

OCALI | Podcast – Episode 22

Margaret Burley Award

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SIMON BUEHRER: Welcome to Inspiring Change from OCALI, our forum of stories and connections from our ongoing work of inspiring change and promoting access for people with disabilities. I'm Simon Buehrer.

MARGARET BURLEY: As a father of two sons with autism, Brady and Tyler, Jerod is an active, passionate, and dedicated father, public figure, and community leader.

REGGIE FIELDS: For over 25 years, Amy has served parents and families in Adams, Brown, Clinton, Fayette, and Highland counties through her work as a parent and family engagement consultant at the State Support Team 14.

REGGIE FIELDS: Tabby is never not thinking. She's never not thinking about families of children who are deaf or hard of hearing. Her advocacy and support for the equal rights of parents and support of their child is more than a job. It is her lifestyle.

SHAWN HENRY: Gwen believes and lives the motto of Blue Spectrum. Life is not to be viewed through a single lens of a diagnosis, but to be lived through the spectrum of potential promise and purpose.

SIMON BUEHRER: What do a sportscaster, an executive director, a transition specialist, and a band manager/roadie all have in common? Take your time. Phone a friend if you need to. Ah, there are so many possibilities. What could it be? It could be anything. Give up?

OK, again, what do a sportscaster, an executive director, a transition specialist, and a band manager/roadie all have in common? The answer? All of them were recipients of the Margaret Burley Family Impact Award, presented by OCALI.

REGGIE FIELDS: The Margaret Burley Family Impact Award-- the Margaret Burley Family Impact Award--

SHAWN HENRY: I am pleased to announce the 2020 Margaret Burley Family Impact Award winner.

SIMON BUEHRER: The Margaret Burley Family Impact Award was first given in 2016. It's presented annually at OCALICON, our marquee annual event. It's an open nomination process. Anyone can nominate anyone.

We've even had people who've nominated themselves. Which is perfectly legit. There's a cacophony of noise out there. And sometimes you've just got to toot your own horn.

But before we can talk about the award itself, you first need to start with the question, who is Margaret Burley? And then you need to ask, how do we pack 50 plus years of contributions to Ohio families and children with disabilities into a 20-minute podcast?

JEN BAVRY: --in a paragraph or two that Simon would say that you were--

SIMON BUEHRER: Well, let's start from the beginning.

SIMON BUEHRER: I think we could call you our resident historian, former.

DONNA OWENS: Right, yes, resident historian.

MARGARET BURLEY: Yeah, OK, yes.

SIMON BUEHRER: How long did you work for OCALI?

DONNA OWENS: Since OCALI began. 2004 I slid into OCALI. And within that first year, Shawn determined that we needed a family center. And he said to me, every time you talk about parents, your eyes light up. And we need-- we need a family center. Would you be interested in working on that? And I said, "I would love to."

SIMON BUEHRER: That's Donna Owens. She was the very first director of the Family and Community Outreach Center here at OCALI. Donna's passionate about families and knows all about the important role they play in breaking down barriers and building opportunities for children with disabilities.

Donna also knows Margaret Burley. She worked with her for many years and developed a close relationship with Margaret that continues to this day.

DONNA OWENS: I got to know Margaret Burley when I came to Columbus to work at the Great Lakes Area Regional Resource Center. It was a federally funded center out of The Ohio State University. And its purpose was to provide consultation and support to state directors of special education about special education issues.

Each of the directors of special education that were on a board and they developed plans each year or each project year on what they were going to focus on. And those directors of special education determined that they wanted one of their initiatives to focus on parents. And they each identified a parent in their state that they wanted to represent their state. And Ohio appointed Margaret Burley.

I was appointed to work with Margaret on Ohio's Parent Project, a project based on a study that the Rand Corporation had performed in the late '70s. The focus of the Rand Corporation's work was on that group of children who were born as a result of the rubella epidemic that was identified in 1964. And that relates to Margaret. Margaret's son, Tom, was born with congenital rubella syndrome after Margaret contracted rubella when she was pregnant with him.

JAN OSBORN: Well, Margaret and Bill had three children. Margaret, housewife, Sunday school teacher who was exposed to rubella. Their fourth child, Tom, was born with congenital rubella with multiple disabilities in 1962.

SIMON BUEHRER: That's Jan Osborn, the superintendent of the Putnam County Educational Service Center. Full disclosure-- Jan is also a member of the OCALI Advisory Board. OK, just to summarize a little-- Margaret Burley is the mother of four children, the youngest of which, Tom, as Donna and Jan just told us, was born with congenital rubella syndrome in 1962.

According to the CDC, during the 1962 to 1965 global rubella pandemic, an estimated 12.5 million rubella cases occurred in the United States. And an estimated 20,000 infants, including Margaret's son, Tom, were born with congenital rubella syndrome. In many ways, Margaret's story starts with her son. But that personal connection was simply the beginning of her journey.

JAN OSBORN: When they approached her local school that was willing to take Tom in a public school, they found out that they had to have state approval, if I got this correct. And there used to be things called E1 exclusion cards that children that were deemed too difficult to educate could be excluded from public education. And Tom was one of the individuals that was deemed too difficult to be in our public schools.

I think it's important how far we've come in 40 plus years in education across this great country. I don't want to be demeaning, but a couple of things I wrote down about 1967 is that some children that were deemed non-educable or denied access, I already mentioned that, they were provided several services, but not equal. If you think about Brown versus The Board of Topeka, Kansas, they were denied their civil rights in 1967 through 1975.

Today, some of us have no idea how primitive the public school system in this country was in addressing the needs of children with disabilities, nor do we realize the extent of discrimination against children with disabilities, along with our schools' low expectations for success of children with disabilities and a lack of resources allocated to help our most fragile children. It was not uncommon that children with disabilities that were in public schools didn't get textbooks. Or teachers started out teaching in closets and boiler rooms when they started the programs. What started out as a personal and significant need and cause for their son, Tom, Margaret has transformed into a 48-year crusade for all children. I repeat the term or word "all," A-L-L in caps.

SIMON BUEHRER: Indeed, Margaret's crusade was focused on all children and wasn't just limited to their education either, but encompassed all the services and supports that children and their families need.

DONNA OWENS: They needed services from a variety of medical professionals. Kids with disabilities with complex needs needed medical work or medical care. They needed educational support and educational care. They may need physical therapy and occupational therapy and speech therapy.

And the family may need support. And so these families needed services from a variety of service agencies. And they can be overwhelmed in not only taking care of their child with a disability with complex needs, but also just in trying to find the services that they need.

SIMON BUEHRER: Helping people find what they need was always central to Margaret's work. In 1979, she became the executive director of the Ohio Coalition for the Education of Children with Disabilities, a role that she held for almost 40 years. The Ohio Coalition, as it's typically known, is a parent professional organization dedicated to fulfilling Public Law 94-142, ensuring that every Ohio child with special needs receives a free, appropriate, public education in the least restrictive environment to enable that child to reach their highest potential. Margaret helped to build the Ohio Coalition, working out of her home and with no budget, to today's coalition of over 40 parent and professional organizations and a multimillion-dollar budget.

DONNA OWENS: Margaret's organization was a parent professional organization. 51% of the board had to be parents. But there were also professional organizations. And that was speech therapists. That was occupational therapists. And other service-- other service providers and educators were on that board.

And so they kind of had two functions. They informed the legislators, the legislators about the needs of special education and the need for special education funding. And they also had an interest in providing that parent training that was necessary. Margaret knew, because it was parents and professionals together that pushed for the passage of 94-142.

And she never forgot the importance, how parents and professionals together could be so much more powerful. She knew that the parent voice was important. But she knew it could only be strengthened by having professionals behind it. Margaret responded to a request for a proposal for money to fund a grant for a parent educator training project that would train principals and parents in a particular school district about the requirements of 94-142, about the Individual Education Program and its components, and how that would be implemented.

SIMON BUEHRER: Despite their eagerness and enthusiasm, however, Margaret and the Ohio Coalition learned that it can take a while before the funding train arrives.

DONNA OWENS: Of course, the Ohio Coalition was excited about their grant proposal. And actually, the state director of special education at that time, whose name was Frank New, was also pretty excited about that grant, thought it had a good chance of being funded. Time went on and they hadn't heard from the federal government. And Margaret took the proposal to Franklin B. Walter, the state superintendent. He took it home and read it and then came back and gave the proposal to Frank New and said, "Frank, you fund it. We'll fund this. You go on and start your parent educator training project."

And she hired staff and the grant was moving ahead. And then, finally, what you learn is the federal government moves slowly. The federal government called and said, "We're awarding the Ohio Coalition that parent professional training grant." And Margaret said, "Oh, that's OK. We've got it funded. Our state director funded it."

And the project officer said, "Margaret, you don't turn down money. You never turn down money. What you do is you hire more staff and you expand your program." And I remember Margaret telling me that story. And she said, "and I learned that lesson really well."

SIMON BUEHRER: Margaret learned lots of lessons really well and was able to expand and broaden that learning into knowledge and action to prepare and support all people at all stages of life.

DONNA OWENS: It's one thing to provide an appropriate education for kids with disabilities. But what do you do when they graduate from school? Parents felt like they were led to the edge of the cliff. And then they felt o-- they fell off. And the federal government was realizing that, because they're informed by parents and what parent issues are.

And so one of the additional training projects that the Ohio Coalition developed was a parent professional project. And it was training parents and professionals, and that would include vocational rehabilitation counselors and educators and parents, about this issue of transition. What do kids do? How do they find employment? How do we prepare them for employment? What federal support is there and what local support is there so kids can have a successful transition to the community?

And from that, then there became a focus on preschool and the need for preschool programs, that you don't wait until kids are six years old and then you decide, "Oh, now we're going to educate them," that we really-- the earlier that we can get kids and kids with disabilities, the better we can do-- we can do in preparing them for school and for a successful school experience. And so the Ohio Coalition was a leader in developing specialized training programs that way.

SIMON BUEHRER: Not only was the Ohio Coalition a leader, but Margaret was a leader as well, and recognized as such at both the state and national level.

DONNA OWENS: She became known in Ohio as the informer to state legislators. They'd often ask, "What does Margaret Burley think about this," because they knew who she was. They got to know who she was. They got to know also that they could trust what she had to say.

I mean, Margaret looked at making change not just as a one-track activity. Education is not the end of it. You have to look at the funding for the change that needs to occur. You have to inform people.

And funding is provided basically by legislators. And that's legislators both at the state level and at the federal level. And Margaret was involved in all levels. And she was involved with other parents as they strategize, and how can we push this-- how can we push this forward?

And there was a time in the early '80s when the federal government was considering that they would make special education a block grant. Now, if I hadn't known Margaret Burley, I wouldn't have known what the danger of special education becoming a block grant would have been. But

she taught me really well, as she taught the feds when she and a number of other parents decided that they were going to show up at the White House. And they did, because she knew somebody that knew somebody that knew James Baker who was, I don't know, the deputy something, chief of staff for Ronald Reagan or whatever.

SIMON BUEHRER: James Baker was, indeed, the chief of staff or whatever under Ronald Reagan. And we actually have an archived recording of Margaret herself recounting this story. It's from the main stage at OCALICON 2015, when Margaret received OCALI's Lifetime Achievement Award.

MARGARET BURLEY: The highlight of my experiences was having the opportunity to go to Washington, to the White House when President Reagan was in office. And we were in danger of losing IDEA, although it wasn't called that then. It was in 1982. And there was a plan to block grant IDEA in with other programs and allow school districts to choose whether they would educate children with disabilities or not.

And we were able to get a meeting with the chief of staff, my colleagues and I. And these were family and coalition and alliance and a group of organizations all across the country. And three of us were able to get into the White House, into the West Room, the West Wing to meet with James Baker III.

Now, he'd never heard of us. He could not figure out how we got there. And we did not tell him. We had an appointment, but in politics it's you've got to know the right people. And Sally and Bev Johns from Illinois knew the right people.

And we got that appointment. We knew that politicians have a way of wanting to distract you from your subject. And so immediately, he wanted to talk about his wife being from Dayton, Ohio. And we told him that we didn't have time to talk about that, that we were here because we wanted to let him know that we had organized all these family members across the United States and that we were all going to withdraw our money from the Republican Party if they didn't quit picking on kids with disabilities.

And he said, "What are you talking about?" He had no idea, didn't even know there was a law. But he picked up his red phone-- he does have-- he have one. He called Libby Dole. He said, "Libby, get over here. We have a problem."

And I thought, "Now, this is power. This guy has power." She ran down the hall, I guess, or wherever she came from. She was there in a short order, walked in, sat down. And he said, "I don't know what these women want, but whatever it is, give it to them."

DONNA OWENS: Margaret was always strategic. She was always strategic. And she would say, "Well, you can get this much done here, but how much can you get done locally?" Margaret, she worked in very, very ordinary ways, but she also looked at it as a chessboard to figure out how can you promote change?

They asked the Ohio Coalition to establish or to convene focus groups around the state to find out what parents' concerns were. And what came out of these 11 focus groups was the need for parents to have parent-to-parent support. Well, parent-to-parent support is what the Parent Training and Information Center does. But also what parents wanted was parent-to-parent support closer to home.

And the concept, Margaret kind of got that concept of if we had a small version of the Parent Training and Information Center at the local level, then parents could get that support close to home. And that idea became the Parent Mentor Project. The school district could hire a parent-- that could be a part time-- of a child with a disability who could provide information and training and support to parents of kids with disabilities in that district.

The idea came around in 1990. And it came out of the focus groups that were done in '89 and '90. And then the program began in 1991. And there are now something like 78 Parent Mentor Projects around the state. And they've determined that some rural counties, a local school district didn't need one parent mentor, but maybe one parent mentor for the entire county.

Some school districts even came together and submitted a proposal together and said we'll share a parent mentor, and then some educational service centers saying we want support for parents in the region that we serve. And so we want to submit a Parent Mentor Project and we'll house that parent mentor here and we'll provide this support for the parent mentor. And so projects were also funded that way. And I think there are over 200 to 250 school districts that are now covered by Parent Mentor Projects based on that first pilot project, that pilot run in 1991. And that project continues today.

She never forgot who the parent was at the local level. And she never turned down a phone call from a parent who had an individual concern. She knew the value of that. And the other thing that she said is "If I get one phone call from a parent, I know that issue is not an issue just for that parent, but it's probably that same issue for 10 or 20 parents at this very same time."

So she always had her ear to the ground. And she always had the interests of individuals with disabilities at heart. She was tireless. Ohio couldn't have had a better representative and a better change agent than Margaret Burley.

JAN OSBORN: Maybe Margaret's single most important achievement is that Margaret has met with, listened to, comforted, and counseled literally thousands of parents across Ohio in this nation in their hour of greatest need. Margaret has consistently shared her compassion, strength, wisdom, optimism, and grit with each and every child and family member she has met with in the 48 years. Margaret signifies hope for all.

SIMON BUEHRER: A remarkable woman, a remarkable coalition, a remarkable journey-- this is why the Margaret Burley Family Impact Award was created by OCALI to honor the work, energy, passion, and legacy of Margaret Burley by recognizing and celebrating the ongoing and collaborative efforts of those parents, families, educators, and other professionals who follow

Margaret's example and her lead and continue to build, support, and create possibilities, opportunities, and pathways towards achievement, fulfillment, and success.

SHAWN HENRY: So when we think of the Margaret Burley Impact Award, I think that's what we're looking for, right, is folks that are keeping those synergies alive, that it's aligned with that mission and that respect for parents. It's an honor that we are able to hand that out each year, kind of continuing to honor what she's put in place. But also it sets a bar for people to think about reaching or exceeding, if possible.

SIMON BUEHRER: That's Shawn Henry, OCALI's executive director, speaking about the Margaret Burley Family Impact Award. It's presented annually to a parent or professional who has made a significant impact on the lives of families of those with disabilities. Let's close out this episode with a few words from each of the past award winners.

JEROD SMALLEY: For those of you who are not from the Columbus area or from Ohio, my name-- I'm Jerod Smalley. I'm the sports director at NBC 4 here in town. What we've been able to do at the station, as Shawn alluded to, we've been able to build a autism-specific program, which is-- it's unlike anything that a station in the country does right now. OCALI has been a huge supporter of ours in that effort. So we're certainly-- we're very thankful for our partnership with OCALI because we feel like we're able to reach so many more people because we have good partners.

TABBY BELHORN: It is an honor to receive the Margaret Burley Family Impact Award today. And this morning I was reading about motivation in the workplace. And I couldn't help but think of the motivation that Margaret had as she began her journey. Her motivation has changed the world for families of children with disabilities, for students with disabilities, and the schools and professionals that serve our families and children. To all of us here today, I just want to ask you what is your motivation, and remind you to let that motivation energize you and direct you and sustain you.

AMY LUTTRELL: I looked up the word "impact" when I found out I did receive this award. And it just-- it said it means to have a strong effect on someone or something. And thinking about the work I've done with families, I think that they've had a stronger impact on me. And it's really changed my path. And it has been truly an honor to work with all the families and the Parent Advisory Council over the years.

GWEN HARSHAW: With the help of OCALI and other organizations, we were able to find programs and therapies to help Zayne. And during this time, we began to reach out to other families to connect and share information we have learned. Then in 2013, something totally unexpected happened that completely transformed our lives. My son Zayne taught himself to play the guitar. And he also followed his dream to have a band that was called Blue Spectrum. We always want to express Blue Spectrum's motto, which is life is not to be viewed through the single lens of a diagnosis, but to be lived through the spectrum of potential, promise, and purpose.

MARGARET BURLEY: So basically, we must never fall asleep at the switch. We must always be vigilant. And we always must be powerful. And we can all be as powerful as we choose to be. May the power be with you. Thank you.

[APPLAUSE]

[MUSIC PLAYING]

SIMON BUEHRER: That was Margaret Burley, speaking from the main stage at OCALICON 2015. You can learn more about the organization that she led for nearly 40 years, the Ohio Coalition for the Education of Children With Disabilities. Their website, ocecd.org. Again, that's ocecd.org.

We also heard from each of the winners of OCALI's Margaret Burley Family Impact Award-- sportscaster Jerod Smalley, executive director Tabby Belhorn, transition specialist Amy Luttrell, and band manager/roadie Gwen Harshaw. OCALI accepts the nominations every year for the Margaret Burley Family Impact Award. You can go to ocalicon.org for the most current details and information.

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Thanks for listening to Inspiring Change, because the need for change is everywhere. And inspiration can come from anywhere. I'm Simon Buehrer. See you soon.