

***Unrestrained* Episode 19 - Transcription**

Guest: Chelsea Budde

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Terry: Hello, and welcome to *Unrestrained*, the CPI podcast series. This is your host, Terry Vittone. Today I'm joined by Chelsea Budde, cofounder of Good Friend, Inc., a nonprofit organization dedicated to creating autism awareness, teaching acceptance of differences, and fostering empathy for students on the autism spectrum among their neurotypically developing peers. Good morning and welcome, Chelsea.

Chelsea: Good morning. Thank you, Terry.

Terry: You're welcome. Let me tell you a little bit about our guest. As a mother of two children with differently wired brains, Chelsea Budde has spent the last 16 years discovering how best to interact with, support, decipher, and empower neurologically diverse youth. In 2007, she cofounded the nonprofit organization Good Friend, Inc. in Waukesha, Wisconsin, which has reached more than 35,000 people directly with a message of autism awareness, acceptance, and empathy. Though she received a B.A. in English from St. Norbert College in 1995, most of her related training has come from conferences, workshops, professional collaborations, and field experience. In addition to being a trainer, she is also a writer, regular university guest lecturer, and a frequent state and national conference presenter. Okay, Chelsea, then let's begin.

Chelsea: All right.

Terry: All right. Could you talk about the origins of Good Friend, Inc.? Why were you and Denise Schamens motivated to found the organization?

Chelsea: Absolutely. Well, both Denise and I are parents foremost, and our unique connection is that we both have sons on the autism spectrum. We had met when our children were in early childhood class together. In our area, we have what's called a family engagement liaison—usually a volunteer position, it certainly is in our school district—and she acts as a go-between between special education parents and the Department of Public Instruction, or more localized, we have the CESA, Cooperative Educational Service Agency. And so she helps parents find resources and she interacts with families. And part of that role is making sure that she is aware of resources in the area. So it's a structure that's kind of unique to the State of Wisconsin, but other states have similar kinds of parsing of their states into regional areas that include a number of school districts.

Terry: I see.

Chelsea: And then those areas share resources themselves or decide what resources are more appropriate for their geographic area, for their consumers, so to speak, their school district. So in our CESA, Denise is the family engagement liaison. We're in a rather large school district, in the school district of Waukesha here in Wisconsin, and so she had set up a support group like an information network where families could get together and talk about what works, what doesn't, what resources they wanted to share. I would regularly come to these meetings with a binder full of resources. I'm a binder girl, and so I would amass all of these things that I had learned, because for me as a parent I happened upon these resources by trial and error.

Terry: I see.

Chelsea: And I wanted to save other families the steps. So Denise started putting things together. She started looking at what her training experience as a family engagement liaison was meaning and how she was hearing families talking regularly about how their kids with autism didn't have any friends. And she was looking at me coming to these meetings with my binder of resources and what a nerd I was and how much I had been organizing information, and she would hear me talking about how I was going into my son's classroom. After early childhood our kids went to different schools; we went into our neighborhood schools. So we went from a school that had this early childhood program to our neighborhood schools, and she would hear how at my neighborhood school I was connecting with my son's kindergarten class and first grade class to tell his peers about what made him tick, so they would understand him better. Because autism is a hidden or invisible disability, they could tell something was different but they didn't know what was different, what that meant, how they could interact.

Terry: So that outreach prefigured Good Friend, and it was maybe sort of a model for what you guys do a little bit.

Chelsea: Right, it helped us . . . we already had gears turning in different directions. Denise had this idea to make a movie for elementary school kids to teach them about autism. She approached me with this idea thinking that perhaps I would be willing to make the movie with her, write the script, do whatever organizational needs that went around that, but as she brought up the idea I said, "That's a great idea, but it needs to be so much bigger than that." I said, "It needs to be a curriculum. It needs to be a presentation that would be in classrooms. It needs to be something that we take outside of our school district, outside of our sons' classrooms. It needs to be much bigger."

So that's how the gears got turning back in 2007 when we first discussed. We discussed early in that year, and by August we were well on our way to making our first film and creating our curriculum.

Terry: I see. That leads into my next question about your identity—your logo and tagline. I imagine that these initial planning meetings, this was something that you and Denise discussed pretty much at length.

Chelsea: It is. We talked about it a lot—what did we want to have as a corporate identity, which then became a nonprofit identity, and so as a nonprofit it becomes more about your mission and about your brand, but obviously they're intimately connected.

So in the autism universe, there's a puzzle piece and the puzzle piece has become a matter of controversy over the years. When we first started we just saw the puzzle piece in the sense of bringing people together and making them fit together. That's how we have the two puzzle pieces of the different colors. The whole point is that you can take two different people and make them fit together if they have the right information, and that's why we also wanted to be called Good Friend. That's what this is about; it's about creating the proper foundation for meaningful healthier relationships.

Now, specific to us as autism parents, we knew that's the direction we wanted to take this in. We want to talk about autism. We want to talk about it positively, accurately, using consistent terminology in order for kids to take that positive information and be able to build their relationships on that information.

As we started talking about our mission and what we were looking to do, Denise and I ran in a lot of disability circles, and so we had other parents or teachers say, "You know what, it would be really

great if we made a movie for kids with Down syndrome. Wouldn't it be amazing if we made a Good Friend movie for kids with epilepsy?"

Denise said, "Wow. That could really open up some opportunities and make it neat and how nice that the name of our organization doesn't really have anything to do with autism." Well, as you might be able to predict, all of those people with those great ideas kind of fell off because they saw how much work we were putting into what we were doing. So we've just been able to stay true to autism, acceptance, and empathy.

Terry: Which is your tagline.

Chelsea: Right. Exactly, yes. It's really funny how National Autism Awareness Month has evolved. There's been this movement the last couple of years to call it Autism Acceptance Month, and we were like, "We've been talking about that for a long time." I mean you'd have to live under a rock right now in 2015 and not know anything about autism. Everybody is aware of autism; they might have misconceptions about it, but they're aware of it certainly. Then where do we need to go?

We need to go to this level of acceptance. If we are not being accepting of people with autism, we're going to constantly be trying to change them or conform them as to our neurotypical idea of what they should or should not be, and that's not what we're trying to do at all. We'd gotten calls before from teachers or administrators wanting us to "fix" the social problems of their kids with autism. That is not remotely what we're about. Yeah, we want to go in there and tell people why these individuals are amazing. We wanted to help them tell their own story about why they are amazing.

Terry: Your logo, with the two puzzle pieces—one green and one blue—could suggest that someone on the spectrum and a student who's neurotypical can fit together without this sort of radical behavior agenda that some administrators might initially approach you with.

Chelsea: Absolutely. Right. We really believe . . . and I think sometimes we will have jaded parents come to us or even teachers come to us and say, "Kids are mean," and that is the furthest thing from the truth. We really believe that generally kids want to be good people, and if you give them a good message, if you give them the correct message, they will be able to make magic happen that you never expected. So that's what we want to be able to do.

Terry: So do you believe in your heart that good behavior can be as contagious as rude behavior?

Chelsea: Without a question. In fact, I think it's more contagious to behave well. It gives people a good sense of doing good. When you see these prospective bystanders in bullying, it makes the bystanders feel really uncomfortable, but they're looking at the power dynamic and they don't want to be on the low end of that power dynamic. So they jump in where the energy is, whether positive or negative.

If we're creating a culture where that kind of behavior is not the kind of behavior we want to promote because we know that this is not a healthy behavior to promote, we are going to promote a culture of acceptance—accepting of all differences, not just differences in the way our brain is wired. We're accepting the wide range of diversity that we're talking about as a society, and we're going to make sure that when we see that kind of bullying behavior happen, we know how to change that power differential instead of making it worse, exacerbating their problem.

Terry: And how does this sort of vision you have of the culture in the classroom and the way the students interact, how did that help define your evolution of services at Good Friend, Inc.?

Chelsea: Yeah, it's so interesting because I don't think (Denise and I not being classroom teachers), I don't think we appreciated the differences that can occur between schools and even within classrooms in the same school, even at the same grade level. So as we've been travelling to these different schools, there are some things that we noticed. I mean we can walk into a school and, based on the greeting that we receive, start to make some assessments about what the culture of this school might be like. Sometimes it's amazing when we're greeted by the principal who has made it a point to welcome us into their school and either take us themselves to where we're going to be presenting or assign someone to do that. So to us, that says, "We value the message that you're bringing into our school. This is a valuable use of our time." So that's a really nice thing.

Sometimes you meet the classroom teachers and maybe they're shuffling papers on their desks and they had a really busy day, and they don't really value this. This is coming from on high and they don't really feel like they have the time for it. They're going to spend the hour that we're there grading papers.

Terry: Let's talk about the hour that you're going to spend or the other things that you would do before you experience, say, a school culture and the services that you might be bringing into them.

Chelsea: Right. We have differentiated services for our elementary school level and our middle school level. On the elementary school level, when we were first building services, the whole point was to be able to talk about a specific student with autism. That's what we really wanted to do. That's what we were doing as parents. We were going in, we were talking about our sons, and we have seen the value of that on a personal level. So that's called the peer sensitivity workshop; that's something that we do for kindergarten through fifth grade. We spend a little less time with the kindergarteners (due to their attention span and their development for growth) than we'll spend with the fifth graders. And we will share different levels of information as obviously as developmentally appropriate.

With the peer sensitivity workshop, we first get parental consent to be able to talk about this student specifically. Once we get that parental consent, we have a phone interview that we do with the parents so we can learn how that student ticks. What makes them fantastic? What are they really good at? What's their special interest? What does friendship mean to them? Because it's going to look different for them than it might for a typically developing classmate, and then we find out what are some of the things that they struggle with. What are ways that we can be supportive as a community of the child?

Then after that conversation we have a follow-up conversation with the staff member. Sometimes that's the special education teacher; sometimes it's the classroom teacher; sometimes it's the speech language pathologist—really whoever has the connection with that student.

Terry: I see.

Chelsea: And we ask some follow-up questions. This is what mom or dad sees. Is this what you see in a classroom? What kind of classroom dynamics do we need to be aware of? Is there a bullying problem going on, on the playground or on the bus or something that we need to address? That's what we do, and then we come in the second through fifth grade that's an hour-long service.

Terry: So let me ask this on a practical level. Do you guys actually have, in addition to maybe schools who are having problems, parents that contact you directly and say, "My son is autistic; I know what you guys do and I would really like it if you could somehow go in and talk for an hour, do a presentation"?

Chelsea: Yeah, definitely. The referrals come from all aspects, but I'd say the majority of them are from parents who are noticing that the child is having some social problems in school. We want to make sure that we are not stepping on any toes. We make sure we walk through with the parents some steps that they can take ahead of recommending that we come in, and maybe there are some things in the communication that they can work out with the administrators or the teachers.

Sometimes teachers or administrators are more than happy to have us come in. They know it's a problem but they have their own agenda for what they need to get accomplished in the classroom, and they haven't given a whole lot of thought about how to talk to peers about autism.

So it just kind of makes sense to turn that over to people who've been doing this in hundreds of different schools being able to work with that kind of a message. So there's a wide range of how that works out.

One thing that we have done over the years is sometimes we have parents say to us, "My school doesn't have the budget, and I want to pay for this service myself," and we have to say no, and the reason that we do that is we want to make sure that the school values the message that we are bringing. We liken it to saying what if we came into a classroom and we talked about long division for an hour and we left. Nobody was going to keep up on that. We need to make sure that they know that this is worthwhile. This is a good message. This is something that they can continue to practice after we leave. We make sure that the school has an investment of a little bit of time and a little bit of finances as well.

Terry: I see, and so that's an elementary/middle school staff service. I know that you have a pre-K class as well.

Chelsea: Yeah, we do. In the elementary school and the middle school level, we also have a general assembly where we're not talking about a specific student. It's a general presentation on autism and then we can get multiple grade levels together at the same time. We never recommend more than three grade levels at a time because the message will change a little bit for developmental reasons. We can do up to 500 kids at one time during those general assemblies, and then for staff and services we talk about the importance of autism and social rapport.

We do a lot for kids with autism in schools about teaching them social skills and being able to kind of help them understand where neurotypical people are coming from, but we don't do a whole lot with the neurotypical kids to teach them where the kids with autism are coming from. So we talk about the importance of that because when you create that culture of acceptance, you're going to help prevent disability harassment. You're going to help prevent some of that bullying, and so we talk about ways that they can do that as a staff and administrative culture as well.

Terry: I see.

Chelsea: For the pre-K, for the early childhood we just start the conversation. Sometimes this might not seem like they run on parallel lines but it's like a discussion about sexuality, right? You don't start talking about sexuality when a child is entering puberty. You start telling them when they're three years old, when they get out of the bathtub that they should wrap up in a towel or maybe not run naked through the house, and that's a modesty discussion. We unveil information about autism and disability and neurological difference as those kids are able to grasp that. So if we're going into an early childhood situation . . . it's a very little short movie. It's got a really catchy hip-hop music video that goes along with it and it just starts introducing about how we all fit together.

Terry: One could see almost on an intuitive level that the earlier you introduced this concept, the greater your chance for acceptance throughout the life of the person who is exposed to it is going to be.

Chelsea: Yeah. I think so, too. Sometimes as people get older and more set in their own cognitive ways, their own neural pathway, they start to look at autism like this A word. We can't use the A word. It's kind of like saying you can't talk about glasses and vision differences. To me it makes no sense. I think it's important to start this conversation early and have it continually unfolding so that we can unpack some of the complexities. So it's not mysterious; it's not hidden; it's not negative. I think a lot of people in our society have gotten so used to the negative connotations to deficiencies that used to be talked about with autism. Even when you look at the diagnostics, we're talking about deficiencies, and we really want to talk about it from a more positive aspect, an accurate aspect but definitely nothing to be afraid of or concealed.

Terry: I see that's an important message. I see you also do individualized classroom presentations as part of your services.

Chelsea: We do. I think that's so much fun. We as an organization have evolved as our kids have grown. So we didn't want to be this ingenuous about any service that we were offering. We wanted to make sure that as an organization we thoroughly understood the subject matter. So we didn't start offering middle school services until our own boys were in middle school and we could really devote some attention to researching that. Because we go to conferences and people go, "This is great that you have this for elementary school, but middle school is really where the social rubber hits the road. What have you got because it gets serious?"

Terry: I bet.

Chelsea: Yeah, and so we said, "It's coming. Give us some time to wrap our heads around this idea." So the primary difference between elementary and middle school students is middle school students just want to blend, whereas elementary school students have pretty similar likes and dislikes. I think for the most part you can say "Minecraft" right now to a group of intermediate elementary school students and they know exactly what you're talking about. In middle school, no one is going to go in wearing their Minecraft tee shirt on the first day of school. They want to blend in. You've got this coming from different elementary schools, different friend bases, and all these middle schoolers just want to hang out against the wall and watch what happens. They're not looking for something.

Terry: Okay. Chelsea, your children Justus and Noelle, correct? How old are they?

Chelsea: Yes, Justus and Noelle. What's that?

Terry: How old are they now?

Chelsea: They are 16 and 14 right now.

Terry: So you have just gone through the middle school years.

Chelsea: Yes, Noelle just got out of middle school, her last year of middle school. Now, I have two high schoolers, and guess where Good Friend, Inc. is going next?

Terry: Right!

Chelsea: Is that a big surprise?

Terry: No.

Chelsea: No, we will be talking about that next. In middle school, whereas it makes sense in elementary school to talk about a specific student because those kids are looking to make those individual connections, and they just want to know how, they just want the right tools in their tool box, but in middle school we're not going to out an individual with autism and say, "Hey, we're here to talk about Jordan and he's got autism."

Terry: My God.

Chelsea: Because how awful is that for Jordan?

Terry: Yes.

Chelsea: So we want to make sure that Jordan—and I'm just using this as an example—has an opportunity to share if he wants to or not if he doesn't. We are not really sure where Jordan's level of self-awareness is. We don't know how much he understands about his autism and his differently wired brain.

We always make sure no matter what age level we're going in at for what student, that that individual knows that they have autism; that's been spoken by name. And their level of understanding is going to be different, but we want to make sure we are not the ones telling him that. That's absurd that the parents have had that discussion, the caregivers have had that discussion.

So when we go in there then mom might prepare Jordan and say, "Hey, these people are coming to talk about autism as part of your biology class because we are talking about human growth and development. Autism is related to brain development, but they are not there to talk about you. But if you want to share something, you're an expert on autism because you've got it in your body. So if you want to share something, you feel free, but if you don't want to you don't have to."

Terry: I see.

Chelsea: They're not there to talk about you. What happens is we're in there for 10 minutes and before you know it, the student with autism is raising their hand, "I have autism and here's what it feels like for me, and yes that's true for me, and yes I know some people really like that but I really like this." What a rich opportunity for discussion and disclosure and transparency. It's fantastic.

Terry: I see. One of the things we talked about in our pre-interview is that working at schools through Good Friend, Inc. gives you the opportunity to absorb and evaluate different school cultures. I'm wondering if you could talk about administrative attitudes, whether the school does or doesn't accept violence or other repercussions of culture in schools that you see for people on the spectrum.

Chelsea: Yes. I think that social and emotional learning sometimes have different priority levels in different schools. A lot of times, Denise and I can walk through the hallways, look at the artwork, look at what they are celebrating at the school, and notice how maybe different abilities could be celebrated. We're kind of . . . we're just focusing on superstars who are doing extraordinary things in sports, or extraordinary things in academics.

We walked into a school (and this was after we had been at this school a number of times), and their artwork was titled "What does it mean to be a good friend?" and I think Denise and I just both started crying. We were on the way to the presentation class because we could see the language

that we've used over the years in these kids' artwork. How do you want to be remembered? And some kids say, "I want to be remembered as a good friend." How fantastic is that?

Those kinds of things we know can tap into that language, and it's so much fun to walk in a school, see their mission, see that their mission maybe relates to no put-downs, and to be able to put that right into a presentation that we are doing, so that some of that social and emotional language that they are using already as a community we can say this relates to that, too, and here's how. So we like that.

Sometimes we go into a school and there are different challenges. There might be socioeconomic challenges; there might be levels of incarceration. Really, connecting with kids with autism might not be a high priority for them.

Terry: How do you mean levels of incarceration?

Chelsea: Well, sometimes when you're going into a school that's got maybe lower parental involvement and so you've got higher rates of kids being able to use community resources, poverty-based resources, school counselors, social workers.

Terry: I see.

Chelsea: There is a different emphasis there. One of these presentations we went to in such a community, and I wasn't really sure what this meant, but this was for a fourth grade girl and one of the things that we do in our presentation is we give the teachers these colored note cards, blank note cards, and we have them pass them out to the students, and have the students write down a question either specific about autism or specific about their classmates for whom we've gotten parental consent to discuss. They can write these on these cards. They write their questions anonymously and they hand them in.

I'm going through these questions, and usually we review the questions while the video is playing so that we can answer them afterwards, and a lot of these questions focused around: "Who is this girl going to marry? Is she going to have kids? Is she going to have a job?" Really, it kept going back to "Who is she going to marry? Who's going to marry this girl?" And I thought what a strange question for fourth grade students to ask.

I consulted with a colleague and she said this is really a poverty issue. They want to know who's going to take care of her when her parents aren't there anymore. Marriage for girls at this . . . the way this cultural . . . this school, having a spouse, having a partner was critical to your survival. They want to make sure she is going to be able to do well out in the community, and that really changes. It went from why are they sexualizing this fourth grade girl because this isn't about that at all—this is about who is going to provide for her.

For them it wasn't necessarily about her having good friends now because who cares? Who is going to be there for her after school gets out? So I found that a fascinating discussion. Wow, that really changes the emphasis and the message.

Terry: But if the people around her are taught the value of being a good friend to someone who is not a neurotypical, she is going to develop a lot more skills that will help her attract and sustain a long-term relationship when she is older. It can't spring out of nowhere. She has to have that support ongoing throughout her formative years to be able to participate in a relationship like that, I would suspect.

Chelsea: Right, and that relationship might look different for her. So maybe a marriage for her or a long-standing relationship isn't a marriage relationship. Maybe she started a really close relationship with a neighbor or a family member or a lifelong friend, or maybe it's a guardian at some point. But having that conversation about relationships is really important no matter what the culture of the school.

Terry: I can see how it would be very important. You touched on some examples about what it means to be a good friend. That's an example of a real impact that Good Friend, Inc. has had for students in schools. Could you talk about that a little more, maybe some anecdotal successes or challenges?

Chelsea: Sure. I have a couple of favorite stories at the different grade levels. One of them was at elementary school level, this young man named Nick. Nick clearly had heard a lot of negative messages about autism, and he was only in third grade at the time. When we were introduced to him by his teacher, he stood behind her and growled at us. That's fine, no problem, we're strangers, we get that. We get in the classroom and mom was there. We had spoken with mom ahead of time and she was able to come to the presentation, which was great, and she was seated. Nick was behind her knees just scowling at us, terrible look on his face for us, and we started talking about it.

As we were talking and he was seeing that our message was not a condemning or judgmental one but was positive, within 5 minutes he was out in front of mom's legs. Then within 10 minutes of this presentation, he was fully sitting with his peers, raising his hands, engaging. He wasn't saying a whole lot about himself, but he was part of that group, and he was engaging in the presentation that we were doing.

At the end of it, we got a high five, which was quite different than the growl that we had gotten in the beginning. We felt that was a pretty good turnaround in the course of an hour.

Terry: That's a good transformation an hour indeed from hiding behind literally his mother's legs to joining the group and participating. Maybe that's not verbal, but that speaks quite loudly for his own sense of inclusion and acceptance through the message that you guys were giving.

Chelsea: Exactly. Right. It's funny because as we were developing *We All Fit*, we had a community conversation, and the name of the community conversation, the meaningful inclusion in the elementary school. So it's one thing for him to be sitting in a classroom behind mom's legs and it's another thing for him to be sitting with the group and attending the way they were attending. It was pretty cool.

Terry: That's exciting.

Chelsea: Yeah. Another one was at a middle school level so it was an individualized classroom presentation. This was initiated by the school. The school was actually communicating with the mom. We don't do a parental consent form for middle school because again we are not disclosing anything about that student, but mom had expressed to the teacher that her son was mortified that we were coming; he just didn't want this to happen. We had made it clear—no, no, we're not going to talk about you. This is part of your biology class. It's not about you. You don't have to say a word. He knew he had autism. Again it was the same kind of thing. He was trying so hard, those middle schoolers try so hard to blend no matter what they've got going on.

He's sitting there blending in with his class, and as we start asking questions, because all of our presentations have an interactive nature so we can learn from one another, he starts raising his hand and answering some basic questions that had nothing to do with autism. Then as we got closer

to the subject matter that might be most relevant to him, he just flat out said, "I have autism." The whole class did a "Whoa!" kind of a thing, which was adorable, and he just rocked that. So for the next 10 minutes before we started the film—and we didn't expect him to maybe say anything until after the film—but he was just right in there talking about autism in general, not necessarily talking about himself specifically, and then following the film, he shared some specific information about himself.

We beam as parents and professionals with that because really what . . . again another wonderful, unintended, but fantastic benefit of what we're doing is creating self-advocates. Maybe they were never armed with the information that we're providing. Maybe their diagnostician or their ongoing medical or mental health professional has not given them this language, this lexicon. Maybe their teacher has not, maybe their parents have not, or maybe like most middle schoolers, those people have and they don't believe them, and they need to hear it from someone else.

It was just really neat to be able to see him have those seeds of self-awareness and self-advocacy starting to grow.

Terry: Well, I mean, talk about the most impossible dream in middle school, I can be myself and still blend in.

Chelsea: Yeah. As students get to high school, they become more comfortable with who they are and they're more willing to stand on that, but in middle school they're really just trying to figure that out. They don't want to stand on it just yet, but they're exploring who they are. When it comes to the IEP process in the Individualized Education Plan, by federal law, students have to start participating at age 16. In the State of Wisconsin they have to start participating at 14. So it's critically important that they understand their own strengths and challenges to be able to advocate for themselves throughout that process.

Terry: During our pre-interview, you said something that I wrote down. You said autism interventions are good for everybody. Could you talk about that a little bit?

Chelsea: It's kind of funny because there are so many qualifiers that go along with that statement. There's asterisks all over that thing. We know, those of us who work with people with autism, that you can have 24 evidence-based practices, but it doesn't mean that all 24 of those practices are going to be good for every individual with autism. But when we look at some of the bigger things that we have discovered are good for almost all people with autism, we know the visual supports are helpful. Denise and I always laugh at that because we're like, "We have visual support. We have phones that have our calendar on it that remind us where we're supposed to be and why." That's a visual support. So visual support is good for people with autism; they're good for everybody.

When we're putting the daily schedule on the board or the supply needs on the board, that's going to be helpful for everybody. A test analysis is good for so many people with autism. That's good for everybody. In fourth and fifth grade when you're trying to create these long-term assignments and maybe it's a science project and it's going to last over the course of six weeks and what do the students with autism do? They wait until week five and a half to start the project because you've not broken it down for them and so why would they work on it ahead of time? But, no. Look, if we break this down, if we provide some scaffolding for our students with autism, they're able to accomplish that. That's good for everybody. They learn how to scaffold for themselves.

Terry: I see.

Chelsea: Yeah. In social skills training, social skills training is good for people with autism. Social emotional learning is good for everybody, important for everybody.

So those are the kinds of interventions I'm talking about. Even when we look at PBIS, Positive Behavioral Interventions and Supports, it was something that was developed for the student with autism. Something that was developed for special education students who needed concrete positive examples of expected behavior, and look, when we provide that for them, it's good for everybody. So those are the kinds of things I'm talking about.

Terry: I see. Now, you guys have also had some academics. You had a Whitewater evaluation study. Could you tell our listeners about that?

Chelsea: Sure. The University of Wisconsin-Whitewater has been partnering with us the last few years to study our intervention. I mean, really the way Denise and I went about this is very unconventional to the point of an intervention. Generally speaking, you identify a problem through research. Through research you develop an intervention, and that's how things kind of get into that best practice evidence realm, but Denise and I had good ideas as moms, and we said, "If this is good for our kids, it's probably good for other kids. If it's good for other kids, it'll take off. If it's not, it won't. Let's just put all of our eggs into the we think this is going to work basket because we have a good hunch and go with it."

Terry: That's gutsy.

Chelsea: Thank God we have the kind of husbands that thought it was a good idea, too. So as we started getting into that, it's funny because the research has kind of caught up. There's a lot of parallel research out there when we look at what's been done on PMII or Peer-Mediated Instruction and Intervention; that is kind of a parallel universe to confront but on a smaller level. So when we wanted to do things on a broader level whether it be with the peer sensitivity workshop or the assemblies, there was no evidence for why peer education was important. So now Connie Kasari out of UCLA has done a lot of really good stuff on peer education and brought a different perspective for all learners.

Terry: How is that last name spelled?

Chelsea: It's K-A-S-A-R-I. She's got some good stuff out there probably in the last five years or so, five or six years on peer education and what they're doing with it out in the State of California and beyond with her colleagues who co-authored these studies. But we needed something on our specific intervention. So we approached a couple of different researchers and Whitewater's Dr. Simone DeVore and Dr. Brooke Winchell were both ambitious enough to do this as an applied research.

What does the intervention that you are providing look like? How can we measure this, and then what are we going to find out about what you do? Is it valid? Is it effective or isn't it? So we narrowed down looking on the peer sensitivity workshops just for grade levels 3 through 5. So when we went in to provide those services, there had to be an identified student with autism in that classroom whose parents were on board, and that child was on board with us doing this intervention, and then the whole class had to be on board. Their parents had to be on board with their children participating in this research study.

Terry: I see.

Chelsea: And then the way Whitewater did it is they wrote, without of course us knowing what the questions were, some pre- and post-survey questions. So they would go in; they would administer the survey before we did our service. We would do the peer sensitivity workshop, and then they would go in and administer the same questionnaire following the service. And they had qualitative and quantitative data that they collected. We also measured the staff in services and how that worked out to talk to schools and teachers about autism and social support and available resources. Then again there was the pre- and the post-evaluation for that. So they compiled all that data and as it turns out as we expected that we are glad to see, our services are highly effective and they definitely change both student and teacher responses on those surveys.

Terry: So you have clinical research to back up the effect of Good Friend, Inc. and the staff services and the student services that you provide.

Chelsea: Right, yeah.

Terry: We'd love to see a copy of that.

Chelsea: Yeah, I'll send you . . . it's so funny because the speed of academia is so much slower than the speed of nonprofit organization. And they've presented at several conferences with us and without us. I know it's out there but whether it's published or not, that I'm not real sure on. So I will get with them and certainly will try to get whatever they have that's published or not.

Terry: That would be great.

Chelsea: Yeah, absolutely. Now the other cool thing that they're presenting now . . . so as they saw how our operations work and that we had these question cards that I talked about before where students would anonymously write questions about autism or about their classmate with autism, and again I'm an organizing nerd; I love all of that information. And I think it's important, students' handwriting, so I didn't get rid of them. I had the question cards over the years. Dr. Winchell was like, "I want those question cards. I want to do a text analysis on both question cards." So we turned those over for the purpose of research and now that's a new presentation item that they're going to say, "Look at what kids in grades 3 through 5 want to know about their classmate with autism." So how frequently similar questions come up, the types of questions they have—it's fascinating. So that's the thing that they're going around on conferences this conference season to be able to talk about those question cards.

Terry: It would be fascinating to know what those repeated questions from the peers of the people on the spectrum are regarding how to understand them or approach them.

Chelsea: Sure. When you look down at the first grade level it's what is their favorite color, and when you get up to third or fourth grade it's what sports do they play. Then the questions get more sophisticated as the kids understand more about autism in the schools that we've been at repeatedly, then we get questions like are autism and ADHD the same thing? Or how are they different?

Terry: That's excellent.

Chelsea: And it starts to get really more complicated and in depth. Let's say they've learned about autism over the course of years, and they look in the general population and they're trying to make some connections themselves. And so they'll talk about, "I heard that the creator of Pokémon has autism," and so we can talk about that. It's interesting.

Terry: So examples of awareness, creating acceptance.

Chelsea: Right, exactly. You've got awareness as the foundation of the pyramid. You've got acceptance as the middle of it, but the empathy, that's where the magic happens on the very top. As kids learn and accept that these students have differently wired brains, they're going to process information differently, including environmental information that's coming in. They contain their own behavior, or they can make their own prediction about what things they're going to do well or not so well because then you have that empathy key.

Let's say you've got a substitute teacher coming in and maybe they've seen a snapshot of their classmate Jacob, but they didn't know that if you put on low-level music in the background it's super distracting for him. That student can go up and say, "Hey, Mrs. Smith. I know you like this music. I know it's here, but right now that's super distracting and we're trying to work on math." So now you've got a community watching out for one another, which is really, I think, what the social aspect of inclusion is all about.

Terry: You mentioned earlier—and just to change gears just a little bit—about you and Denise talking about making a film presentation. I know you have a *We All Fit* video, and I want to talk to you about your evolution of your work as filmmakers because I think that's a really interesting aspect of Good Friend, Inc.

Chelsea: Yeah, it is; it's fun. Denise was the one who had the idea of this video to begin with, but really that's what it was. It was an idea. We just knew that kids' first language was no longer reading a book, as sad as that is. Their first language now is tech; they want tech and so we wanted to be able to communicate with them in their first language. That was kind of the idea of the video, but then what information did we want to convey and then how do we communicate that to the filmmaker? Denise and I have an interesting professional relationship because we're kind of like a yin and a yang.

Terry: Chelsea, let me stop you for one second. You said their first language is?

Chelsea: Technology.

Terry: Technology. I didn't understand. Okay, it's tech. T-E-C-H, okay.

Chelsea: Exactly.

Terry: I'm sorry to stop you there. I just wanted to understand myself, but you were going on to you and Denise being yin and yang. Go with that. Sorry to have interrupted you.

Chelsea: Yeah, no problem. That's what we wanted to focus on with this video for them. Obviously YouTube is where so many kids are getting their information. Websites are designed for kids that have tons of small video clips, short videos. So we knew we wanted to keep it short and we knew that there were certain messages that we wanted to convey. So I was kind of the person who would come up with the language part of it, the written part of it. So I would write the script and then Denise would visualize how the script would play out in video form.

When we found the filmmaker who was going to help us make this, he was kind of a jack-of-all-video-trade, which is really almost unheard of now as the technology evolves and becomes more layered. You have lots of different people who do different things, but he was a videographer; he was an animator; he could help out with lighting. As Denise came to him with the idea, he's like, "Great. Now storyboard it." I was like, "What? What do you mean storyboard it?" Then Denise had

to create all these images to be able to storyboard. So we understood the camera angles and the feel we were trying to get for the film. "Okay, now what do you want the animations to look like? What do you want animated?" "What?"

There were just these different layers that we hadn't thought about. What about music? How do you want it to loop? What kind of energy do you want? Oh, for heaven's sake. All of those things that we hadn't really considered and that was our . . . so our first film was released in 2007 and had this cumbersome title, *How Can I Be a Good Friend to Someone with Autism?* Because in our mindset we were going to have this video of how can I be a good friend to ___ so someone will fill in the disability blank. Of course now we know that's not what happened, but that was our first attempt and it wasn't awful. There was nothing else out there and it was good.

Terry: Can listeners find that on YouTube?

Chelsea: They cannot. We sold the film to be able to pay for the production.

Terry: I see. Okay.

Chelsea: We sell them on DVD. That one is no longer available because *We All Fit*, released in 2014, replaced that original film because obviously we learned a lot about filmmaking. We learned a lot about child development; we learned a lot about collaboration over the years. *We All Fit* is the new one but in between —

Terry: What would I see in 2014's *We All Fit*?

Chelsea: I think the most exciting part is the music video that we have. We know that especially kids with autism will latch on to a song and learn language and concepts from music. We know from research that that information is going to be more deeply ingrained into a student's brain than just having the information and language alone. So we worked with The Figureheads—they're a nonprofit music group, a hip-hop group in Milwaukee—we told them what was important to us, what we were all about. As we had the script available, we provided them the script and we said, "Hey, will you give us a theme song that we can put together in this film?" We didn't tell them how it had to sound or what the title of the track had to be; that really wasn't what we were about. We wanted to give them free creative license. The song they came back with was just awesome and called *We All Fit*, and that is available on YouTube.

Terry: Excellent.

Chelsea: Yeah, that music video is closed-captioned and available on YouTube so you will be able to find it.

Terry: We'll link to it right on the page about your interview. That's great.

Chelsea: It's great. It's so much fun. That video has been seen more than 25,000 times all over the world.

Terry: Bravo.

Chelsea: It's really been neat to see people taking that puzzle piece imagery that started to get kind of a negative connotation and flipping it around. Now, when we're doing a presentation and we show the autism awareness ribbon and the autism awareness ribbon has the different colored puzzle pieces, we're like, "Hey, who has seen this? What does this mean?" And increasingly we were getting, "It means we all fit," and that's the best feeling ever.

Terry: Excellent. I'm going to ask you about something that we talked about in our pre-interview that I think is really important, and that's the difference between something you term disability harassment and bullying and why the distinction is so important.

Chelsea: It's funny because listening to the other podcast and hearing Annie Fox talking about bullying we see how it's become kind of a ubiquitous term in education. For some people, everything is bullying. Someone being mean is bullying. "Bullying" has such a disputed and overrated use that we're not really calling too much attention to bullying. We're doing what we can do to create a culture where bullying is not something that we do. We recognize it hopefully and hopefully we're responding to it, but that disability harassment piece is something that has been defined in federal legislation. We wanted to make sure we differentiate it.

The US Department of Education in the year 2000 sent out a Dear Colleague letter that talked about disability harassment specifically. It defines it. The way we simplify it is bullying on the basis of disability, and it could be really denying opportunities that an institution provides on the basis of differences.

Terry: I know that you gave an example of a type of harassment of a student in a gym class that would qualify as disability harassment. I think that illustration could really make clear to our listeners how disability harassment is a little bit different.

Chelsea: Okay. The example that we have is there was an eighth grade boy, and he was having a hard time in his physical education class. It doesn't seem on the surface that that could be a big deal. So the comment was he's getting poked when they're on a run during the warm-up in his physical education class. What does that mean, he's getting poked? He's getting pushed? He's getting shoved? He's getting punched? No, they're just poking him. Like what, poking him with an object? No, just poking him with their fingers.

Terry: So these are kids running laps in the gym or something?

Chelsea: Yep, they're running laps in the gym. There are 100 students in this gym class, and they're running laps around this gym as part of their daily warm-up, and it has come to light that this young man absolutely hated this running lap time. We started to drill down why does he hate it. Is it the physical activity? Is it repetition? Is it the loudness in the gym? What does he hate? It turns out he hates getting poked by this group of boys that thinks it's hysterical. Every time they run past him, they poke him.

Terry: Because they realize how deeply upsetting it is to him.

Chelsea: Right. He's got a tactile defensiveness, which means that that poke to him feels like a punch to somebody else. So this is a painful experience for him. He's already not particularly enjoying his lap running, and he's not paying a whole lot of attention socially to the other kids who are around him, and he is not as fast a runner as these other boys. So these boys are lapping him regularly, and every time they lap him they think it's funny to poke him. Every time they poke him, his mood escalates. He gets more agitated, he gets louder, and that's what's observed by the teacher is this student's loud tone of voice. As that is not attended to, his rhetoric increases. "I'm going to punch you! I'm going to beat you up; you're bad boys," and so then that has to be addressed. Meanwhile they haven't seen the poking, and that's really the source of what would be the disability harassment.

They are repeatedly doing this for their own social benefit and for his detriment, and so that's why this becomes disability harassment. The nature of his disability is to be not only unable to respond

effectively to that kind of repeated negative action, but it's also that this action is more negative to him than it would be to another individual. This is painful for him to be able to endure that. That's what makes that disability harassment.

Terry: I see. How are the remedies for disability harassment different than regular bullying?

Chelsea: Well, I think it really comes down to education first. I think the most interesting thing when we're doing a presentation at a middle school level is we talk about, "Hey, guess what? Disability harassment is against the law." Before we come out with that statement, we talk about what happened if they're caught bullying at their school. Sometimes there are some very meaningful ramifications that students are aware of, but then when we say disability harassment is against the law, we get this kind of response. "What do you mean it's against the law?" Well, it's against three federal laws. So it's in violation of the Americans with Disabilities Act, the Individuals with Disabilities Education Act, entitled to the Rehab Act. There can be serious repercussions to this.

I tell the story about when my son actually was at a public pool in the city and he was talking to some young lady. I think there were some young men who were with this young lady who did not appreciate the fact that my son was talking to this girl. One of them had the brilliant idea to go and slap him on the back as hard as he could, and he left this big hand print. Now when I look at this from a disability harassment standpoint, this boy had assessed even though my son was probably five inches taller than him and outweighed him by a good 40 pounds that he would be able to get away with this physically because my son would not be able to respond effectively in time. He would not be able to turn around and pop off and hit him back or something like that. He took the calculated risk that he was going to get away with it.

What he didn't calculate was that the lifeguard would see this, and that the therapist that my son was with would see this, and that they both knew that that's disability harassment. And so instead of this young man just getting kicked out of the pool or a call to his parents, he was kicked out to a waiting squad car.

Really, the kids were like, "Oh my God. Did he go to jail? Was he arrested?" I don't know how the rest of the story played out and quite certainly he didn't go to jail or was arrested. We weren't contacted to press charges, but at the end of the day they need to understand if you are harassing some of the more vulnerable members of our society because you think they're an easier target, there is a steeper penalty for that. They need to understand that this bears more weight than a bullying situation.

Terry: I see. Well said. We talked a little bit about the neurodiversity discussion, and you had some ideas about pros and cons of that. Could you speak to that a little bit? Neurodiversity being sort of the . . . well, I'll let you define it. You're the subject matter expert.

Chelsea: Well, I don't know how much of an expert I am on it, but I have definite feelings about it. The great thing about autism, I think, is the way that we speak about it continues to evolve over time, as we understand people with autism better and give them more of the lion's share of the conversation as they should have. It's about them.

So the concept of neurodiversity is understanding that not everybody is going to have a brain wired the same way, and it doesn't necessarily mean that those with differently wired brains are disabled or dysfunctional or defective.

Terry: That's the definition of neurodiversity.

Chelsea: Right. Exactly that there's this range of neurological ability and experience, and that they are all worthy, that none of them is defective or deficient. The concept of neurodiversity, I think, where it can get a little dangerous is that, okay, if this is neurodiversity and people with diverse neurological experience are not necessarily disabled or defective, how do we make sure that we are making the proper accommodation for people who are atypical neurologically?

So for example, if you have an individual with autism who as part of their autism is unable to speak reliably with verbal communication, are we able to mitigate for them? I want to make sure that we are providing the tools and resources and accommodation that that individual might need in the workplace, in school, out in the community, to be able to mitigate for that aspect of their disability.

It's really interesting because there was just [an article that came out in the last week or so in *The Washington Post* about this very issue](#). And John Elder Robison, a very well-known adult with autism, weighed in on it and said that exact same thing. It's important for us to see the value to not try to fix people with autism, adults with autism, and see this as neurodiversity, but it's also important for us to recognize and see the value in providing accommodation as needed for people with diverse neurology.

Terry: It's used to add the appropriate balance to the overall view of neurodiversity and how it should be approached.

Chelsea: I think we need to recognize that autism is a spectrum. It's why it's called autism spectrum disorder; that's the only definition now in the DSM-5. People's experience is going to vary widely. I think probably the best benefit of the neurodiversity movement is listening to people with autism. Listen to what they want; listen to what they need; listen to what's going to work for them. If they don't have a form of reliable spoken language, then do your best to understand what their needs are. If we're continually putting on people with autism what we think is best for them, we are not doing them a service; we are doing them a disservice.

Terry: Could you talk a little bit about your connection with CPI and how we've worked with you?

Chelsea: Yeah. CPI and Good Friend, Inc. have been good friends for a long time, which I think is so neat. The idea of nonviolent crisis intervention was certainly something that was important to me as a mom. My son also has some mental health challenges, and so to be able to understand what you guys were doing as an organization, even before I formed Good Friend, Inc. with Denise, was really pretty neat. Then as we got formed, one of our board directors is an employee of CPI. We were able to exchange ideas both personally and professionally back and forth.

Then CPI, being in our professional backyard, has just been a great supporter of Good Friend's mission over the years. Every year we have a bowling event and CPI continues to bring out more teams. I feel like poor Jeff Schill who helps organize those teams every year probably spends a week of work just trying to organize the teams. It was really neat.

Terry: You might be right about that.

Chelsea: It's really increasingly complicated for him, but he also feeds off the energy that the CPI staff has for this idea. Our bowling event is Hawaiian themed and CPI had a luau this year. CPI was our first corporate partner for our Highlight It Up Blue campaign, which we have people put blue highlights in their hair to be able to start that discussion with community members about people with autism, and how we're willing to stand out and stand up for those individuals. It's really been neat. It's been neat to watch that grow over the years and see the symbiosis between CPI and Good Friend, Inc. It's very cool.

Terry: Excellent. Chelsea, do you have a final thought for our listeners, maybe someone who inspired you or just something that you would like to conclude our interview with?

Chelsea: Well, I think really my inspiration and my closing message are very much the same. My inspiration started out with my son, but as my daughter was diagnosed with autism and I thought how different her autism was, I thought that I couldn't apply all of the same principles to my daughter that I do with my son. I think this really carries over into everything Good Friend, Inc. does as we continue to draw inspiration. I mean that word is a breathing in, and so I want to breathe in every student with autism that we've ever talked to, every adult with autism we've ever interacted with, and make sure that we're staying true and relevant to their experience. They are the experts.

So it started out with the inspiration from my kids, and it continues with every other person with autism we interact with.

Terry: Very nicely done.

Chelsea: Thank you.

Terry: Yes. Thank you, Chelsea. My guest today on *Unrestrained* has been Chelsea Budde. She is the cofounder of Good Friend, Inc. that's a nonprofit organization dedicated to creating autism awareness. Thank you so much, Chelsea.

Chelsea: No problem. Thanks for having me, Terry. I appreciate it.

Terry: You're welcome.