

ELCA Christian Education Network
Our Family's Experience with Autism- Alison Gale

Tell us about yourself and your family

My husband and I have been married for 37 years. We have four children, two sons by birth, a son born in Korea, and a daughter born in China. Our daughter, Linnea, came home to us as an almost-three-year-old, with an unrepaired cleft lip and palate. She also demonstrated many institutionalized behaviors, which was not unexpected, as she had lived in an orphanage from the time she was a newborn. It was only over time, and with the help of an amazing speech therapist (and fellow church member), that we slowly came to the realization that we were also dealing with autism, speech apraxia and significant developmental disabilities.

Describe some of your experiences raising a daughter with autism

Over the years we have experienced many challenges as we navigated the uncharted territory of Linnea's behaviors and diagnoses, while also trying to keep up with her three active older brothers. Linnea's preschool and early elementary school years were the most difficult, as we struggled with screaming outbursts, and destructive and aggressive behaviors that were frightening in their intensity. We were asked to leave more than one daycare, and were close to being told she could no longer attend a public elementary school. We learned that the maze of disability services is hard to navigate, and finding the resources available can be difficult.

Thankfully, as Linnea learned to communicate, first through sign language and then through speech, her frustrations eased and her more severe behaviors subsided. We were also fortunate to find good doctors and other health professionals along the way, and the services and guidance they provided over the years has been invaluable.

Linnea's three brothers are between 7-9 years older than she is, which has been a huge blessing, as they were old enough to help when needed. In their middle and high school years I would often (probably unfairly) judge their friends by how they treated Linnea. I tended to like those who "got it", meaning they accepted Linnea for who she is and were comfortable around her.

Linnea is 20 years old now, and will soon be graduating from the 18-21 year old Life Skills program in our public school district. She has amazing, unusual ideas, and a funny sense of humor. She's good at math, and is an expert in negotiating for the things she wants. She has taught us to see things differently and has opened our eyes to new ways to experience the world around us.

How does your faith community support you?

Over the years, our church family at Hope Lutheran Church in Eagle, ID has shown Linnea nothing but love and acceptance. She rocks constantly when sitting, which can be distracting for those sitting behind or beside us in church, but we have never been made to feel unwelcome. Several members of the congregation have formed a special bond with her over the years, and she seeks out these individuals each week to share a fist bump or a hug. She has always been welcomed in Sunday School, Vacation Bible School, and Youth events, and the teachers and leaders have shown flexibility in allowing her to participate (or not) in her own way.

One of my favorite memories is from a service several years ago, when the congregation was seated for one of the songs. Linnea really liked this song, and she stood up and started clapping and dancing to the music. It didn't take very long for a few members of the congregation to join her, and before the end of the song the entire congregation was standing and clapping. This was a true expression of Christ's love that still brings tears to my eyes.

How can congregations overall be welcoming places for special needs youth?

Tolerance, acceptance, patience and flexibility are the words that come to mind when I consider this question. Children and youth with special needs may exhibit behaviors or make noises that are distracting. When participating in youth activities or Sunday School, leaders may need to find creative ways to allow those with special needs to participate as they are able. Parents are the best resource for what works or won't work for each child, and they are usually very open and willing to assist as needed. These parents can be dealing with some extremely difficult situations. Please know that the gift of acceptance you are providing to a family who needs it is worth the inconvenience or extra work that may be required.