

“You Know Your Child Better Than Anyone”

A mom shares insights on helping children with disabilities get the most out of life.

For Patricia Houseworth, and maybe for any parent, there’s always a tension between the perfect, unattainable vision of parenting, and the reality.

The reality, with a grown daughter who has had developmental disabilities since birth, is sometimes hard, sometimes funny, sometimes frustrating, sometimes rewarding, and can sometimes leave Patricia feeling like her efforts are never enough.

Then Anissa turns to her in the checkout line of the grocery store and says, “Mom, you’re a beautiful person. I love you.”

“And she really means it,” Patricia said.

The affection and connection between them has been forged through 40 years. So when Patricia, who is Anissa’s legal guardian, sets out to find a new situation that will help her daughter thrive, you’d better believe she is going to track down the absolute best arrangement—even if it’s not perfect—on Anissa’s behalf.

“I tell parents, ‘Do not be intimidated by professionals. Remember that of all the people in the room, you are the ultimate expert on your child. You know your child better than anyone else here,’” Patricia said. “Don’t ever feel awkward or embarrassed about asking questions. Professionals sometimes may use unfamiliar terms or acronyms to reference forms, services, categories, etc. in discussions with parents. Parents should never hesitate to ask for clarification.”

Patricia uses all the tools at her disposal—determination, a gift for research, hard-earned experience—to set up Anissa’s schedule. Anissa attends two different facilities for day services (MRSI and Benchmark), and lives with two other adult women at a home in Celina where they receive round-the-clock care. While a daily routine promotes a sense of security for Anissa, changing up her activities helps limit her obsessive-compulsive tendencies. It’s a delicate balance, to be sure. So Patricia creatively alters her experiences.

Younger parents who may sometimes feel overwhelmed can learn a lot from Patricia, said Erica Lange, the



Anissa Houseworth with her mom, Patricia, in Anissa’s house in Celina.

SSA from Mercer DD who works with Anissa and her family. “Patricia keeps open communication with all her daughter’s providers and her SSA,” Erica said. “Her daughter may not always accurately be able to communicate her thoughts and opinions. Patricia shares her expectations with providers, but is also open to fresh ideas and approaches from providers. Patricia is also very creative and thinks outside of the norm, bringing up ideas that have helped her daughter be successful.”

There’s another thing that Patricia recommends, and that’s a big binder. She’s got one, and she keeps it current with all of Anissa’s medical documentation, insurance information, and family/care provider contacts. If they go to a doctor’s appointment, the binder (or a condensed version of it) usually comes along.

If Patricia sounds like an expert, she is—but she and her husband, Patrick, were anything but experts on developmental disabilities when Anissa was born.

“When you first find out that your child has a disability, you’re desperate to find that doctor, that intervention or therapy that’s going to fix it. You call an expert to make an appointment, and they tell you, ‘Yeah, we can get you’
(Continued on page three)

See Patricia’s Pointers for Parents, page 3

What's in a Name? It Turns Out, a Lot!

There is no way that Cheryl Ann Coate or her family had an idea that her name would carry so much meaning in Mercer County, Ohio. For over 50 years, the name Cheryl Ann has resonated in Mercer County, and in nearly every instance, the name Cheryl Ann provokes thoughts of goodness and helpfulness.

In 1967, the state of Ohio created county DD Boards, and our forefathers chose to continue using the name of Cheryl Ann instead of the Mercer County Board of Developmental Disabilities. Probably due to the positive feelings it emitted and maybe because being a board of developmental disabilities sounded a little cold and bureaucratic. Over time, everyone in Mercer County thought of Cheryl



**Cheryl Ann
Superintendent
Shawn Thieman**

Ann Programs as the single organization that assisted all individuals with disabilities and their families. “Cheryl Ann” became a term that described all the services offered

to individuals with developmental disabilities. We (the Board of DD) used her name to describe buildings such as the Cheryl Ann School Building, the CA Workshop, and CA Employment Offices. There were also programs and businesses like CA Industries and CA Group that were created. Over the years, we tinkered with some other names to try and provide some distance from the Cheryl Ann brand—like GBS, Serenity Springs, Diverse Endeavors, Off the Beaten Path, etc. However, there were many times when using all those different names has caused confusion. It is our goal to better explain who we are throughout 2020.

To be clear—our intent is not to run from the Cheryl Ann or CA title. That name has meant too much, for too many, for too long to be easily swept aside. Besides, our largest agency provider in Mercer County (CA Group) continues to use the abbreviated name of Cheryl Ann. I am not interested in changing names as much as I am in clarifying who we (the Mercer County Board of Developmental Disabilities) are.

Mercer DD is the political subdivision that levies tax dollars from property owners to fund the wide array of services needed by all of the individuals with developmental disabilities in Mercer County.

Mercer DD contracts with over 30 agency providers with nearly 200 employees to serve all of the individuals with developmental disabilities in Mercer County.

Mercer DD employs 10 bachelors- or masters-level individuals within its SSA Offices to write plans, budget Medicaid dollars, and manage day-to-day emergencies that impact the individuals we serve.

Mercer DD employs eight bachelors- or masters-level individuals within its Early Intervention Department to serve infants and children under the age of three.

In total, Mercer DD employs 33 individuals to serve approximately 500 families in Mercer County annually.

It is increasingly important that the citizens of Mercer County understand that Mercer DD is the entity tasked with the responsibility of procuring, funding and measuring all of the services that are offered to every resident living with a developmental disability.

In recent years, I have been known to tell staff, “I don’t care what the families and people of Mercer County call us as long as they are happy and positive about the services they experience or see in the community.” I think I was wrong. It is increasingly important that the citizens of Mercer County understand that Mercer DD is the entity tasked with the responsibility of procuring, funding and measuring all of the services that are offered to every resident living with a developmental disability. Our first step is that we have created a new Mercer DD logo (see it at the top of page one), and our second step will be the development of a campaign to educate the public in 2020.

We’ve had a good response to our issue about independent providers. If you are interested in learning more/becoming an independent provider, please contact Mercer DD at 567.890.0214.

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(Continued from page one)

scheduled eight months from now,’ and that’s just an initial visit. Meanwhile, you’re so desperate to do something right away,” she said.

Patricia learned everything she could about Anissa’s disabilities, then she learned all she could about all children’s disabilities—she went back to school and earned a degree in what was then called special education, and later earned a master’s degree in counseling.

“I tell parents, ‘I’ve been on both sides of the desk. I will be honest with you.’ Most parents appreciate that,” she said.

Erica underlined that thought: “If there is anything parents could learn about Patricia’s approach is to be upfront and honest about your child, what your child’s needs may be, and what you are looking for in a provider. Your SSA can help, including setting up tours and interviews with different providers and helping you come up with questions to ask to make sure a provider is a good fit.”

Patricia added that what works for one family or individual may not work for another. Providers, whether independent or an agency, change their hours or services from time to time. Last year’s list of providers may not be accurate this year, she warned. “Finding a provider for our situation doesn’t mean it’s going to fit the next person,” she said. “It’s important to get references and talk to other parents about their experiences. Interview potential providers if at all possible. Be specific and clear about your child’s disability.”

There’s help out there, Patricia found, and many people out there who, like her, want only the best for children with disabilities. Do all that you can to seek them out, make sure they listen to you—and then make sure you listen to them, she said. She added that in addition to SSAs, there are parent advocates who can be a great help; contact them through any of the local school districts.

“Sometimes you’re so focused on your child, it’s easy to miss areas of progress. But other people can be so insightful,” Patricia said.

As a child with disability grows into adulthood, his or her needs change and evolve, just as with any other person. For the Houseworths, that meant helping Anissa find an assisted living arrangement. It was also important to obtain guardianship so that Patricia could continue to help and guide her. “That’s one of my recommendations: you want to secure guardianship and a waiver by the time your child turns 18,” she said.

It is Patricia’s duty and mission to see that Anissa has what she needs. And just being around her daughter is the reward. “With Anissa, you learn what are the important things in life,” she said. “She is very good at keeping me grounded, in a very loving and compassionate way. She has made me a better person.”



Patricia and Anissa catch up at Anissa’s house.

Even so, it can be challenging to find the right situation for a child or adult with disabilities. In the midst of the struggle, Patricia stressed, parents should remember that they have needs too. “Take care of yourself, even if that’s easier said than done. There are respite services that are available, even for younger kids. Take advantage of them whenever you can, because it’s very, very helpful to have some time away,” she said. “Sometimes you feel pulled in a lot of different directions. But if you don’t take care of yourself, you can’t take care of your child’s needs. Just don’t try to go it alone. Don’t be afraid to ask for help when you need it.”

Patricia’s Pointers for Parents

Be your child’s advocate:

Expect to go to bat for your child.

Know the law and your child’s rights.

Know the agencies that can support you.

Be proactive:

Tell a new doctor or agency about your child’s disability; offer strategies to make appointments and interactions go smoothly.

Be patient with caregivers:

Speak in a normal volume.

Sometimes you will need to teach them gently; make sure you have their attention before speaking.

Keep an ongoing accurate medical binder:

Include dates, doctors’ names and contact info, medications, immunization records, allergies, insurance info, family medical history, emergency contacts.



Congratulations, Sparks!

Our Special Olympics cheer team won first place in the cheerleading competition in the State Games at Bowling Green on February 22–23.



Mercer DD Events

March 4: Walking Club at the Galleria in Celina, 4-4:45 p.m.

March 7: Dinner and a Move Night. Movie tickets sponsored by the Arc for all those served by Mercer DD. RSVP to sflederjohann@mercerdd.org.

March 9: Creative Card-Making Club, 4:30 p.m., Chickasaw Library. (No reservation required.)

March 13: Dinner and game night at the Mercer DD gym, 4980 Mud Pike, Celina.

March 17: SALT presentation, Individual Paths to Employment, panel discussion. Individuals will share their employment journeys, from full-time work to fulfilling volunteer opportunities, 6–7:30 p.m., St. John Lutheran Church, 1100 N. Main St., Celina.

March 26: Toddler open gym, 6–7:30 p.m., Mercer DD gym, 4980 Mud Pike, Celina.

March 26: Spring painting on canvas class, 6 p.m., Mercer DD gym, 4980 Mud Pike, Celina. RSVP to sflederjohann@mercerdd.org.

April 21: SALT presentation, Charting the Lifecourse.

Explore tools to support your loved ones in achieving the good life they desire. 6–7:30 p.m., St. John Lutheran Church, 1100 N. Main St., Celina.

Mercer DD
4980 Mud Pike
Celina OH 45822

*For more info on SALT, contact Karen Leigers, 567-890-0264.
All other events, contact Sam Fledderjohann, 567-890-0265.*