

Waiting for Family Support

Supporting Families Who Have
Children with Disabilities

Beth Swedeen



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WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES
Promoting Independence and Equality

Introduction

by Beth Swedeen

For much of this century families felt pressure to place their children with significant disabilities in state institutions. Some families always resisted this pressure. By the 1970s the families who chose to keep their children at home was high enough to effect public policy. The voice of families arguing the merit of supporting children with disabilities in their homes and communities became loud enough for elected officials to notice.

Passage of federal legislation beginning in 1975 served as a catalyst for a partnership among families, policy makers, and communities.

The Wisconsin Legislature made a commitment to this partnership to families by passing legislation creating the Family Support Program in 1987. Since then, the Family Support Program has provided a small amount of very flexible funding for families to use to support their children with disabilities. Family Support is often the only assistance some families receive.

This successful program currently serves about 2400 families across the state. Unfortunately, the number of families on waiting lists exceeds the actual number of families served. We know that at least 2600 families wait for Family Support, some for more than five years.

The following stories tell of the incredible spirit, courage and potential of these children and their families. The stories also describe the challenges they face and what life is like for families and children who are waiting.

Beth Swedeen is the parent of two daughters, one of whom has a disability. Her family has been on the Family Support waiting list for 5 1/2 years.

Devastating Choices

Carrie never thought she would be in a position to have to consider out-of-home placement for her son, Owen, who has autism.

“I always felt that if a parent needs it, I can understand,” she says. “But placing Owen someplace else wasn’t an option for me. Even now, at age 8, I can’t stand to leave him overnight if I have to go somewhere.”



But when Owen was between the ages of 4 and 5, Carrie began considering the unthinkable.

She had struggled with a series of challenges since Owen’s birth. Carrie, 38, is a single parent with another son aged 20. Owen’s father has not been in his son’s life by his own choice. Carrie has only started to receive child support from him in the past year.

Because she was working full-time at a low-wage job, she had to place Owen in unregulated, low-cost day care when he was just 9 weeks old. He lasted five weeks at the first day care; two weeks at the second.

The third child care situation lasted six months. In retrospect, she realizes he was a “difficult” baby because of his need for deep-pressure touch: he screamed the instant he was put down and wanted to be held all the time. By the time he was 18 months, Carrie was spending a third of her take-home pay on child care.

When Owen was 2, he was diagnosed with autism. About six months before that, Carrie’s family started receiving services from a Birth to 3 program in Dane County. She was told then to get on the waiting list for Family Support and respite care, with the warning that it could be 4 years or more before Owen’s name came to the top of the Family Support waiting list.

At age 4, Owen started having severe behaviors. He put holes in their apartment walls, broke mirrors, and bolted from the car the minute it stopped. Carrie stripped his bedroom of all belongings because he ruined them or used them to damage the walls. Her

chest and stomach were bruised where he kicked her during diaper changes. He also wasn't sleeping, so Carrie was operating on less than three hours of sleep each night.

"I felt like I was going to have a breakdown," Carrie says. "Even though I knew we were still on the waiting list, I called Family Support and asked for help."

One of Carrie's biggest problems was trying to connect with the community services and supports Owen needed. She worked at a job that didn't allow her to make personal phone calls. So, she finished work each evening at about the same time that Owen's doctors, school personnel and other service providers were leaving for the day. It was impossible to maintain contact with the providers working with her son.

"Family Support said they could provide resources so I could receive some service coordination," Carrie says. "That way, someone else could make the phone calls during the day while I worked. It really pulled me back from the brink of having to make some devastating choices that I wasn't sure I could live with."

Carrie had to wait three years before receiving service coordination. Even with the extreme challenges she was facing, her family was on the waiting list a total of five years before she received any money from Family Support

Carrie says Family Support is a critically important resource for families like hers, who have children with high levels of need, but few medical problems. For instance, Medical Assistance (MA) would pay for special formula if Owen had a medical problem. Instead, sensory defensiveness in his mouth limits his diet to a certain brand of yogurt and baby food that cannot be reimbursed by MA.

Since Carrie's family has come off the waiting list, she has used Family Support resources to pay for Owen's special diet. She also has used the money to reinforce and repair her apartment. But most of the support she receives pays for quality after-school child care so she can return to school and pursue a career.

"Family Support allows me to be a student now, so I can get a decent job with health insurance for my kids in the future," she says.

"It's also helped me reduce the stress in my life. And when I'm stressed, Owen's stressed," she says. "Everybody says they can see it in my face- that I'm not so stressed now. And Owen's doing so much better because of it."

Courage to Ask

Kara and Todd are doing everything they can to make sure their little boy, Noah, succeeds. Noah, who is almost 6 and has Down Syndrome, participates in Sunday School and Wednesday night church youth programs. He plays flag football and likes to sing in his church youth choir. His mom also drives him 90 minutes round trip each week for occupational and physical therapy in Green Bay.

But Kara and Todd, who live in Lena, believe that many of the formal systems set up to support Noah are actually disappointing him.



The local school district did not invite Noah to kindergarten registration, and told the family that if Noah began kindergarten in the district this fall, he would not be included in most classroom activities.

“We were told that if he did go to kindergarten, he would not be able to participate in anything but class parties, calendar time, and lunch,” Kara says. “We asked if Noah could ever be in an inclusive environment, and the school said no.” Kara is currently home-schooling Noah for kindergarten.

The family also has repeatedly wrestled with an unwieldy Medical Assistance program, which often delays approval on prior authorizations so that Noah goes weeks without therapy. His latest appeal for speech therapy has been denied, because MA administrators first said his parents could provide it. When the family appealed, MA said his therapists needed to prove “medical necessity”.

Adding to the family’s sense of frustration, Noah has been on the Oconto County Family Support waiting list for 2 1/2 years. While Family Support funding has not been a critical issue for Noah’s family in the past, now it is much more important.

“We’re doing home schooling because the local public school treated Noah very poorly and he was not respected,” Kara says. “The teacher called him names, like ‘putzy.’ Now, we feel we have been forced into home-schooling, and we have a lot of home-

schooling needs that Family Support could help with. Our home is not a school—we need curriculum, materials and could really use access to other programs that could enrich Noah’s learning experience, like Kinder Music.”

Kara sits on Oconto County’s Family Support Advisory Board, and highly values the program. For their family in particular, service coordination has been extremely valuable as they wait for funding.

“We’ve bounced so many ideas off our family support service coordinator,” Kara says. “We’ve gotten so many ideas from her and books to read. It’s been an important source of personal support just to know we have someone who understands and offers us encouragement that we are doing a good job. But most of her time needs to be spent with families who are currently using Family Support.”

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Kara sees the frustration so many families face when they are told, as her family was told, that they must wait several years for funding. “There’s pride involved in asking for help. If you are told you have to wait after you’ve gotten the courage to ask, it’s like a slap in the face,” Kara says.

Kara says her family, like most she knows, wouldn’t ask for something if they really didn’t need it.

“When you have a child with special needs, it increases family stress. That stress shouldn’t be added to by having to wait for everything you need. Why should families be reduced to calling to check to see where they are on waiting lists for each thing they need?” she asks.

“If this is a program that’s supposed to be there for us to use, then make it work.”

Never Get a Break



After developing jaundice as an infant, 2-year-old Jeremy now has chorea athetoid cerebral palsy and a profound hearing loss. His family receives a variety of services from their local Birth to 3 program in Dane County, including therapies, augmentative communication and help from a deaf educator.

Jeremy's father, Ian, is a full-time student and works part-time, while his mother, Laura, coordinates Jeremy's care at home and cares for both Jeremy and his 5-year-old sister, Kaili. Because their income is low, the family qualifies for SSI for Jeremy.

"We're trying to put together a long-term plan so that eventually our family doesn't need all these services," Laura says. "I want to be a contributing member of society and be able to give back to the community. But we didn't plan to have a child with special needs. We need support now to get on our feet so we'll need less support later."

Laura says that while her family appreciates the services they receive, some of the family's highest-priority needs still aren't met. Jeremy is hard to hold and position because of his fluctuating muscle tone. He can suddenly arch his back and overextend when excited, which makes it hard for him to participate in daily activities and difficult for him to stay comfortable sleeping through the night.

"I am constantly sleep-deprived because I have to reposition Jeremy every hour during the night, and I can't even bathe him each day by myself without getting in the tub with him. If I want to give him a bath, I know it will take 45 minutes," Laura says. "Each feeding takes more than 20 minutes. We have a borrowed car seat from our Birth to 3 program that fits him well, but we have to give it back when he turns 3. The stroller that Medical

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Assistance would pay for hasn't been adjusted properly, so it doesn't fit right and he's not comfortable in it."

Laura also says she is spending a lot of time each day dealing with stressful living situations, rather than spending time with Jeremy and Kaili.

Her apartment is located in an older house with steep stairs in the front, and a gravel driveway that makes using the stroller very difficult. She is considering another housing option, or a way to better accommodate the stroller. She also is looking for an affordable, bigger car so she can transport all of Jeremy's equipment when they go places. Because she lifts and holds Jeremy all the time, she now has a back problem and is seeing a chiropractor. Finding time to get to appointments is challenging.

When she signed up for Family Support last year, Laura was told the wait would be long - as much as six years. However, she was able to make a one-time request for temporary funding this year. She chose to ask for funds to cover respite care services, and received \$200 per month for seven months.

"It literally saved my life," she says. "To me, stress is when you never get a break, and I was so stressed out. I felt like I could reclaim some of the control in my life by having a little pot of money to pay someone when I needed to get away or just take control of my household by cleaning and doing the dishes. The sense of helplessness and hopelessness went away."

Laura was able to take some time to resume her spiritual practice, which she says replenishes her. Respite care also has given her some time to explore other options for child care, including finding families who will exchange child care with her.

But in another month, her temporary family support funds will be gone. While she has a few people she can ask to do respite for free, she can't ask them again and again without being able to compensate them.

"I like the idea of Family Support because families can choose what is of highest priority to them," she says.

"And because of the one-time funds we received, I can see how even a relatively small amount of money can really affect a family's ability to cope. But when I think it could be another five years before Jeremy gets off the waiting list, I just think why bother. How can anyone predict where they will even be in five or six years?"

Stressful Summers

For the Bob and Jo Ann's family, summer is always stressful. It's not so much that the spring and summer bridal season is the busiest time of the year for their cake-decorating and floral business in Ellsworth. It's the challenge of finding and paying for suitable activities for their 13-year-old daughter, Briana.

Briana has a rare metabolic disorder that means her body can't absorb nutrients properly, causing frequent illnesses and chronic pain. She also has a thyroid problem and high-functioning autism. But her biggest issue, according to her parents, is her obsessive-compulsive disorder, which is heightened by an anxiety disorder. She has some behaviors that can get her into trouble, including aggression toward her younger brother, Kyle, 11.

One of her current obsessions is books. That means no books in her sight are safe, because she wants to use them as accounting books like the ones her parents use in their business and write in them. Bob and JoAnn believe that finding appropriate summer care can boost her confidence and skills, while giving them the time needed to run their demanding business.



"We try to save up money during the year so we can afford to make it through the summer," says JoAnn. "Our Family Support money is a godsend, even though I have to save it all for summer care. Sometimes during the year, I pull my hair out because I need respite, but I know I have to save that money for the summer."

Options in rural areas, like where Bob and JoAnn live in Plum City, are also limited. This year, they checked into a YMCA day camp, which was willing to work with the family to accommodate Briana's needs. But the program was more than an hour away from their home. Each day of the program, JoAnne would have to drive more than three hours to get Briana there and back.

Instead, they are paying \$160 per week for a two-day camp experience with a behavioral consultant. The consultant works with another girl and Briana on outdoor survival skills, as well as appropriate social behavior and some academics.

Bob and JoAnn say they understand why some people might think it's every family's responsibility to provide their own summer child care. But, JoAnn points out, most families don't have to find child care for a 13-year-old.

"Raising a child with special needs is not easy," she says. "It's not like anyone can come in and fix things, and then later everyone is O.K. Families do the best they can with what they have. But the level of responsibility that families have is bigger, and it stays with them longer than most people realize."

The Larsons have received funding from Family Support since Briana was young. Like most families in their area who receive Family Support, they spend most of it on respite care.

When Briana was first diagnosed, there were no waiting lists in Pierce County. But now, families are wait-listed between one and two years before receiving funds. JoAnn, who is a member of the Pierce County Family Support Board, says the county has a budget of only \$24,000 to serve all eligible families.

Because JoAnn is on the Family Support Board, she knows what families in the county are going through.

"They're just overwhelmed," she says. "People are crying and at their wits' end. Social workers in Family Support need to spend time with families, but their caseloads are so high. If families just had someone who could come out and see them and relate to where they are it, it would be so helpful."

JoAnn believes that if every family on waiting lists in Wisconsin could get one weekend of respite per month, it would make an incredible impact on their lives.

"If you don't have a child with special needs, you just don't have a clue," she says. "If our lawmakers had to live in some families' shoes for just one day, we would be seeing more money for respite out there. Even minor support is so critical."

"If families just had someone who could come out and see them and relate to where they are it, it would be so helpful."

Funding Shortages

Janine and Steven of Elk Mound realize that if their beautiful 5 1/2-year-old daughter, Cora, had been born 40 years ago, she might have ended up in an institution. Now, because of funding shortages in Dunn County, it looks like the county's Health and Human Services may have to consider transferring some people with significant disabilities to a nursing home or Northern Center residential facility.



The county's Health and Human Services department has also taken the stand of saying "no" to any additional services for those currently receiving supports, and continuing to allow the waiting list to grow because of chronic underfunding from the state.

The family has already waited more than five years for Family Support funding for Cora, who was born with medical problems and diagnosed with autism at age 3.

"If we could just get the help we need to allow our daughter and other children with disabilities to become productive members of society, we wouldn't have to even consider putting away people in institutions," Janine says. "Family Support is one way to help families support their kids to become productive citizens. I really believe that each of us has some things we can do real good. Family Support could help us explore those things that Cora is good at."

Cora receives speech and occupational therapy at school, and the family drives to Chippewa once a week for more OT and speech. She also sees a psychiatrist in Eau Claire.

Cora's parents say one of her strengths is reading. She's also a visual learner who is very interested in computers. But the family, who lost their dairy farm in 1996, can't afford a computer or the educational programs available on disk on Steven's salary as a cement hauler.

Another concern for Janine and Steven is Cora's tendency to run off. They can't let her out of their sight, because she doesn't have a good understanding of personal safety,

and is likely to leave the yard or run into traffic. They would like to build a play structure that would keep her interested and motivated to stay in her backyard. But again, they don't have the money to do it alone.

Family Support could also pay for the pull-ups Cora uses, and the special foods she eats because she can only tolerate certain tastes and textures. One aspect of Family Support that Janine really appreciates is that it allows families to make the choices they think are most important.

"Medical Assistance would pay for diapers for Cora, but we use pull-ups because we want her to learn to use the bathroom, and diapers are too hard for her to get out of," Janine says. "Besides, a 5-year-old shouldn't have to wear diapers. But no one will cover the cost of pull-ups, and they are really expensive - more than \$100 a month."

Bob and Janine would also love to use Family Support funds to attend educational conferences on autism, so they can learn more about their daughter's disability and effective interventions for her. But for now, all their plans need to remain on hold.

"People tell us all the time that because Cora has a disability, we must have SSI or other funds to help us take care of her," Janine says.

"But even though we've been on waiting lists since she was a baby, we're still expected to wait. Almost everything in her life, from special clothes with velcro, to the food she eats, costs more than it would for another child. And all we're told to do about it is wait."

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Heartbroken

Ever since their daughter, Cassandra, was born 12 weeks premature nearly 7 years ago, her family has been waiting. They waited three months just for Cassie to come home from the hospital. Then, they had to wait until a crisis hit their family to get any support in caring for their daughter.

Now, they wait to see Cassie from week to week. She lives in a foster home in another county where services are more readily available to her foster mother than they were to Georgia and Mike when they cared for Cassie at home.

“Putting Cassie in foster care has been the most horrible thing I’ve ever gone through in my life,” says Georgia. “I’ve cried more this year than any other year in my life. I’m on medication for depression and anxiety attacks. I have a panic attack any time I pick her up and drop her off because I haven’t learned how to let go. I don’t know if a mother should have to learn something like that.”

Georgia and Mike say the sad truth about their experience parenting a child with significant health and developmental needs in Wisconsin is that it’s easier to place a child out of home than to keep her.

Cassie has a host of medical diagnoses and chronic health concerns. She has hyaline membrane disease and other neurological problems, spastic quadriplegia, hypoplasia of the cerebellum, reactive airway disease, and is legally blind. Cassie is g-tube fed and has had surgery for reflux, her hips and her legs.

Yet Cassie’s parents, Georgia, an educational assistant, and Mike, who works in a glass factory, were getting no help in caring for Cassie when she was home.

Although Cassie received Supplemental Security Income (SSI), Mike and Georgia often made too much money during the month, and would have to pay back the SSI. Then, they received a Katie Beckett waiver to qualify Cassie for Medical Assistance. But they couldn’t get nursing or personal care through the program that would come to their rural Delavan home in Walworth County.



After appealing to Congressional representatives, the family did receive respite funding, but couldn't find qualified workers in the county. While Cassie's name was on Family Support waiting list almost since birth, her name has never come to the top.

Georgia was caring for Cassie full-time with help from Mike and her mother-in-law, but they were so short on money that she had to go back to work, finding a job that coincided with the hours when Cassie was in school.

Then, a year ago, Cassie developed pneumonia. Georgia says she was never the same again. She quit sleeping and lost all ability to process sensations around her. Lights, noises and movements caused her to cry inconsolably for hours. Once she began to cry, she couldn't stop. Her 14-year-old sister, Ashley, loves Cassie. But she was under constant stress from her crying, and had recurring fears that Cassie would die.

"I remember the day our family fell apart," Georgia says. "I went to work and Mike was taking our daughter, Ashley, to school. Mike backed into a mailbox and lost it. He called me screaming he was going to kill someone at the county for not giving us any support. I called the county and told them they had to take Cassie away right away."

In December, Cassie was placed at Central Wisconsin Center. She stayed for six months, at a cost of \$350 per day. At CWC, medical professionals did further testing and began drugs that allowed Cassie to stop crying after she began.

While Cassie was at CWC, the family tried home visits. But Cassie had a hard time with some of the stimulations at home. And her parents continued to hear that there would be no in-home supports for them if Cassie came home.

They found a foster mother about an hour away who provides care to children who are medically fragile. Cassie has been living there since June, although Georgia still takes off work for her doctors' appointments and follow-up care, since she still knows the most about Cassie. The foster mother receives \$3,200 per month and has access to 13 hours a day of nursing and personal care for Cassie.

"We feel heartbroken," Georgia says. "We are wondering if we should sign a CHIP petition to pay the 12.5 percent our family is responsible for in placing Cassie in foster care. We can't even afford the foster care fee on our own. SSI and CIP now pay for Cassie to stay with the foster family. But we really want to take care of Cassie ourselves. No one will give us any money for her care, but they're willing to pay so much to let others care for her."

Shattered Family

Roxie doesn't think the government has a right to decide where a family lives. But different levels of support offered in different Wisconsin counties forced the family to make very hard decisions about where to live and whether they could stay together.

In the end, their 16-year-old daughter, Krystal, was placed in out-of-home care since Chippewa County did not provide Family Support, respite and other services the family had in Eau Claire County.



Roxie and her husband, George, have four daughters, ages 17, 16, 6 and 4. Their second daughter, Krystal, was born not breathing with the cord wrapped around her neck. She had unstable blood sugar levels for nine months after birth. A year old, she had her first recognized seizure. At age 2, she was diagnosed with Lennox-Gastaut Syndrome, involving a severe form of epilepsy, physical and cognitive disabilities. Krystal needs total care, including feeding, diapering and supervision. She can walk with assistance around the house, but can't talk, walk distances, or do any self-care.

At the time of Krystal's diagnosis, George and Roxie were very young. The stress of being young parents with a disabled child caused them to divorce. Roxie moved with her two daughters to Eau Claire County, where they were eligible for Supplemental Security Income (SSI), respite care and Family Support. The family received nursing care while Roxie was in school or at work. George maintained a close relationship.

In 1994, George and Roxie remarried and moved to Bloomer in Chippewa County. "We just assumed the supports we got would be transferred - we weren't moving that far away," Roxie says. "But as soon as we moved, the social worker told me Krystal was ineligible for respite, services and equipment. I was pregnant and doing total care for Krystal because everything was gone except some nursing care."

Eventually, the family received respite after Roxie advocated for it. But even with respite care funding, Roxie had to find her own respite provider, who she met in Eau Claire, but lived an hour and a half away. Family Support only provided them with a cell phone for emergencies. There was no other funding from Family Support.

Meanwhile, Krystal's medical needs became more serious. Her seizures increased, and she was only attending school about once a week. Krystal's home district contracted special education services from a district 50 miles away. Krystal often had to be medicated for the long bus rides. Finally, the family and Krystal's doctors had her declared medically homebound. She received instruction and therapies at home.

Krystal's walking became more unsteady, and she could pull down an adult helping her. The respite provider Roxie had located couldn't take care of Krystal anymore.

"She wasn't in school, I got no help from the county, and I had two other children to take care of," Roxie says. "Nurses often wouldn't show up, or would quit soon after they started." Their family life was nearly gone. Roxie couldn't attend any of her older daughter's volleyball games. Nurses were coming and going as they tried to eat a meal. Or, nurses would cancel and the family would have to scrap their plans.

In the winter of 1998, Roxie and George decided they couldn't care for Krystal by themselves anymore. In August, Roxie located a health care center to take Krystal.

"I never thought I would do it. It just kills me," Roxie says. "I had a hard time even visiting, because it was just so difficult that someone else was taking care of her."

Eventually, Krystal moved to an institution, then to a group home where she lives with a roommate. Ironically, once Krystal left home, services started to flow. She received summer therapy, including swim therapy. She got a new wheel chair and became eligible for SSI since she no longer lives with her family. Now, all medications and transportation to and from appointments are paid for.

But Roxie wishes Family Support could have helped their family more with reliable nursing care and a closer school district. The Chippewa district, where Krystal attends now, would have been closer to her home than where she attended 50 miles away. It is also better-equipped to meet Krystal's needs.

"What I really would have liked was to get the funding from Family Support to add on to our house, with a separate part for privacy," she says. "Then, Krystal could receive nursing care or therapy while we were eating dinner, and people wouldn't have been on top of each other. If we could have gotten more reliable supports, she'd still be living with us today."



Hard Decisions

Sarah and Andrew know what it's like to wait. They have waited nearly four years for Family Support and Respite Care for their 6-year-old son, Gordon, who has been on waiting lists since he was diagnosed with cerebral palsy at the age of 2 1/2.

Gordon was first on waiting lists in Douglas County when the family lived in Superior. Then, when they moved to Milwaukee County a year ago, the family had to start all over again on a new set of waiting lists.

It's especially hard for the parents to watch their children have to wait. Gordon, who uses a motorized wheelchair to get around, often must wait days to go on simple family trips to the store or out to visit relatives. The family doesn't have a wheelchair ramp at their home, and they don't have a lift to get the wheelchair into their van. Instead, they must take the wheelchair apart and lift Gordon into the van whenever they want to take him someplace.

"Sometimes we are just in too much of a hurry, and we have to tell Gordon that he can't come this time," Sarah says. "It's very hard on him and very frustrating for all of us." Sarah says that while Gordon is physically very involved, he is cognitively at age level, so he understands that he is being left behind.

Because the parents work long hours and the family doesn't have adequate child care, their two preschool-aged children are currently living with their grandparents in Minneapolis. Extended family are used as resources more among people in the Hmong Community, nonetheless, Sarah says it was a hard decision, but a necessary one because of all the extra steps involved in Gordon's care.

"All of his care is done by us," she says. "It is physically and mentally draining because there is no one else to turn to, and no shoulder to cry on. It's a very stressful situation, especially with no respite care to help release tension. Sometimes, it can cause family problems."

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The family has no funding to pay for after-school child care for Gordon because they have never received respite funding. Gordon stays with teenaged and pre-teen cousins after school until his parents come home from work. Even more difficult are the steps required to get Gordon out of the house and onto the school bus each morning for his ride to a Milwaukee public school, where he is fully included in first grade with supports.

Andrew built a homemade wheelchair ramp at his relative’s house down the block, where the family lived when they first moved to Milwaukee last year. But then the family moved to a house of their own. Both are older homes with steep stairs that require a wheelchair ramp in order to get Gordon’s heavy power chair up and down the steps and into the house. Andrew couldn’t move the ramp he built, so it remains at the house down the block.

Each day, Gordon’s parents must go down the street to get the chair, then they carry Gordon down the steps of their home to place him the chair. That’s where the school bus picks him up and lifts the chair into the bus.

So far, the family has only tried this method in warmer weather. While they have been told that their request for a wheelchair ramp has been approved by Family Support, Sarah wonders what will happen if they don’t get a ramp installed at their house before winter.

And while the ramp is a pressing concern, she feels the van lift is just as important so Gordon can participate in family life. But she doesn’t have much hope of getting the lift any time soon. Likewise, her hopes of getting respite care seem distant.

“It seems like I’m on the phone all the time trying to find things out and get information,” she says. “Usually, all I find out is that we have to wait some more. I’m sure it is going to be a lot harder as Gordon gets older. He has been asking why his legs don’t work. We told him, ‘You’re special.’ His reply back is, ‘I NOT special.’”

Ode to Be Human

Cherise wonders how much stronger she has to be and how much more she has to do before she can get the appropriate supports for her 12-year-old daughter, Azuree, who has severe mental health issues.

Azuree has been kicked out of school, handcuffed and taken into police custody, and her behavior has resulted in police calls to Cherise's home.

Meanwhile, Cherise herself has a narcolepsy, a disability that causes fatigue and extreme sleepiness during the day. Because of the stress of her own illness and the extreme behaviors her daughter has, Cherise's hair fell out, she has gained a lot of weight, and she is feeling totally isolated from her community. But Cherise believes much of her family's troubles could have been avoided if the proper supports were in place.

Azuree has a host of diagnostic labels, including bipolar disorder, oppositional defiant disorder, poor impulse control, attention deficit hyperactive disorder (ADHD), and severe emotional disturbance. Cherise says she has hallucinations and has cried every day of her life.

Cherise's disability makes it much more challenging to deal with her daughter's overwhelming needs and the needs of her typically-developing 6-year-old son.

"One moment Azuree feels this way, the next moment she has completely changed," Cherise says. "Who knows from moment to moment how she will feel. She is a danger to other people. A couple of years ago, she cut my son's wrists. I have tried to tell her stories, given her examples. I've talked to her until I'm blue in the face. But it's mental illness. You can't reason with it."

Azuree has been in therapy since she was in first grade. She has had extended hospitalizations and seen several psychiatrists. She now receives both mental health treatment and her education at a day treatment center. Azuree also is served by Wrap-Around Milwaukee, which is sup-

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posed to provide services based on the family's needs. Every other weekend, Cherise receives respite.

But Azuree has been on the Milwaukee County Family Support waiting list for two years, and Cherise feels there is little continuity among service providers.

"Nothing is ever set up for smooth transitions," she says. "Azuree is missing part of the education she should have each day because the medical services she receives overlap with the education program at the day treatment center. And there's no follow-through. Just recently, I found out the educators don't know about her behavior at home - the care coordinator had not shared that information with them."

Cherise feels strongly that her daughter's educational needs, including some non-specified learning problems, are not being met. She says her daughter is very intelligent, but struggles with writing and spelling. If Azuree received Family Support, Cherise would get a computer and programs to help Azuree academically.

She would also like to use funding to send Azuree to a learning institute that could design a complete learning program to meet her daughter's needs. Extra funding would also cover the costs of structured after-school programs for Azuree, which Cherise feels are important because Azuree does better in structured settings.

"This can't be considered a life," Cherise says. "Every weekend that my daughter is gone to respite, my son tells me he doesn't want her to come back. I would like to get my master's degree in psychology or something like that, but I can't even think about it. Every morning, I'm getting my daughter up off the floor because she's scared to sleep in her own bed. No one realizes what this system is taking away from us as a family, and away from her as a human being. With the kind of life we lead every day, you forget you're even human."

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Needs Don't Wait

Sandy thinks it's ridiculous that her 15-year-old daughter, Danielle, has to live in an institution at taxpayer expense and her husband, who is terminally ill, has to live at a hospice center 45 minutes away. Sandy knows Danielle and her husband Ron could both be living at home now if the family had gotten any support at all.

Instead, care for Danielle and Ron costs more than \$10,000 per month, and neither of them are living close to their home in Waupun. Ron lives in Fond du Lac, while Danielle lives in a private residential facility in Plymouth.

Sandy works three jobs to make the court-ordered monthly payments for Danielle's care, and then spends more hours in the car just to visit both of them. She says her 12-year-old daughter, Kayla, does a lot of babysitting to meet her own expenses, because the family's resources are quickly draining away.

"Danielle needs a structured setting and assistance, but she could be more independent than she is right now in a residential center," Sandy says. "I'd like her to live in a group home, but it's a three- to five-year wait for a group home in Dodge County and across Wisconsin. I was told she could go to a group home in Illinois or Indiana, but I said no, you're not sending her out of state."

Sandy believes that if she could have gotten some nursing assistant support and respite care, her daughter could still be at home. But Danielle has received no county services since the family moved to Dodge County when Danielle was 3. The family had never heard of Family Support or Respite Care, and no one in the county told them about the programs.

Danielle has cerebral palsy and epilepsy resulting from a birth trauma. She needed a blood transfusion as a newborn, and the blood was infected with Hepatitis C, which never leaves the body. She is legally blind and is doing academic work at about the first grade level.

Sandy says Dodge County didn't know her family existed until 1997, when Danielle began having some challenging behaviors. When their family was in crisis, they learned about and got on the waiting lists for Family Support, the Community Options Program (COP), the Community Integration Program (CIP) and Respite.

But the family couldn't wait years to come off the waiting lists, so Danielle went to Winnebago Mental Health facility three times.

"If we had just known about the supports ahead of time, we wouldn't have been looking at Winnebago at all," Sandy says.

Since learning about the county programs, Sandy has joined the Family Support Advisory Committee in Dodge County. She says while 26 families in the county are receiving Family Support services, 36 families are on a waiting list.

"I have since found out that if I lived across the street in Fond du Lac County, my family would get funding," she says. "When I bought my house, I wasn't thinking of services for my family. I love my house and it's newly-built. But I've actually had it on the market because of the lack of services on this side of the street."

Likewise, Sandy says Ron is in a Fond du Lac County hospice facility because there are no county-covered services in Dodge County. She would be responsible for the co-pay, which is about \$70 to \$100 per day.

"What are you supposed to have to give up to keep your child home, to keep your husband home? When Ron and Danielle were home, no one would help me and I couldn't afford to hire someone. I went weeks without leaving the house- people went grocery shopping for me. I had to take a leave from my job until they finally told me I'd be let go. By the time we got in the system, we were in crisis," Sandy says.

"All I wanted was a nursing assistant for both of them a few hours a day that you pay maybe \$10 an hour. Now, it's costing \$10,000 a month. It would have been so much cheaper to get home help, and so much less stressful for our family."

"I have since found out that if I lived across the street in Fond du Lac County, my family would get funding ... I've actually had it on the market because of the lack of services on this side of the street."