligent, asks so many amazing questions, and has become a true leader. Today she swims, plays baseball, and rides horses. We've watched her help organize her family and friends and lead them in games and songs. Carly is often singing Hebrew songs and prayers she learned at home and Hebrew School thanks to all of you.

One of Carly's heroes is Rudy Ruettiger. Carly learned about him from watching his movie. For those of you who don't know Rudy, he was an undersized student athlete who's goal was to play football for Notre Dame. Rudy struggled initially to get into Notre Dame, and then to make the football team. Rudy was always told that he wasn't big enough, or good enough to make the team. Rudy finally was accepted to the

school and made the football team but only as a practice player not dressing for games.

Rudy refused to give up his wish to play, and in his final game he was permitted to put on his uniform. With just a few minutes left in the game Rudy received the call to charge the field. Rudy not only played but sacked the opposing quarterback. Rudy was the first Notre Dame player to be carried off the field in victory.

Why is Carly drawn to Rudy? He is very important to her. She will often tell us she runs like Rudy. She saw the movie once, and yet this connection. His story is an example of what Carly and others deal with daily. They may struggle at times but much like Rudy given opportunities, who knows what they can achieve and what roles they can fill in our community.

Thank you for letting me share a little bit of our journey with you today. We continue to be excited by all the positive changes we are seeing in our community in regards to inclusion and supporting those with special needs. Although we have made many positive changes there is still much more that we can do. And together our journey continues.

Shabbat Shalom