TRANSCRIPT OF THE DELOVELY PODCAST: ON THE IMPORTANCE OF HUMILITY WITH JANET SAUER AND ZACH ROSSETTI

Introduction:

Hello, I'm Roy Gerstenberger of Firstperson Services and this is Delovely; a podcast featuring conversations with people who are creative curious and committed to building whole communities where inclusion and diversity is celebrated the concern over health and educational disparities experienced by marginalized groups in the United States intensifies by the day. Whether it's access to acute care or long term care services. The Centers for Medicaid and Medicare Services has made it a priority for service programs and professionals that lead them to become more skilled and understanding and accommodating the range of variation of cultural backgrounds of people needing to access services. The same is true for educational systems, the US Department of Health and Human Services has the following statement on its website culturally competent programs maintain a set of attitudes perspectives behaviors and policies, both individually and organizationally that provide positive and effective interactions with diverse cultures, practicing cultural competence to honor diversity means understanding the core needs of your target audience, and designing services materials to meet those needs strategically, it's important to regularly and honestly evaluate your organizational and operational practices to ensure all voices are heard and reflected. Our guests today have written a book called affirming disability strength based portraits of culturally diverse families, the authors are Janet Story Sauer, a professor of special education at Lesley University, and Zachary Rossetti an Associate Professor of special education at Boston University's Wheelock College of Education and Human Development. In their opening chapter they write in this book, we present six portrait narratives of culturally and linguistically diverse families of children with disabilities, focusing on their experiences within their social, cultural and educational contexts. All are immigrant families, and all are led by mothers who are fierce advocates for their children. We document experiences reflecting biases and marginalization that may be frustrating to read that on many occasions were upsetting for the families to retell, but our intention is that our readers will acknowledge these inequalities, and turn your energy into action that can bring forth positive change. We seek accomplices in our pursuit of creating equitable school cultures of excellence. We were pleased to have Janet, and Zak join our conversation, listen in.

Interview:

Host: Well, Jen Sauer and Zach Rossetti, welcome to the Delovely podcast.

Janet: Our pleasure

Host: Your book is called Affirming Disability: Strength-Based Portraits of Culturally Diverse Families, could you please start us off with helping us understand what you mean by that term culturally diverse families

Zach: CLD technically specifically refers to culturally and linguistically diverse, and it's a broad term referring to anyone and the research broadly refers to anyone whose primary language is other than English and who identifies as anything other than White and European American, and it's important to dive deeper than that, because there are many important distinctions among this broad category but it is a, a broad group. We felt that it was important to use the term and kind of focus the book on those who would be captured under it.

Host: Well, just from my own experience in reading the book, it was very accessible, very easy to get through. And I found it fascinating about it was that you created this sort of environment where you allowed the family's voice to come forward and to be showcased in some way. And I got the sense, as I read through it that you created a sort of a learning environment. The reader, sort of traveled through from one conversation to another, listening to parents talk about their experience living as new Americans in different communities around the country and talking to your students as I understand it, in the context of your graduate courses, and every once in a while, it felt like one of you would sort of emerge and put your hand on my shoulders a reader and give me a little bit of a background in terms of the historical perhaps the history of colonialism and the impact on their country of origin at some level and issues around gender and history, it was just fascinating. And then you would just sort of disappear. And then you would bring the voice of the mom or dad forward again it was just such a real neat experience as a reader, and I'm interested in you telling us a little bit about how you engage these families, and it was my understanding that you brought them into the classroom, is that correct.

Janet: Yeah, so I'll start with the response to this question. The families, Zach and I knew each other before I moved to the Boston area, probably seven years ago when we started working with families, and I had worked with families back in Colorado in Iowa, but when I came here. What I noticed in my own experience as a white woman from the Mid West that I didn't have enough experience working with families for whom English was their second or third language. And so when I recognized that that limitation in my own expert experience and expertise. I wanted to learn from the families and that's something that I think we both value is learning from the families and having it be more of a reciprocal relationship. So, it did begin by asking families to come into our classrooms, and just a point of clarification I was teaching undergraduate students and Zach was working with the graduates. And so, working with our pre service practitioners. We knew how important it was going to be for them to hear directly from families, and people with disabilities themselves in our classrooms and not just be our professional experience or experience as family members ourselves of people with disabilities. Do you want to add to that Zach?.

Zach: Sure , I have always valued the family perspective, as well, as a sibling of a fantastic guy with a disability, I've always had that insider knowledge of disability and families and much of it is inherently inclusive and strength based and growing up I remember just being surprised and shocked so many times that many different examples of people not seeing my brother as we did you know staring and saying things and, you know, my mom would our mother would, would speak about having to fight for services or fight for general education placement and things like that and as I got older I started going to some my meetings with her and realized what she meant by that. And so when I became a professor I feel like I've, one of the first things I would do and I feel like I've always done this is reach out usually to the Parent Training and Information Center, wherever I was and ask for families, parents, guardians and it's usually mothers to come and speak to our classes and looking back the last few years I've kind of realized the same thing that Janet was speaking of the special education engagement and advocacy for families is difficult across the board, but there are these additional barriers systemic due to systemic issues for CLD families and looking back I realized that most of my speakers and panels, had been pretty much White upper socioeconomic status, parents, which was beneficial but you know there was this extra layer that we needed to start addressing, and especially in, I'm in Boston, especially in the greater Boston area, or we both are, that's critical. And so we started to specifically reach out and ask families to come to our classes and I imagine we'll talk more about this in the student reaction but another layer this was that, as we started doing this and getting to know these families and kind of reciprocating by speaking to the groups that they ran many some of our families, some of the parents ran their own support groups with other families in their culture, etc. And we would speak to them in different formats and contexts, we realized that asking them to come to speak to our courses repeatedly could take a toll and was taking a toll in times I mean they had to schedule time away from work and there's an emotional labor involved in sharing their stories and there are difficult parts to these stories and having them do it over and over to our small groups in our classes, was so impressive, but also on their part but a huge as we started to realize on our part, as we learned more about them in the cultural context and linguistic context. And so we had to kind of check ourselves a little bit and realize that dynamic, and so we thought that by capturing their stories in this book that it not only would it reach a wider audience but it would save the intensive labor we were asking them to commit and allow us to kind of proceed in our project as well and relationships as well.

Janet: Yeah , thank you might add to that, what I've been studying myself about white privilege and being a white woman, the intersectionality research around how complicated things are. And you mentioned how when you read these stories you felt that they were accessible which was really important to us. And yet, trying to get the complexity. The situation was really important to us. So when we might talk later about this as well but the idea of how Zach mentioned the emotional labor of the families. One thing I learned from Black Lives Matter and some other research and work I've been doing is, we often put the onus on the people who are already marginalized to educate those of us who don't know about their situation, and it's really on us to do the work. To learn more about the families that we work with that that's our approach, I think, I wanted to point out.

Host: Mm hmm. And the approach that you've taken and what comes forward as a strength based perspective. And I can certainly say from my own experiences that there's a sensitivity to cultural experience as being something that we're trying to bring forward and in the field of education and supporting people with disabilities, but the approach to cultural awareness is oftentimes one of where, as you described to Janet us figuring out the problem and coming up with a solution as opposed to us entering into a discourse on the topic with a sense of what can I discover that this rich cultural experience that this family brings to the conversation is that something that you established at the beginning of the series, or did that emerge as you started working with the families over time. Well I think we talked a lot about the title.

Janet: We had a lot of discussion around what was something we wanted to as you say put forward and emphasize strength-based portraiture. The portraiture element gets at the complexity of strengths based or affirming disability gets at how important it is for us to recognize, not just, I mean we're not in what some people would say, denying the disability that's not what we're talking about. What we're saying is acknowledging the complexity. But if all of our focus is oriented from. I don't want to get too philosophical here with theoretical frameworks and whatnot but if we approach something as a problem to be saw as a very different way of thinking. Then, what can we learn here. How can we identify the talents within the team that we have here, or the knowledge within the team that is intrinsically valuable. it's the words that we say a firming disability or string space. I think are just terms that people throw around more quickly these days but I think the underline approach is key and I think we keep learning I for one can say it's something I learn and learn again and over and over every time I entered into the discussion with families who have kids with disabilities or people themselves who experienced disability.

Host: Interesting. Zach Were there any epiphanies for you. In the process of writing this book

Zach: Part of the desire to write the book also came out of how impressed I, and Janet were by these families. And so there are lots of examples of things that are just remarkable knowing the stressors the limited time. The low expectations around disability, or around the culturally diverse family, basically, issues of racism or prejudice and yet these families found time to educate themselves in various ways and one of the examples from one of the family stories that I just love is that, Oanh, who is the mother of Tiny who's a young woman with autism and a couple of genetic disorders who emigrated from Vietnam, and she was here without her husband and the rest of her family learning the language trying to find a diagnosis for her daughter, who was not walking at the time, who was not used to food in the US and so food feeding her daughter was a concern, she was didn't have access to a wheelchair, in at first and was walking around with Tiny her daughter on her shoulders, while she herself was in a master's program, but the one example that I mean above all of this that really stands out to me is that her daughter likes balloon animals, walking around Boston and seeing balloon artists in the park, she realized that she liked balloon animals so on, taught herself to, to make balloon animals for her daughter. And not only that, but would as her daughter was learning to use a communication device her daughter does not speak. She tied in the balloons to that which is, you know, like, best practice in teacher education and following the child's interests, letting her choose what type of balloon she wanted using the device and then tie the balloon and give it to her. And as she progressed in her language, and in her use of the device on would ask her color what type and build it so that she could build more complete and complex sentences. Now the strength based focus and all of this and the importance I think and what we're trying to do what we're all trying to do here is that while on is doing this and a million other things, there were teachers, tiny school who had low expectations for her as someone with a disability and I also think as Vietnamese immigrant who didn't think that she had the capability to use the communication device and so she didn't have access to her device in school a lot of the times, which then prompted Oanh to take videos of Tiny, her daughter Tiny, using the device at home and keeping track of the number of words, then number of sentences, and the amount of time that she used it, and even with that evidence, if you will, she still encountered difficulty in supporting or advocating for teachers to give her daughter access to the device at school, so just wrapped up in all of that is, I think, a really important focus on affirming or reframing both children with disabilities and the families who are trying to support them in a new system compared to what they were used to in their home countries.

Host: Janet, do you see that as something that comes from a cultural bias, in the sense that this is how new Americans are treated, typically or is it that we're the professionals and we're experts, we can tell you what to do, what do you think the origin is of the problem that Zach just described.

Janet: I think it's I think it's both. I don't think it's one thing or another. I think what we're talking about here is a combination of factors that come together and make this work, so challenging for everyone involved. I think it involves a sense of fear and adequacy on the part of some of us in the field, who might say to themselves well I don't know Vietnamese, or I don't understand the history of Iran, or India or any of the home countries from which the families come from so I think some of it is lack of knowledge, fear of incompetence, on behalf of professionals. And so sometimes we just need to give ourselves permission to recognize that we don't know everything, and that it will take a team. We refer to in the book this circles of support by hair maps, these are very accessible techniques that any team can use anywhere to start to assess, we have in our possible circles of support to help us work together, because I do not believe any one person can do this work by themselves, it really does take creativity, I know your your intro says something about people who are creative it necessitates, it requires risk taking and humility and collaboration on behalf of everyone involved in order to keep the focus on the children that we're serving and not on ourselves and our own egos but how can we work together on behalf of these children so that they can become full members of our society I mean we say these this praise right but the work that needs to be done is daily. And it takes a long time to work through it and it is complicated. That was a short answer.

Zach: And I can I add to that too because, at least in the K through 12 or K through 22 area, you know, teachers and teams are with a family for one year, usually so it's hard work. It requires lots of self-reflection and it takes time. And a lot of what we learned from these families and co-wrote with them co constructed with them in the book, took us a long time I mean we have we've been engaged in this project for five plus years. And so we know that that time constraint is a huge challenge. And so I think part of the advice is, you know, recognizing that not only can this be uncomfortable when you, you feel like you don't know someone's culture or country of origin and that awkward or uncomfortable feeling of like well how do I start is exacerbated by this time constraint because teachers in teams need the start as soon as possible because the school year, flies by. And that part of what we hope with some of the specific strategies, and the nature of the action plans that we discuss at the end of the book. Hopefully it gives people a way to start. And, you know, we mentioned in a related research article from this project to just pick one or two strategies to start with, usually one, maybe around self-reflection and one around getting to know the family and just jumping in, so that you can begin the process as soon as possible, especially for school folks, you know, during that one year that you're likely with the child and family.

Host: Interesting. It seems to harken back to some of the person centered practices where you set aside some time to have intentional conversations to discover and explore and take that position as you described it Janet, of being comfortable with not knowing and wanting to explore and learn. I really loved their one parent, I forget which one but they were very open and comfortable with saying. First, don't generalize or use stereotypes based on culture, but use them to guide your questions and ask that it's okay to say, tell me more about this or am I right about this, that, that it's okay. And that kind of gives a permission level that was nice to hear.

Janet: Yeah, that was in the Arora family piece (Ch. 5). I hope we do get to read a little bit here and there, it's not our voices, it's their voices, but there's so many powerful quotes in there I didn't know Roy if there were any that struck you pull if you have one that you'd like to regenerate that would be great yeah I have too many bookmarks in here, but one that comes to mind that you just mentioned was, we had guided in each chapter we think, or we tried to provide a very specific, personal family story, but also contextualize it within the more complex culture. So, Susan, for instance, says, I'm just one person with one experience and mine is going to be different than all the other Chinese immigrants that you work with so you have to do your homework and get to know that specific family, which is very true. But though the page I just was looking at now was from Kimiya, and the chapter on lessons of abundance of an Iranian American family. And this chapter was co-authored between a daughter and a mother and focusing on a sister so it was very interesting. But what she mentioned was the. Let me read I'm reading from page 108. It says, “The need for normalcy demonstrates the impact of normalcy on Shirin's daily language and perspective. However, my parents also pushed back against the Iranian culture of hiding individuals with disabilities.” And then she quotes her mother saying, “For my husband and I, that was a pain because we wanted, we were taking her everywhere. We didn't have a headache, a hidden agenda. We said, this is it. This is our daughter, we are not going to come if we cannot bring her any celebration or anything going on in our families or relatives house. My brother in law we always took her in. And they are always with open arms.” I think that's one example of how this one particular family was themselves struggling with their own cultural negotiation within their community. So they weren't necessarily a traditional stereotypical family, I think each of these families emphasize their unique stories within their own immigration experience.

Host: Thank you. That's a very powerful story. Zach Do you have one that you'd like to highlight for us.

Zach: Yeah, I had the excerpts from the Arora family related to the idea or approach of using generalized generalizations to guide your questions. That's on page 89 in the book, and Punita, who is Sachin’s mother says,” I think that my son is as typical in many ways of what you would expect of a 17 year old autistic boy but in many ways he is not. If there's one thing that you take away from our story, let it be this rather than depending on stereotypes of what you assume a person with a disability is like use generalizations to guide your questions. You might ask me. ‘Oh I hear that Indians eat a lot of spicy food, is that true?’ So there would be a stereotype of what a typical Indian mom at that event would look like and I probably look like typical Indian mom, but that is used as a segue to a question, rather than a stereotype which doesn't allow me the flexibility of climbing out of that little box that a stereotype is general questions allow for opportunities for growth through learning about people.” I'm glad you brought that up, Roy, because we we've found that to be so powerful, as well and in many ways that gets at, I think, one of the underlying challenges with all of this, I think there is a discomfort in lack of knowledge but for why Americans, especially upper socioeconomic status, and we have diversity in our classrooms, but many of our students do fit that category. There's a general discomfort of just naming and speaking and using the words around cultural and linguistic diversity, people are worried about being perceived as racist or maybe haven't done a lot of work to kind of check their own biases we all have biases. And so there's just a hesitancy and real strong discomfort to even ask someone a question like, “Do you like Indian are spicy food?” You know, and I think that's a nice example and she and as she says it's, it's an entryway to a conversation, rather than a stereotype from her perspective but I think from us as a white man from, you know, pre service teachers who fit that category as well. It's also an entry point to the conversation and saying it's okay, like just be open about what you don't understand as we said before, and have the conversation. Rather than avoiding it because of all of these reasons so I just, I just found that to be such so useful.

Host: It sure was and wondering, I'd love to talk before we finish up about your final chapter. It's called cultural competence versus cultural humility and the term that of art that we so often use is that one of cultural competence and, as we've been discussing before that has some connotations of fixing or winning the battle in some way, you know, we'll all be competent and then we'll move on. But what you're advising is a posture of humility and your recommendations in that chapter fall into three areas. One is that people should research, you ask your students to go forward and research by asking questions and explore. The second is practice cultural humility, and the third is develop your own brokerage skills, and I'm wondering if we could just chat about each one of those, starting with research, do you have recommendations. First of all, of course we want everybody who's listening to this to buy your book and read it it's a wonderful resource in itself, of course, but how do you see people taking that first step. Janet?

Janet: I think it's more of a personal journey. I think that's my response. I think that I your, your first part of your question was, the stance, establishing a stance of humility, and I was remembering a specific example that we do mention in the book, if I might refer to it it was in an earlier chapter, it was the one called a goat among lions, and we had learned about the difference between refugee immigrant how people identify themselves. And one of the key things and takeaways from the project was trying to find out from families just like our own work, when we work with individuals with disabilities themselves is how do you define yourself, how do you describe your family. And so the humility comes from, not necessarily what we see in writing in some family report that was written by another professional but how does the family describe themselves. And an example of cultural humility that I learned even after the book was in press was presenting about the book with the mother, that's in that feeling like a goat among lions chapter. In that case, it's a pseudonym because the family was in a situation that they didn't want to use their, their real names, which is a whole other part of the project. So, when we were taking pic they wanted to take a picture and at that point it was all women in the room, and the mother took off her scarf and put it on my head for the picture and I was saying, after we did the picture I was giving her back the scarf and she looked at me almost offended, and our cultural broker Amy Goodman who co-authored the chapter said, like, her eyes popped and said, You can't give it back. That was a gift. Like, that was..that's rude, like, stop doing it. So are these years of work with families, I think we fall into habits of interaction. Here I was at a conference in my professional clothing in my dispositional space. My embodiment of what it means to be a professor or a teacher, and then here was just a human to human interaction in which this mother wanted to give her scarf to me and she said I have many scars, this one's for you. So now, every time I put it on I think of her and I think of how much I am continuing to learn from the family so I think that's an example of cultural humility, in which we positioned ourselves in our in our lives.

Zach: And if I could jump in there, in terms of some of these gestures that manifest cultural humility and help develop the relationship, again, I think one of the lessons, though, that we learned is that the onus should be on us. And so some of the similar or gestures might be attending a community event sharing food or drink specific to one's culture, and one of the events that both Janet and I have attended is the annual Tet New Year celebration that Oanh, who's who I had mentioned earlier related to the balloon animals, that she puts on for families of children with disabilities and the entire community. And I had known she had done this, and I just kind of thought initially like, Oh, that's cool. That sounds great. And I didn't attend for a couple of years, and I didn't give it a second thought, until, you know, then over time I got to know her more and realized how much time and effort, it took for her to put on this event and what it meant for the community. So it took me a couple of years before I started attending and then I and I felt badly about that, as I realized, like how much it meant to her that I can only attend, you know, our relationship kind of progressed and deepens based on that but it was, it was a really, that was a real moment for me to kind of slow down and realize the importance of some of these things. And to kind of dive into that, that personal element, and it was a little hard, for anyone who knows Boston it's across town from where I live and you know as the crow flies it's just a couple of miles but it feels like it takes like half an hour 45 minutes with traffic. To get there, you know, so, but that was a minor inconvenience compared to the importance of this event for on her community for us for our relationship and as an example of me kind of who I thought I was culturally competent and then kind of transitioning to this stance of cultural humility and going beyond. I think that one aspect that's really important about this is the difference between cultural competence and cultural humility is, is that the cultural competence implies as you said Roy in the beginning, like you can achieve it, and we've become we've done it we're victorious, and maybe why things haven't changed is because people think, like I did that we're culturally competent and we need in the, the idea of cultural humility bursts through that barrier, and we're always learning and can always do more. And I've I've spoken with people who think well it doesn't matter what you call it as long as you do it, but I think in this case if it is important because you might think you're done, and that you are culturally competent versus having a stance of humility.

Host: You bet. And I love how you've accomplished that I think with the book in a wonderful way, sort of, that reframing and the use of the term brokerage, the idea that family members, in some cases, bring a capacity to broker relationships with other members of the community, but also as you say, one of our tasks can be to develop our own brokerage skill.

Janet: Yeah that's what that if I may, um, honor, the fact that when this terminology cultural brokering was introduced to us, I think it was through our work with own, but in in the chapter with the Latino Mother, are one of our doc students, who's multilingual thought of herself as a cultural broker, working with this mother because they conducted everything in Spanish for the project. But we also worked with another woman, Olga Lopez, and that on 59, we talk explicitly about cultural brokering, and that negotiation or bridge was one of the things I tell all my students and colleagues, is if you don't feel that you know anything about a culture with a family, identify a broker, someone who can help you, and you, again you don't want the onus to be on the family themselves to do all the explaining and teaching, but maybe you could find someone else who can give you some insights that might get you started to learn about culture to help you even learn some common do's and don'ts around anything from shaking hands to that someone might not but that doesn't mean they agree, just these, these things that can make a huge difference if you can think of developing your own cultural brokering skills but if you don't feel competent, find a broker to help you negotiate that meaning.

Host: Wonderful. I'm wondering what has happened since you were working on the series with the parents, and what do you see doing in the future. The two of you working together on additional projects in the immediate future?

Zach: Well, Janet, I can add her vision for this as well but in the immediate aftermath of the book we were planning for this spring, a couple of panels with the mothers, the families in the book that unfortunately have been postponed due to, you know, the recent events with the corona virus and so I think we want to honor, not just their experiences and expertise that are captured in the in the book but the time and efforts that they put in to co-construct the chapters with us and to really kind of continue pursuing the goals of the book, one of which was to kind of reframe traditional hierarchies between parents and professionals between researchers and the researched and by constructing or engaging in these panels. We were hoping to do that. So, we hope that we can do that once we're able to go outside again in one room.

Host: Well that's great and we'll certainly put information in our episode notes on how people can stay in contact and follow your work is there any final points you'd like to make.

Janet: I can't say enough about just thanking the people that we've worked with, we, we could not have done this without the dedication of these families, and the professionals, who also gave their time to support the families so that they could come to our classes and work with our students, our students in some cases volunteered their time as well. So, this was really an example of a collaborative project, I feel very honored to have had the families, share their tears and their joys and afforded us this this was a huge learning opportunity I just can't thank everyone enough, and I'm hopeful that some of the families want to continue writing and blogging and thinking about how they can move forward, at least some of the people, the young people in the book, we've thought about co-authoring their stories, themselves, having their voices be more prominent maybe in a future publication so thank you for the opportunity to share this with your audience. Thanks.

Host: Absolutely. And thank you both Janet and Zach it's been tremendous having you as guests and I appreciate you spending time with us today. Thank you. Thank you.

Closing: Well, that's our show for today, please be sure to check the show notes for links to our episode page where you can learn more about the great work of our guests today. The Delovely podcasts podcast is immediate production of First Person services and realize that support from listeners, like you pitch in well you find out more at www.patreon.com/delovely, where some levels of support can provide digital audio systems to your nonprofit. Have fun everybody.

Transcribed by https://otter.ai