

How Self-Contained Schools Can Help Kids with Special Needs Transcript

- Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.
- Margaret Storey is the mother to a 15-year-old super girl, Josie. Josie has Aicardi Syndrome, a rare disorder that causes intractable seizures as well as other physical and developmental disabilities. Margaret is also a professor of history and an associate dean at DePaul University, as well as being an incredible parent-advocate for children with disabilities and medical complexities.
- Kelly Cervantes: 00:40 I was first introduced to Margaret through one of Adelaide's therapists as a go-to resource for all our special needs parenting questions. She has since provided us with a wealth of information. We are talking with her today about how to improve the quality of special education programs for kids with severe epilepsy.
- Kelly Cervantes: 00:59 Thank you so much for chatting with me today, Margaret.
- Margaret Storey: 01:02 Of course. I'm happy to.
- Kelly Cervantes: 01:03 I'm so excited to have you here. You wrote this incredible blog for the *New York Times* several years ago about the need for special needs education to go beyond the IEPs, the Individual Educational Programs, in the integrated classrooms. Explain your thought process and your concerns about the standard available education system.
- Margaret Storey: 01:27 Sure. A self-contained school is a public school that's purposely built for students who have disabilities. This is really a rare thing. By the time Josie was able to attend a self-contained school for kids with disabilities, she was seven. We'd seen the models, and she's very severely disabled by her syndrome, so my desire was to find a place that would suit her and support her in ways that the self-contained classrooms she'd had up to that point hadn't been able to do.
- Margaret Storey: 01:59 When she was in preschool, it was fine, but, when she hit first grade, it was devastatingly segregated. In the public school she attended in the city, where we lived at that time, she was part of a group of students who rolled in, literally, through a separate entrance. They could not even go through the same doors as the rest of the kids. They rolled into their entrance.

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They stayed in their classroom all day. They sometimes got to go out for school assemblies where they were rolled out, pushed into the front row, pushed back out, and returned to their self-contained classroom. This was always wrong to me. I just felt that this was a terrible segregation of my child. I knew that she could not be educated alongside typical peers because of the severity of her needs, but I also knew she could learn, that she loved learning, and that she needed to be stimulated and challenged in all the ways that other kids do.

Margaret Storey: 02:56

What I found was, in this little corner of a school, she was in daycare. They just did things like make Rice Krispie treats. They weren't teaching her in a real robust way. I had heard about a school in Evanston through a colleague of mine at DePaul whose son went there. We went and visited it and decided that's what we wanted for Josie because she rolls through the front door. The whole school's built specifically for them. There's no place in that school that a kid can't go. All their peers are disabled, but they have peers who love them. They have friends. It's rich. There's a curriculum. She's got dignity. Her disability isn't a thing to tuck away. Most importantly to me, her disability isn't used as a way to train other people how to be sensitive to disability.

Kelly Cervantes: 03:45

I think such an important point is that, when you're talking about integrated classrooms, is it best for the able-bodied kids, or is it best for the disabled kids? You would hope in the best-case scenario that both groups are getting something from that.

Margaret Storey: 04:04

Exactly.

Kelly Cervantes: 04:06

You're talking about the self-contained classes mostly for these severely disabled kids. What, in your mind, quantifies that? What is that ...

Margaret Storey: 04:17

It's really hard. I mean, it's going to depend from kid to kid. One of the things that I think is problematic though, right now, is that, ideally, we have a spectrum of services for kids with disabilities. I went to great pains in that article to say that I am not denigrating inclusion as an approach. For some children, it is exactly the right thing. I absolutely laud the parents who fought tooth and nail to make that happen. They were pioneers. So I want that full spectrum. But, for some children, either their medical needs, the complexity of their developmental needs, or

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their physical needs are so significant that to really be able to have them fully access an education, which is what they are promised by federal law, they need the structures and the trained personnel to do it. We cannot do that in a cost-effective way by segregating people out into the mainstream classroom. You really do need the support that's focused in one place sometimes.

Kelly Cervantes: 05:25 I think you bring up such an interesting point about the array of disabilities and the array of options. You think of your typical able-bodied and minded child, and you have educational options oftentimes within the public-school system. They could go to a Montessori school, or the traditional school, an IB school, or whatever. There are all these programs where you can pick the best learning style for your able-bodied and minded child. When it comes to your disabled children, those same options aren't necessarily there, depending on your school district. What is the other side of that argument? Why aren't there more options for parents of special needs kids to try and customize their child's education?

Margaret Storey: 06:09 I think there are two reasons. One of them is about money. This is expensive. It's expensive to educate children who are complicated. The mandate that this is required is a federal mandate, but the funding to support it is not always available. We have a real disparity, a terribly tragic disparity, as we do in all public education, for children who are impoverished in poor neighborhoods who will just simply not be able to access this. We had the great privilege to be able to pick ourselves up and move to a community that is dedicated to this kind of thing and has the resources to support it. So there's that. There's a question of financial need, like how much it costs.

Margaret Storey: 06:57 There's also a philosophy that developed pretty strongly in the '90s that we don't want to segregate people with disabilities. And I get it. I totally get it. It's part of an inclusion movement that Josie has benefited from in so many ways. We think about what the world was like in 1960 for children like Josie, if she would have even lived, and I doubt she would have lived. If she had been alive, she would have been institutionalized, much less had access to school. So, parents advocated early on for access to education for children with Down Syndrome. They changed attitudes. They changed laws. They opened things up. And we moved to a more inclusive system.

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- Margaret Storey: 07:46 That inclusion may be over-corrected, like it can go a little too far. We can over-articulate that as the only way to do it. So I always found it ironic that people who are very, very committed to that way, almost to the exclusion to anything else, will say that you're not being educated, you can't have a good life if you're not educated with typical peers. And I thought why? What does that say to us about the dignity and richness of the lives of people with disabilities? My daughter has taught me immeasurable things that I never would have learned if I had a typical daughter. Do I wish her suffering didn't exist? Absolutely. But, at the same time, the idea that these children can't have relationships with each other, that they can't learn, that they aren't happy when they're only educated with children with disabilities, is just not true.
- Margaret Storey: 08:43 You have the self-contained, and she has the specialized education piece, which is all important. But, at the same time, she still does have a lot of medical needs. She likely has seizures in school. [crosstalk 00:08:59]
- Kelly Cervantes: 08:59 Yes. She certainly does.
- Margaret Storey: 09:01 How is the school better equipped to manage that than a typical integrated school? In my experience, and there certainly will be exceptions to this, what's great is that, because her school has got a therapeutic bent, the orientation towards families is different. The orientation towards families is more that you're a partner in this project rather than this outsider who's trying to tell the experts how to do things. That's essential, as you well know, when you're working with any kind of healthcare provider. You need that partnership. Most of these kids are getting healthcare at school.
- Margaret Storey: 09:45 They're both education providers and healthcare providers and therapists. That therapeutic reality means that you're able to explain, like for Josie. Josie regularly has seizures that are going to be longer than five minutes. If we were going to look at a standard protocol for the use of a rescue medication for a five-minute-long seizure, then you give Diastat. If we did that for Josie, she'd be having Diastat all day long. We don't do that for Josie. Josie can have a seizure that lasts 15 minutes, and it's okay. I know it's okay. The doctors know it's okay. And the nursing staff and the teachers there learn how to take care of her within that context.

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- Margaret Storey: 10:21 I give them the parameters for what is her seizure plan. That's what we set up every year, a seizure plan. That plan is highly individualized. They know to call me or Jonathan at whatever moment is the kind of trigger point where we need to go into some other protocol. But because of that, they're not afraid. They don't treat her like she's a china doll. She's able to have a normal day. She lives her life, and she has seizures every day of her life, pretty much. Sometimes she doesn't.
- Margaret Storey: 10:54 It's wonderful to be able to partner with a team and to feel that they understand your kid and you're able to shape that. At the same time, they then trust that you're open to being shaped, too. That team helps me understand how to communicate with Josie better, or helps me understand certain things that are going on at school that I don't know about. She has a life that I don't know anything about, which is exciting.
- Kelly Cervantes: 11:20 How exciting is that?
- Margaret Storey: 11:22 It's awesome. It's awesome. I want her to not have my eyes on her all the time. That's a great gift.
- Kelly Cervantes: 11:33 How can parents find out what schools are available to them? If they do have the financial means that they can move into that neighborhood or to ...
- Margaret Storey: 11:45 If they don't assert the right to get their kid there, right?
- Kelly Cervantes: 11:50 How do you find out if that school exists?
- Margaret Storey: 11:54 It's really hard. It's really hard. It depends on where you live. In some places in the country, the process is really transparent, but in a lot of places, it's just not. Again, this gets to the way that budgets hide behind philosophy. The budgetary desire not to invest in that way can sometimes cloak itself in the idea that this is what's best for the kid. To get around that, you need to talk to other parents. Almost always our best information is going to come from other parents.
- Kelly Cervantes: 12:33 Hence how we met and our friendship.
- Margaret Storey: 12:36 Yes. And how I learned about the school was through a friend. How I learned how to advocate for her there was through friends and their examples. Fellow travelers are a great

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resource. My advice would be to start asking questions. If you're stone-walled, just keep asking questions.

- Kelly Cervantes: 12:58 This is probably... I can't even imagine a massive undertaking because this building needs to be accommodated for all sorts of special needs equipment and that sort of [inaudible 00:13:08]. This is a long process to get a school like this up and running. But what options are available if there are a group of parents that are like where ...
- Margaret Storey: 13:18 Band together.
- Kelly Cervantes: 13:19 Yeah. That we need this. How do they lobby for that?
- Margaret Storey: 13:22 Well, you know it's funny because Josie's school was originally invented by parents. They founded it in their house in 1954.
- Kelly Cervantes: 13:32 Oh my word.
- Margaret Storey: 13:33 Sometime in the next 10 to 15 years, the school district said, "Oh, we'll take that and help you with it." Sometimes, what it takes is that kind of thing. You find like-minded parents, and you figure out if you can make something happen. I also think it's reasonable to start to talk to your local elected officials and your local school board. Find your school board member and say, "Have you ever considered this as a possibility?" What's interesting is that sometimes these are solutions that can, in fact, be within budget, but they don't assume it.
- Margaret Storey: 14:05 I think that talking to your local officials, talking to fellow parents, looking at other models, coming and visiting other schools, is critical. Some of these kinds of schools are run as consortium-based enterprises. Multiple districts will band together to fund a school that kids from different districts come to so that they can share the budgetary challenges and create a place that works for these kids.
- Margaret Storey: 14:31 It's always possible to make it happen, but it is hard, and it does require dedication. I always say it's hard because so many... I mean, if you're in this situation, you're parenting a child like your bandwidth is not always there.
- Kelly Cervantes: 14:44 I can't even imagine sitting down and trying to create a school out of nothing. It's an overwhelming thought.

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- Margaret Storey: 14:52 It is overwhelming. I think that the problem is that this is unfortunately often where we are, which is that the people who know best what's needed are in the least flexible place to make it happen. If you can't do everything, you can do a little thing. Try to find an advocate who you can talk to. Try to get the idea out there. If you can't do it yourself, there might be someone else who's in a position who can. But it is challenging. It's a reality.
- Kelly Cervantes: 15:26 Talk to me about Josie's typical day at school. What does that look like? What are the programs that are available to her? What makes it different than being in an integrated school?
- Margaret Storey: 15:41 The day starts with everybody coming to school, obviously. Some kids are dropped off by their parents. Some kids come on the bus. We all come in the front door, which is important, right? Through the front door, and they go to their various classrooms, and then they have a normal day of schedule. So, they have the range, depending on if they're in preschool or if they're in high school. Depending on their age group, they have the range of appropriate curricular structure. Josie has language arts, social science, arts, drama, and theater. They have a hugely rich curriculum. She changes subject's hour to hour. She has PE every day, which is adapted to her needs. The staff is fantastic. The teacher-student ratio is really low. I mean, we're talking about a teacher and four paraprofessionals in a classroom of six students.
- Kelly Cervantes: 16:32 Wow.
- Margaret Storey: 16:33 That kind of a setting is the kind that can allow you to support a child like Josie. I'll give you an example. In the last three years, she's made incredible strides with communication. Josie is non-verbal and non-ambulatory, which means she can't walk by herself. She can use a gait trainer, but it's limited. In her verbal communication, it's never developed at all, but she has been able to develop some eye-gaze, or picking pictures, strategies around communication which has been super. A lot of that I attribute to the introduction of Epidiolex. When she started to take that medicine, we saw real changes in her cognitive function.
- Margaret Storey: 17:20 Her teachers worked laboriously to teach her how to do this eye-gaze system. Then I said, "Do you think we could try now

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with a device?" We tried other devices. Her disorder means that she's not really able to functionally use her hands. She doesn't really want to pick anything, like a switch. She'll do it, but it's not what her go-to is at all. I said, "Could we try again with another device?" They said, "Sure." I said, "Well, I'm going to take her down to the Shirley Ryan Ability Lab, and let's see what we can do." They evaluated her for an eye-gaze device. We did a trial. She took to it like water because they taught her the strategies. It's set up, and it's got a little thing that gets your eyes calibrated. Then you pick a picture, and it speaks for you.

- Kelly Cervantes: 18:05 Wow.
- Margaret Storey: 18:05 So her teacher, her speech therapist, her OT at school ...
- Kelly Cervantes: 18:11 All of those therapies are provided within the school?
- Margaret Storey: 18:13 Absolutely. They are part of her IEP. Those people have been with her since she was seven. I mean, they know her very well.
- Kelly Cervantes: 18:20 Are they employed by the school?
- Margaret Storey: 18:22 Yes, by the school district. They structured a trial and figured out how to see if she could use it. She clearly could use it. We pitched it to the insurance company, crossed our fingers, and, amazingly, it was approved. She's had it since September in school. They've integrated it across the curriculum, and she's using it in ways that aren't just to pick things. I'll give you an example.
- Margaret Storey: 18:50 We were talking to her dad, who was visiting his mom in England, on the iPad. We do FaceTime. I had the device up, and she was... I'd set it up so she could start to say some phrases that are related to being happy. She kept saying, "This is fun. This is fun. This is fun." Then she navigated out of that to another weird screen with a bunch of animals. I thought that must be from school. She kept saying, "Lobster, lobster, lobster." I was wondering, why is she talking about lobster? We joked, "Oh did you know Nana loves lobster?" We had no idea what she was talking about, lobster. Off we go.
- Margaret Storey: 19:28 Then she starts... Her dad says, "I want you to find the crab. Is there a crab?" She won't find the crab, but there's a crab right there. I say, "What do you know about crabs?" Crabs have

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pincers, and, sometimes when we're crabby, we're crabby because our words are like pincers. And the next morning, she's 15 and doesn't want to get out of bed anymore, moaning and groaning and complaining and cranky, cranky, cranky. We get her to breakfast and set up the device on the table next to breakfast. She starts looking at it. I set it up for the breakfast panel. She gets out of there. She goes back to the animal thing, and the first thing she picks is crab. "Crab, Crab."

- Margaret Storey: 20:05 I say, "Are you telling me you're crabby? Are you crabby?"
- Kelly Cervantes: 20:09 How incredible that your nonverbal daughter is able to communicate with you, and you can communicate with her, and that ... the therapy and the training that that takes. It couldn't have happened in an integrated school.
- Margaret Storey: 20:22 Exactly. Never. It would not have happened.
- Kelly Cervantes: 20:24 It's just the resources aren't there.
- Margaret Storey: 20:25 And the time, the dedication, the expertise. It could not have happened. Moreover, everybody, me included, and I have a lot of faith in her, didn't know for sure she could do it. There she is trapped. And we're thinking, "Well, can you do it?" I'm so literal. I have no way of thinking about that lobster comment that she made. When I get her to school that morning, I say, "Oh, we used it this weekend. The device was great." And the parapro says, "Oh, did you notice how much she likes her lesson on the coral reef?" And I say, "Oh, that's why that's there."
- Kelly Cervantes: 21:06 Oh, my gosh.
- Margaret Storey: 21:06 He says, "Yeah, you know, her favorite animal is the lobster." I thought what I needed to do was to go find a lobster video. As weird as that is, right? Yeah, let's talk about lobsters because what she was trying to do was tell her daddy that she had learned about lobsters at school, which is what a kid does, right?
- Kelly Cervantes: 21:28 Yeah.
- Margaret Storey: 21:29 So there are these moments which just take my breath away because I think I underestimate her every day. What we all can do when we have a setting like that is not make that mistake.

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We train ourselves. But if she's stuck in a room with three other people and that's that, it's not going to happen.

- Kelly Cervantes: 21:51 It's not going to happen. It absolutely isn't. I do think that the integrated classrooms probably have their purpose for some children who are higher functioning and who can gain from that experience.
- Margaret Storey: 22:05 For sure.
- Kelly Cervantes: 22:06 But for our kiddos that are going to need a lot more help... I mean, I didn't even know that something like this was available.
- Margaret Storey: 22:17 Exactly. I know that Josie blossomed when she went to school. I had this terrible time thinking of her riding on the bus. But for kids with epilepsy, this is also an issue. For her to ride on the bus, she has to have somebody on the bus who can administer Diastat. That took some advocacy so she could ride the bus. There are these kinds of things that you need to push for. At the same time, if you can make it work, even for just an hour or two a day, they have an identity beyond your caring for them. This is tough. When you're constantly a caregiver, we do circumscribe their existence, right?
- Kelly Cervantes: 23:00 I think, more to your point, when Josie is in the self-contained school, you get to focus on her abilities and what she can learn versus being in an integrated school where everything is focused on her disability and how she's different.
- Margaret Storey: 23:18 And getting her to more of a place... Well, she's never going to be in that place. I mean, for me, I'm not shocked by that. This doesn't disturb me. I've long since stopped being disturbed and upset that she has these losses, but that's not about meeting her where she is and helping her be a fully expressed human being.
- Kelly Cervantes: 23:42 The best version of her.
- Margaret Storey: 23:43 Absolutely. Having her be happy. When Josie was little, things were really really bad, I mean, she was having tons of seizures every day. She couldn't do anything. She could barely sit up. She couldn't smile. It was horrible, as you well know. It's just heartbreaking and terrible. I remember Jonathan and I looking at each other and saying, "You know, if she can be happy, that's

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what we want." I'm not praying for seizures to stop anymore. I'm not praying for her to walk. I'm not praying for... I'm praying for her to be happy. That's been the thing that's made me move in everything I've done, every point of advocacy I've made. It's about how can we have these children fully experience happiness in life? If that means less drugs, then it's less drugs. If that means a self-contained classroom, then that's what we're going to do.

- Margaret Storey: 24:37 I'm not so concerned about whether or not she fits in or she's like other kids. She isn't like other kids. She's her own special version of a kid. And Josie World is okay. It's a great place, in a lot of ways. It's not easy. I don't put all roses on it and say this is just fantastic, because it's not. But within that reality, you can carve out these places of joy and real recognition of her as a person, not just the subject of our constant anxiety.
- Kelly Cervantes: 25:13 Margaret, thank you so much for coming on. This conversation was incredible, and I learned so so much. I hope everyone watching and listening did, too. I appreciate you taking your time.
- Margaret Storey: 25:24 It's my great pleasure. Thank you for doing this whole series. It's wonderful. Thank you for all the work that you and Miguel have done for CURE. It's amazing. And kiss Adelaide for me. She's such a love. You're always in my thoughts. I know it's not an easy road.
- Kelly Cervantes: 25:40 Thank you so much. It sucks, but...
- Margaret Storey: 25:41 It does.
- Kelly Cervantes: 25:41 ... we appreciate having people like you around.
- Margaret Storey: 25:43 Absolutely.
- Kelly Cervantes: 25:44 Thank you.
- Kelly Cervantes: 25:48 The devastating effects of epilepsy on children's development and education is just not acceptable. We need a cure before more children suffer the consequences of severe epilepsy. That is why, for the past 20 years, Citizens United for Research in Epilepsy has worked with researchers around the globe to fund patient-centered research, focused on finding that cure. Help us

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today by donating to CURE at cureepilepsy.org. All donations, no matter the size, have the potential to make a huge impact on children with severe epilepsy. Thanks so much.

Disclaimer: 26:28

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