

WE DID WHAT GOD LED US TO DO

We are parents of adult twins with Down syndrome. We have been very blessed with a lot of joy from them, but we were worried about their futures as we won't live forever. Now because of Glory Community, a new Broomfield residential community for adults with developmental disabilities, we know they can carry on their own faith journeys in a place called "home," where a Christian environment will continue. My husband and I co-founded Glory Community. The first home is complete, and the residents moved in October 1. The story is full of miracles; I cannot begin to talk about them without crying.

The home is drop-dead gorgeous, complete with a theater room and dance floor, as well as a two-bedroom apartment for a live-in couple. Eventually five homes will be built on the cul-de-sac, housing a total of 40 residents (one gender per home). The first home is for eight males. The second home will house eight females, and we are praying it will be completed in 2014. Already four women have committed to living in the next house.

This project has been God-led from day one, and it will remain His project. It's way more than we envisioned 10 years ago. Yes, we have been fundraising and planning for 10 years. Nothing happens overnight.

Our church has been supportive of creating a special needs adult Sunday School, though it took three years to make it happen. Last year the church jumped in big time on our residential project and matched a \$250,000 grant. That donation is what pushed us up and over the edge to build the first house. Glory Community is now considered a "local mission" project and will be part of the church's budget.

All I can say is, if the Lord puts something like Glory Community in your heart, you'd better listen. Some people He appoints to carry out his work. Don't turn your head and say, "not me." He has the plan, we don't. The rewards are many. He helps along the way. Just when you say "It's more than I can handle," along comes someone or something He puts in your path. This whole journey has been faith affirming.

www.glorycommunity.org

LEAVING MY FAITH IN SEARCH OF COMMUNITY

I was literally asked to leave Shabbat services at a Boulder synagogue when my two children, both on the autism spectrum, were young. At that time, my son couldn't sit still. He was rocking and made a thumping noise when he hit the back of his seat. Someone came by and asked me to "quiet my son" so I stood in the back with him while

he spun in circles. Finally a man asked me to leave with my children. He said we were "bothering people."

I didn't give up. I was a young single mom, and I had lived much of my life in Israel. I was hungry for a Jewish community. So, when the high holidays came around and I barely had money to survive, I called the synagogue and asked if we could attend services without purchasing tickets. I was told to "ask a friend or neighbor to buy me a ticket." So, that was the end of that. I hope that by now (it's about 10 years later) this synagogue has adopted a more compassionate stance, and I hope that the next young single mother of two special needs children is not turned away when she's at her most vulnerable.

Unfortunately, we had a similar experience with a second Boulder synagogue. It's a little funny and slightly weird, but I ended up taking my kids to church. I just told them, "Listen you guys, we're Jewish, but we're going to church because it's cheaper and more accepting."

What would have been helpful is if the synagogue could have treated us more in the way the church did, actually. The church embraced us fully. When my son was loud, fidgety, etc., congregants offered to help. The pastor sometimes addressed my son directly by smiling at him or placing his hand on my son's back. We were invited to dinners, given gift cards to grocery stores, and the congregation even helped me move when I needed to lower my rent. All the while, the church understood that we are Jews, and we do not accept Jesus as our G-d. It didn't matter. They truly acted out of love, and love alone. It was a tremendously beautiful experience.

Today, we live in outside of Boulder, and we attend both a local congregation and a Shabbat Group. Here, we are not judged and it doesn't matter whether or not we can pay for tickets. We are always welcome. In the past, it was a great joy for me to have a community of Jews where I could speak Hebrew, discuss Israeli life and politics, express my spirituality, feel at home, etc. The Judaism I grew up with was centered in tzedakah (charity) and was sometimes loud and chaotic, but it was always steeped in love, and was for ALL Jews. Unfortunately, that is not what I found in Boulder.

INVOLVED ADULTS ARE THE KEY TO SUCCESS

Basically, we had a very challenging experience in church when our son with Asperger's was young. Due to sensory and dietary issues, he had difficulty with toilet training, so he was not allowed to advance to the next Sunday School class with his peers. At age 3 ½, he was hypervocal, but he ended up in a nursery with toddlers who barely walked. This caused us to change churches.

As he became older, Sunday School continued to be difficult for other reasons. Our son had trouble staying with a group, challenges with transitions, and he did not tolerate chaos, such as during the last few minutes when kids run wild until their parents

arrive. As a result, we pulled him out of children's programming and kept him with us during services. We went through probably hundreds of dollars of stickers to keep him occupied during sermons.

Our church had a "Time for Young Disciples" when the speaker of the day would invite all the children to come to the front for a short story or lesson. At first, we went with him, but eventually he'd go himself. And as he became older, his contributions were really valued by the pastoral staff and enjoyed by the congregation. He always had interesting answers to share, and no shyness about speaking into microphones to share them.

Another sermon-occupying activity was copying scripture. We brought markers, which satisfied three needs: quiet entertainment, handwriting practice (desperately needed), and memorizing the scripture passage of the day.

When our son was around 8, he wanted to be baptized. Through this exploration he developed a relationship with the senior pastor. When that pastor left to take a position in another church, our son, then age 12, invited himself to be one of the speakers at the farewell service. With my help, he crafted his thoughts about the pastor into a short speech, thanking him for his support. He read the speech to a packed crowd of hundreds.

Later, when I observed the youth program from afar, I was petrified at the chaos I perceived, but it proved to be a positive experience. In middle school, there were more than a few social misunderstandings and hurt feelings among the boys in his small group. But the opportunity to have one-on-one time with young adult leaders who truly listened to him boosted his confidence during a time when school anxiety was high. As he moved into high school, the chaos became more controlled, and the constant relationship with one or two leaders over several years became more valuable. The church youth group has filled a significant social and emotional need for our son. Since his social needs are supported through the church, we are content (as is he) to keep school focused on academics.

Our son, now nearly 17 and entering his final year of high school, recently made us very proud. He agreed to participate in an interview with the congregation during Autism Awareness month. This required him to disclose that he has Asperger's-- something most adults in our support circle know, but not many of his youth group peers. His trust was well-received, with the middle school director conducting the interview and many fellow students cheering him on from the pews. Through this supportive setting, he has been able to travel on mission trips and choir tours, which have enabled him to make important steps toward independence.

If I could wave a magic wand, I'd create a circle of supportive adults around every child with a disability in our faith community. Having many adults investing in our son's life, over the long haul, has made a significant difference in his life, and the lives of our whole family. Faith matters.

Having a child with a disability can strengthen or shatter that faith, depending in part on how the community responds.

CHURCH LEADERSHIP SET TONE FOR INCLUSIVITY

My son is 41, and he started becoming active at church after graduating high school. Because he uses a wheelchair, we chose a church that was walking distance from our home, so church friends would not need wheelchair accessible transportation for him to be included. While the same-age peers were very friendly and inclusive, the church leadership always seemed “inconvenienced” by my son’s presence at church activities and events. An analogy would be when an elementary school teacher’s decisions are not supported by the school principal, that teacher eventually “gets the message” and defers to the principal’s wishes. In my son’s case, individual parishioners may have been friendly and inclusive, but eventually they were discouraged by the tone set by the pastors.

Personally, I find it abhorrent when faith communities segregate adults with disabilities, such as having “Special needs Sunday School classes”, or “Adults with disabilities Bowling Night.” When my son was ill with very severe pressure ulcers and residing in a care facility for 16 months, his fellowship group from church visited him once at my request, without their youth pastor joining them. Although they spoke of returning, it never happened. There was no encouragement from the church leadership to pursue fellowship with an individual with disabilities.

To resolve this problem for the many wonderful people who just happen to live with disabilities, I would like to see faith community leaders challenge and inspire individual congregation leaders.

WE HAVE NO IDEA WHAT THE FUTURE HOLDS

We previously attended a large church, but my husband and I eventually decided it was too difficult to continue trading off attending church with our two older children. You see, our youngest is affected by autism, and nobody in the church (10,000 members at the time) seemed qualified to hold religious education for our son while we attended church classes or gatherings. The church staff's attitude was "Well, there are too few of these kids, and it's not our job to reach out." They have no inkling about how many children have disabilities.

Many families trade off, which causes strife in marriages and families. Or they simply quit trying to attend church.

We quit trying. Our older children feel very angry at the church for abandoning our family.

My husband was training to be a therapist at a local seminary, where they were so judgmental about our son's meltdowns and running, that the seminary asked us to leave. We had been living on campus, and our family had to uproot, causing very serious problems with our children and our marriage. In addition my husband never finished his training, so we wasted two years and A LOT of money (which we still owe and struggle to pay to this day).

Those were very difficult years. We felt isolated, and during that time we never had a break or took a vacation.

Since then our son has been helped mostly by a 100-member church, whose members are very active in our lives. They helped us find the energy to advocate better for him and get him into an out-of-district school placement. He's 14, and he's excelling. He may even begin transitioning to a regular high school next year. This small church helped us pay for marital counseling and fed us both physically AND spiritually for a few years. After our son progressed to the point he no longer had meltdowns, our family could do some healing, and I finished school. I can now confidently work full time and pay a few bills. Our older kids, now teens, are also healing. We still have no idea what the future holds for our youngest son.

Our first church sometimes attempted to be inclusive of people with disabilities, but their intentions came from a place of misinformation. We wish the church would survey families with disabilities so it could better understand the parents' perspectives. For instance, the church holds a "special" dance each year for older kids with special needs as a replacement for prom, but it mostly offends families who have children with disabilities. Even local disability organizations have stopped participating because the event is condescending and doesn't include students from the local community.

My husband now leads a Sunday group for dads of children with special needs. A local organization donates breakfast food and the meeting space. However, the organization is having financial problems, and they are selling the building. We don't know where our group will meet. We'd love to buy the building for our church so that healing from this kind of pain can continue and so these families can be supported. My husband and I both sit on task forces and committees around the state and want to continue helping. Colorado is not a favorable state to have a child with special needs, as people keep voting down measures to help people with disabilities.

It seems odd that although our original church advertises the dads' group, only one dad has asked for help. The church has tens of thousands of people; according to statistics, there are many, many more children with disabilities in that community. The church doesn't survey the situation, and it seems to not want to know.

HE WAS BORN INTO THIS CHURCH

We attend a fairly small church, and there were only about 60 members when we first joined. It's now up to 200.

My son was born into this church. Because it's such a family/community atmosphere, when our son was diagnosed with autism, I shared his diagnosis with everyone during our "Joys and Concerns." At that time, many people asked how they could help. Some people volunteered to babysit and spend time with him. Sunday school teachers were open to having him in their classes. They just asked for suggestions on how to help him participate (food was usually the thing that got him interested). They also asked for training/suggestions on how to deal with his challenging behaviors. I suggested every trick I knew at the time (and more, as I learned more). If they couldn't manage his behaviors, someone would get me, and I would deal with him. I wanted him to be a part of this community and did everything I could to make sure that he was included as much as possible.

When he was in the sanctuary with me, he loved going up front to look at the stained glass behind the altar. Sometimes, the minister was fine having him up there. If he started to get disruptive, I would need to take him out (usually kicking and screaming), but everyone was understanding. In time, he didn't need to go up front and was content to just look at the stained glass from a distance.

As he became older, he participated in youth group, confirmation class and even went on a trip to the Heifer Ranch in Arkansas with about seven other youth from our church. While there, some of the other groups were being derogatory about differences. All of the people from our church stood up for my son. They were very supportive and proud of his accomplishments.

From middle school through high school, my son regularly participated in overnight camps sponsored by our conference. These camps could have as many as 200 youth, and only a few of them were from our church. Some of the camps were a week long. He loved these camps and when I picked him up, it was obvious he had made friends.

Throughout the years, my son has participated in all of the holiday plays, did scripture readings and now regularly sings in our choir. People talk to him and love to hear what he's up to. He's definitely a part of this community, and the community feels like they have helped "raise" him and made him the person he is.

IT WAS DIFFICULT TO HEAR MY SON CALLED "THE WILD ONE"

Ever since my son was diagnosed with ADHD at 6 years old, I have tried to find the correct treatments for him through psychiatric and behavioral interventions. It has been a lonely process, and nothing has really helped.

My son is now 21. In the last few months he was diagnosed with Asperger syndrome and bipolar disorder as well.

I am Jewish. We never joined a faith community when he was growing up because it was difficult to watch my son be called "the wild one" in group settings, such

as during after-school activities. Even waiting rooms became a place to avoid because of his difficult behaviors.

We tried to join a local group that met occasionally for Sabbath meals, but I didn't feel my son was accepted. I sent my son to a Jewish summer camp a few times so he could be exposed to a Jewish environment. I explained in the camp application as well as to each of his counselors how to deal with his challenging behaviors and how to help him make friends, which he so desperately wanted. The children told him he was "weird," "dumb," and "stupid" because he did not respond to social cues. Although the counselors took care of my son for the three weeks as it was their jobs, the campers did not befriend him because he was different. His Jewish cultural experience was compromised as a result.

Fast forward to the present, and we feel lucky to have found synagogue in in our community. My son is welcome there, although he has chosen to be minimally involved. My son's fortes are music and video games. He is socially accepted by all ages because of this. The congregants and the Rabbi see my son's strengths. I don't feel embarrassed in this setting. I see him happy when he does participate. I made the right choice in joining this Jewish community.

I am involved in many Jewish activities. When I work with children, I model and teach tolerance and inclusiveness for everyone.

I WANTED TO WRING OUT EVERY SECOND OF THE DAY

From taking a bite of our Hanukkah candles, to not waiting to say the motzi (prayer) before we eat, our son's journey as a Jew has taken many turns over the years. His participation in synagogue life hasn't been smooth (and hasn't been fully resolved for me). Early on, his noisy outbursts and physical excitability brought us stares and "shushes," and although it pained me, we stopped bringing him to synagogue. Our son has autism.

This year, however, our son turned 13, and we decided to have a Bar Mitzvah for him. This felt like his true introduction to synagogue life, as he was able to participate. It was a really great experience. The clergy was amazing and accommodating, creating a service for him that was just a few prayers, instead of the extensive study usually required for bar and bat mitzvah candidates.

This is what I wrote that day, a day which I didn't want to end: "Today M. became a Bar Mitzvah. The service was more beautiful than I imagined it could be. And what made it so, was the people surrounding our family and M.; having the service in the context of our community, his friends, family and helpers. I don't want to let him sleep – I keep peeking in at him in his bed. I want to wring out every second of the day." I am searching for ways to keep him engaged at our temple. The journey continues. His Bar Mitzvah didn't resolve the other parts of his synagogue experience, but it was a welcoming event that was meaningful for all of the clergy and for everyone there.

WE ARE ALL JUST DOING THE BEST WE CAN

Our son was a very hyperactive ADHD kid, and in the kindergarten synagogue Sunday school, he and another boy would cause a lot of commotion. One day, the Sunday school principal called, and my husband answered. That was fortunate, because our children were so challenging at that point that the phone call would have been very emotional for me to handle. The principal said if we wanted our son to continue attending Sunday School, one of us needed to attend with him. My husband agreed to do so, and likes to joke now that "everything I know about Judaism, I learned in kindergarten." I'm not sure what would have happened if he hadn't been willing, because as a stay-at-home mother of two special needs kids, I wasn't willing to add Sunday school attendance to my life. That son, and our other children, all continued through confirmation and into the Hebrew High program, and were active in youth group as well.

For the most part, the temple accepted their idiosyncrasies, and gave them a little leeway to behave less than perfectly. We worried about whether one of our kids could handle his Bar Mitzvah, which was typically done with a partner at our temple. I figured his Bar Mitzvah partner might have to cover a larger part of the service. In the end, the temple staff felt our child was unconventional enough that it might be awkward for another child to be paired with him. That was a little sad to hear, but understandable. Our son did his Bar Mitzvah solo with no modifications. This was one of many occasions where he has exceeded our expectations, and he continues to do so, despite a mental illness, and a generally unconventional personality.

All our children identify strongly as Jewish. One sobbed uncontrollably when his younger brother spilled tea on his Bar Mitzvah prayer book. Another kisses the mezuzah outside his bedroom door each time he enters. I think positive experiences at Jewish overnight camp probably led the way to their involvement later on with youth group, which in turn was a meaningful part of their teen years (and pleased us as parents). We generally expected them to take part in Jewish life, rather than offering a choice, and none refused at any point to continue with their education.

As a side note: our child with ADHD once had a major tantrum during an appointment with his psychiatrist. I was there also, and I can tell you the doctor didn't know how to handle him either. We keep hoping to find an expert who has the answers, but people are so individual, there is no set answer. We're all just doing the best we can, day after day.

WE ASSUMED THEY WOULD CATCH UP

We have two beautiful adopted girls from China. When we adopted them, we expected they would be a bit "behind," however we assumed that with love and a little

bit of early intervention they would catch up. Or so we thought...as our eldest child got older, the gap between her and her peers became more obvious, and what we once thought was developmental delay, today, is labeled as autism.

We have no family here to support us. Juggling therapies, school, work and life in general can be a great challenge at times. About five years ago, I got a call from Leah Wilhelm who runs CU Boulder Chabad (an on-campus Jewish organization). She asked if I would like some support for my daughter. Leah Wilhelm, also a mother of a special needs child, was creating a group called "Linking Hearts", matching CU students with families with kids with special needs. The intention was that for an hour a week, someone would come and play with my daughter and to give me a small break. Well, one hour became two hours and the girls that came to our home are our friends to this day. Knowing my daughter liked dogs, they volunteered to take a required class, so that they could take my daughter to the Humane Society to walk the dogs.

As you might guess, we now have a dog, thanks to these great CU girls. Leah also organized Shabbat dinners and holiday celebrations, where the kids can be themselves. It was a welcoming opportunity to bring Judaism to my children in an environment that works for them.

I HAD AN OBLIGATION TO STAY

I'm a Jewish educator and leader, daughter of a Rabbi, and wife of a Rabbi. I'm a mother to a child with autism and other special needs. My family was, is, and will always be very involved in the Jewish community. My involvement has definitely changed and evolved with my son's needs.

In the early days (and years) after my son's diagnosis of autism it was harder. It was a vulnerable time and easy to be offended by people's remarks. But instead of running away from those situations I had an obligation to stay, for my son's sake, for my family's sake, and for my community's sake. I realized that we needed to educate those individuals who were unaware of the challenges our family faced.

When we are given the challenging, rewarding, inspiring, exhausting and time-consuming job of raising a child with special needs, we need to make some serious changes in our lives. And there's always that tough inner struggle: "Do I need to entirely stop something that was a part of my life?" "Do I need to change the way I'm doing certain things? or Do I need to keep doing this and find a way for my child to deal with it/participate/learn to love it?"

Judaism is who I am and how I live my life and raise my family, and so I knew that I needed to find ways to make my son a part of it. So much about Judaism is home and family-based, and in those areas it has been easier to celebrate our faith. The community aspect has its challenges.

Yes, there are difficult moments, painful interactions. In order to move ahead in life I've learned not to dwell on those, and instead to think about the beautiful moments where my son enhanced the spirituality of our community.

I think about a man I will call Craig, who treasures prayer time and values the opportunity to pray in a peaceful environment. And I think about the time my son walked into services and was very disruptive, and was not responding to me. Craig walked over to him and gently talked to him and calmed him down. Because of my son, Craig was able to practice the Torah-values of Chesed (kindness) and Ahavat Yisrael (love of a fellow Jew).

I think about all the members of our community, who experience my son's unbridled enthusiasm for Mitzvot and holiday traditions, and I know they are all the richer because of that.

I think about the Jewish camp that my son attended for the last six years, and I feel inspired by the directors and staff members who go out of their way to accommodate his needs. I, in turn, think about how I can accommodate others. Rabbis, Leaders, Teachers – let's remember how vulnerable a family is and do our utmost to reach out. The community leaders set the tone. When a Rabbi's sermon is interrupted by a Special Child, and the Rabbi stays calm, smiles, shows love, the community will learn to do likewise. Community Members – please talk to our children, show you love them, and try to help out in the difficult moments.

Mitzvah Goreret Mitzvah – One Mitzvah leads to another. Fellow parents, let's not deprive our communities of the opportunity to learn the valuable lessons of including a special child.

NEVER A QUESTION OF OUR DAUGHTER ATTENDING SYNAGOGUE

Our daughter has Rett Syndrome. She's 27, but her abilities are typical of a child of a few months to a few years. She's small -- she appears to be about 10 or 11 -- and small for that age too. She's non-verbal and has limited purposeful walking. She needs assistance for almost everything.

We have not fought for unreasonable inclusion: perhaps she could have been well-served by having able-bodied contemporaries integrate her in synagogue youth groups, but we didn't push this.) More recently there have been more attempts to have youth from Jewish schools or synagogues be involved--usually through the Jewish Family Service's Disability Network--but this is several times a year, rather than every week.)

There never was a question about our daughter attending synagogue services or eating at the Kiddush (the snack after the service).

She can walk if she's bored or if she is ready to go to Kiddush. Most people ignore her when she walks around the room. I would say she creates less disturbance than many typical children, whose disruptions are tolerated at levels that might well be intolerable at many houses of worship. I received more negativity from having to deal with one of my other children needing fatherly intervention while I was leading the davening (prayers) than from this daughter.

Occasionally we encounter some hostility in the synagogue, but mostly people accept her as a family member. I suspect that some persons, perhaps many persons, are troubled by her, and I suspect some have difficulty knowing what to say or do around her--or how to explain her to their families. And the community clearly has an easier time with persons whose disabilities are less profound. And this may have subtle or not-so-subtle effects on our relationships with people in the synagogue.

Nevertheless, integrating family members with disabilities appears to be accepted in our congregation: a young man with Down Syndrome attends daily services (i.e. seven days a week, not just on Shabbat); there are other persons with developmental or physical disabilities (for example, a blind family member attends synagogue services nearly every Shabbat). Many synagogue members support Keshet of the Rockies, a program providing Jewish educational services to children with developmental and physical disabilities.

When our daughter was younger, she was served quite well by Kochavim, a community oriented Sunday School. The Rabbi's support for this program was phenomenal--he felt strongly that every attempt should be made to mainstream the participants in this program.

Our daughter has been involved in Jewish summer camping, both in the Summer Magic program in Denver, and in New York State. She does not meet the profile for the non-Orthodox overnight Jewish camp programs -- her functioning level is too low and her age too high -- although she appears to appreciate getting away from Mom and Dad as much as anyone else. I was happy to learn that NCSY/Yad is working with Taglit-Birthright to make it possible for kids with disabilities to participate, although our daughter may be too old, and too involved, to participate.