

# Iowa Family Story Project

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One in five of Iowa's children and youth has a special health care need – a chronic physical, developmental, behavioral, or emotional condition that requires more than routine health care.

The Iowa Family Story Project illustrates the daily joys and struggles of caring for children, youth, and young adults with special health care needs or disabilities. Photographer Thomas Langdon shadowed eight of these Iowa families. They reflect Iowa's diversity and include those living on rural farms, in small towns, and in bustling cities. The children, youth, and young adults range in age from one year to 28 years and have a wide range of diagnoses, including autism, cerebral palsy, Down syndrome, and genetic conditions.

Although the families are different in many ways, they share a set of common experiences. They must navigate a complex and fragmented System of Care, endless piles of paperwork, financial stress, and sometimes long drives for appointments that are booked months in advance. But they also share a deep, unconditional love for each other and feelings of joy and accomplishment when overcoming obstacles.

# The Hild Family

*"Lucas needs to be challenged every day."*



Lucas Hild is 27 years old and has intellectual disability, autism, and attention-deficit/hyperactivity disorder. He currently lives on his own along with 24-hour support staff. His parents Mark and Nancy live nearby and visit Lucas often. Lucas enjoys riding his bike, swimming, and visiting the dog park. When Lucas was in school, his parents advocated for integrated classroom settings so he would learn how to interact with others. "I think our other children learned how to be more compassionate to other people with disabilities," said Nancy. When Lucas was a teenager, his behaviors became more challenging at home, and school struggled to meet his needs. To receive more behavioral supports, he moved to ChildServe in Johnston, Iowa. After he turned 20, the family was able to utilize funds from the Money Follows the Person program to help Lucas transition into an apartment. Money Follows

the Person provides support to states to increase the use of home- and community-based services and reduce the use of institutionally based services. "I don't know what we would have done without Money Follows the Person," said Nancy. "Lucas is better and so much happier living alone." One of Lucas' main challenges is communication. "His receptive ability is much higher than his expressive ability," said Nancy. "Lucas needs to be challenged every day as it sometimes becomes easier for others to do things for him rather than allow him to grow." He does use some sign language, but still struggles to communicate his needs and emotions. Mark and Nancy are grateful that the Ames community has embraced Lucas, and they hope that he can continue to be a part of the community and know that he is loved by family and friends. "The people of Ames have been wonderful to him," said Nancy. "He's very friendly, and

people recognize him. People in Walmart will give him hugs and Cy, the Iowa State mascot, often sits next to him at basketball games."





IOWA CITY

# The Shaw Family

*"Our typical day is beautifully chaotic."*



Arianna and Parrish Shaw have two sons, Amaren and Arden, and their typical day is "beautifully chaotic." When he was 2 years old, Amaren was diagnosed with autism. "I'm an 'on the go' person," said Arianna. "So I had to learn how to slow down for him." Following his diagnosis, Amaren received occupational therapy and along with his mother, completed Parent-Child Interaction Therapy. He had an Individualized Education Plan for a while, but was able to achieve all his goals, so the plan was discontinued. Amaren's parents have always encouraged him to participate in activities that interest him including engineering camp, wildlife camp, swimming lessons, and soccer. Arianna applied for "summerships," grants, and scholarships to fund some of these activities. "The public library is our second home," said Arianna. "We make weekly trips to find books about Amaren's new interests." Amaren is in first grade and is doing well, but he still has challenges. He won't eat a lot of food with textures, including meat, fruit, and vegetables. "And he can't get wet," said Arianna. "The other day he got a drop of water on the wrist of his shirt and insisted that he had to change." Arianna attributes Amaren's success to the early interventions he received and the support of her extended family. "My hopes are that he never lets anyone determine what he's capable of," said Arianna. "His dream is to be a train engineer, doctor, or police officer."



## NORTH LIBERTY

# The Schminke Family

*"Grayson is happiest when he is at home, with familiar surroundings, and with his puppy Milo."*

Grayson is 2 years old and lives with his parents, Dion and Kristin. In January 2018 Grayson was diagnosed with Late Infantile Metachromatic Leukodystrophy, a disorder that affects both the brain and the nervous system. Although Grayson started walking when he was 15 months old, his parents started to notice balance issues three months later. At first his mother, Kristin, thought it was an ear infection causing his balance issues, but that wasn't the case. Doctors then did a blood test for Muscular Dystrophy. A couple of weeks later his eyes crossed and he was admitted to the hospital for a suspected brain tumor. Eventually the results of a broad scan genetics test revealed the diagnosis of Late Infantile Metachromatic Leukodystrophy. The family traveled to Pittsburgh to talk with specialists about managing his symptoms, and since Grayson's symptoms were still mild enough at the time, they offered an experimental treatment involving a bone marrow transplant. Their doctor explained that even with the

treatment, Grayson's overall prognosis would not change. "They said that although Grayson's brain was only mildly affected, his peripheral nerves were very affected," said Kristin. "The transplant may slow the disease down, but the deterioration is going to happen. Grayson's best time is right now." After four days of consultations, Dion and Kristin made the difficult decision to take their son home. "We want Grayson to have quality of life, not quantity," said Kristin. "He's too smart. He wouldn't want that."

The Schminke's welcomed Milo the puppy shortly after Grayson's diagnosis to be a companion to Grayson as his mobility decreases. The family is now receiving a number of services and supports including physical therapy and palliative care, and Grayson is working with a developmental teacher through Early ACCESS. He is enrolled in the Medicaid for Kids with Special Needs program, but his parents are still not sure if these services will pay for the therapeutic



braces and wheelchair that Grayson will need later. Dion and Kristin have both had to cut back on their work hours and are grateful that both sets of grandparents live nearby and have been able to support the family. "Every day is an increasing challenge," said Kristin. "He's losing function, struggling to sit up, struggling to roll over. It's like when I had an epidural during his delivery where eventually I couldn't move my legs. It's like that. He's trying to roll over and his upper body will go, but not his lower body. People are having a hard time understanding how fast it's going to go."



## SHELL ROCK

# The Sauer Family

*"Respite care without a doubt is one of the most important supports that we have found and use almost every day."*



Paetra is 9 years old and lives with her parents Fritz and Charlene, her grandparents Jo and Bob, and her 5-year old brother Fulton. Paetra has a number of conditions including intractable epilepsy, dysphasia, chronic bronchitis, microcephaly, and developmental delay, but no formal diagnosis. Doctors call this "Syndrome Without a Name," or SWAN. Paetra attends Southeast Elementary School and has an associate with her at all times. The school keeps communication lines open by sending a tablet and communication notebook home with her every day. "Paetra is very much aware of her surroundings," said Charlene. "She loves to be included and loves to be with her friends. Her face is her voice."

Six years ago, Paetra's parents made the decision together for Charlene to stop working so she could attend Paetra's appointments and be available when one of her frequent seizures or illnesses occurs. The family moved into Charlene's parents' home in Shell Rock,

which has been remodeled to meet Paetra's changing needs and to accommodate multi-generational living.

Paetra and her family have been active in their community, participating as a mentor family for Wartburg College students enrolled in a Working with Different Abilities class and moderating parent sessions for Up with Families. Fritz and Charlene say they don't see a lot of people with different abilities out in the community and are always looking for opportunities to include others. "Advocating for accommodations, like accessible parking, is not done just for Paetra," said Charlene. "There are other people who will need this now and in the years to come." Paetra's family has also learned the importance of taking time for themselves. "We find that exercising and taking moments alone or as a couple is one of the best medicines we can give ourselves," said Charlene. "Respite care lets that happen and without a doubt is one of the most important supports that we have found and use almost every day."





ANKENY

## The Dang Family

*"Grandma Thao is a second mom to the children, an 'alloparent.' She cooks and cares for the children."*

Matthew is 8 years old and lives with his parents, Jenny and Bach, his grandmother Thao, and his two brothers and one sister. Matthew was diagnosed with moderate to severe autism, attention-deficit/hyperactivity disorder (ADHD), and intellectual disability when he was three years old. His brother Levi, age 10, was diagnosed with ADHD, and brother Nicholas, age 6, has mild autism and ADHD. Matthew loves going to the park and going for rides, but he rarely plays with other children. He receives applied behavior analysis, speech therapy, and occupational therapy, but is still on the waiting list for community living supports. "It can be very stressful trying to juggle day-to-day needs and meet all the responsibilities of the children's different needs," said Jenny. "Especially balancing activities, school, work, and home." Jenny's mother, Thao, is like a second mother to the children and makes most of the meals for the family.

According to a 2014 UCLA study, the prevalence of children with autism is 43 percent higher among children of parents of Vietnamese descent compared to white Americans. But when Matthew was first diagnosed, and even now, the family noticed a lack of racial and ethnic diversity among the children in photos and other autism materials. The family receives support from neighborhood families and members of their church, and Jenny's participation on the Iowa Autism Council has provided opportunities for information locally she wouldn't have gotten otherwise. Jenny and Bach hope that Matthew will find someone who will love and take care of him, someone who will "take their place" someday. They dream that Matthew will develop and grow in his talents and skills so that one day he can use those in an occupation he enjoys.





RUTHVEN

# The Winston Family

*"My kids are super happy kids."*



The Winston household includes Ken and April Winston, their daughters Savannah, Aleah, and Skye, and April's son, Atreyu. Aleah, 3 years old, and Skye, 1 year old, have been diagnosed with global developmental delay, believed to be the result of PLEC gene-related disorder. Both girls met early milestones and then began to regress. "Skye was on track for the first seven months and was even standing on the couch," said April. "Within two weeks she lost everything." Both girls have feeding tubes and receive physical therapy, occupational therapy, and speech therapy. Their oldest daughter, Savannah, has only one of the gene mutations, and is otherwise unaffected. Atreyu, 8 years old, has autism, intellectual disability, and pica. Sometimes the difficulties of autism can lead to behaviors that are challenging to understand and address. It's hard for the Winstons, for example, to leave the house when respite is not available for Atreyu. "I don't want Atreyu

to get hurt, and I don't want someone else to get hurt," said April. "He's very, very strong." Among their three children with special health care needs, they see 13 specialists, most of them over two hours away in Sioux Falls, South Dakota. Savannah will sometimes get upset when her parents show the other children too much attention. "For the most part she is very caring of her siblings," said April, "but you can tell that at times she just wants some alone time with her mom and dad." The Winstons receive ongoing support from their extended family and the community. "If it wasn't for Community Health, we wouldn't have car seats," said April. "Atreyu's car seat was very expensive. Even the local bank is a huge supporter; they helped us to buy a van." Ken and April find joy in the milestones that their children continue to reach. "My kids are super happy kids," said April. "They have a ritual on Saturday morning where Ken and Savannah dance, while the other kids watch and laugh."





DUBUQUE

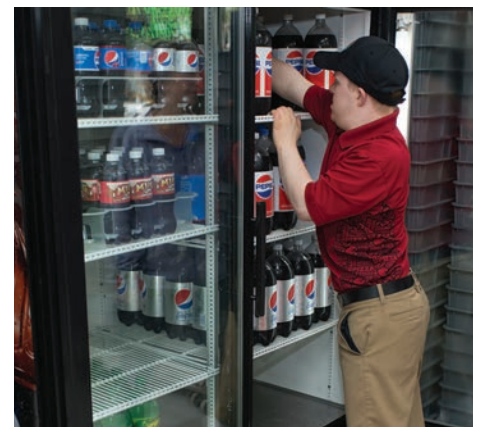
# The Stumpf Family

*"Having Kyle around makes for a happier work environment. He always has this contagious smile on his face. He makes co-workers want to come to work."*

Kyle is 28 years old and lives with his dad, Bill in Dubuque. He has two older sisters, Kristen and Kara, one niece, and three nephews. Kyle has Down syndrome and intellectual disability, and he experienced a lot of medical complexity in his early life. He was born six weeks early and had surgery when he was six days old. Over the next several months, Kyle was found to have a heart defect, had difficulty breathing, and feeding issues.

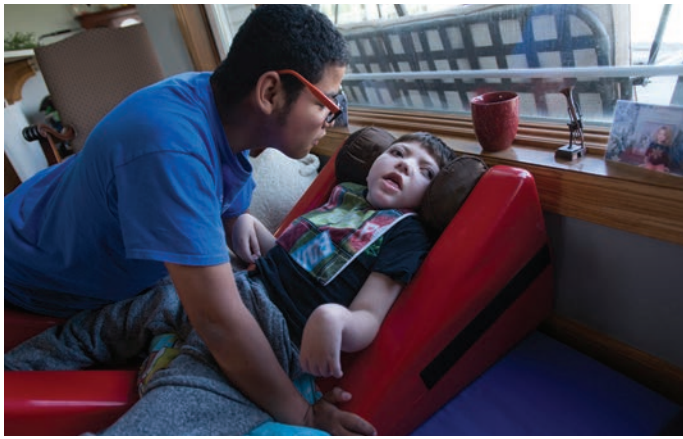
It was always his family's goal for Kyle to be included in school from the time he started preschool. High school for Kyle in a segregated setting wasn't bad, just less inclusive than what his family had envisioned for him. "The early years were more successful than junior high and high school," said Bill. "At that point it seemed easier to focus on finishing school and utilizing waiver services to become more independent." Following high school, Kyle worked in a segregated setting at subminimum wage for about five years. In 2013, while serving on the Iowa

Developmental Disabilities Council, Bill began to learn more about integrated employment and Kyle began using Iowa Vocational Rehabilitation services. During this process Kyle was offered employment from a friend who was managing a local pizza franchise. "With the assistance of supported employment services funded through the Intellectual Disability Waiver and Vocational Rehabilitation, Kyle remains competitively employed," said Bill. Kyle's supervisor, Alica, says that his presence has positively affected other employees. "He always has this contagious smile on his face," said Alicia. "He makes co-workers want to come to work." Looking back at the whole process, Bill acknowledges that he was one of the barriers to Kyle's integrated employment. "The sheltered workshop had become comfortable for all of us," said Bill. "Kyle enjoyed what he was doing, and I was content that he had a place to go every day." Building on their experience, Bill and Kyle have now become advocates for integrated employment and help others make the transition from sheltered work.



# The Metzler Family

*"We're still in touch with our son's birth parents. The more people to love him, the better."*



Lisa and Dan Metzler have two adopted children with special needs: Armando, age 16, and Tristan, age 9, both of whom came to the Metzler family as foster children. They also have three adult children, including a son in college. When Armando was 21 months, his birth mother sent the Metzlers a long letter asking them to adopt him. "At that time we were so naïve," said Lisa. "We knew he had complications from prematurity, but we thought he would outgrow those." Armando was premature, weighing only 1 pound, 2 ounces at birth. He has a moderate intellectual disability and was diagnosed with moderate autism four years ago. Tristan suffered a traumatic brain injury when he was 10 weeks old, resulting in cerebral palsy, cortical visual impairment, seizure disorder, and spastic quadriplegia. While Tristan was in foster care with the Metzlers, they were asked again to consider adoption. "That decision was harder," said Lisa, "because we already had a special needs child."

Armando attends Prairie High School, is part of the Prairie Hawks marching band, and is doing great. He has participated in Special Olympics, attended Camp Courageous, and is involved in the Best Buddies program. "The school district is awesome," said Lisa. "The teachers go above and beyond." Armando is learning cooking skills, attends an autism social skills group, and works with a respite provider on supported community living skills. Tristan is in a wheelchair and is dependent on others to move him around. He also uses apnea, heart rate, and oxygen saturation monitors at night. He attends Prairie Ridge Elementary School and is learning to ride a specially adapted bike, which is helping to develop his strength and coordination. Both boys are on Home and Community Based Services Waivers, but the family still struggles to get all the adaptive equipment and home modifications they need. "Tristan could benefit from a device called a Light Aide," said Lisa. "This has been shown to help children with cortical

visual impairment rewire the brain to enable them to see." Lisa hopes that in the future, Armando will be able to live in a supervised setting and work in a job he enjoys. "My older children gave up a lot growing up," said Lisa. "But now, as adults, I think they all feel good about their experiences of having been a foster family and seeing what others go through."



# Credits

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**PHOTOGRAPHER**

Thomas Langdon

**DESIGNER**

Leigh Bradford

**CENTER FOR DISABILITIES AND DEVELOPMENT STAFF**

Julie Christensen

Cindy Pauk

Deb Westvold

**CHILD HEALTH SPECIALTY CLINICS STAFF**

Jennifer Cook

Anne Crotty

Martha Hanley

Sharon Rettinger

Thomas Scholz

Saira Steen

Rachell Swanson-Holm

Jean Willard

Diane Zaerr Brenneman

The Iowa Family Story Project is based on  
the “Super Parents” project developed by  
the Lucile Packard Foundation for Children’s Health.

For more information about the exhibit visit  
[chsciowa.org/programs/iowa-family-story-project](http://chsciowa.org/programs/iowa-family-story-project).

