Transcript Tammy Bachrach

Marjorie (00:07):
We all know that parenting is hard, so how do parents with disabilities do it? With creativity and because we know of the value of interdependence! Come hear about ways experts say we can best empower these families and let's all learn about how parenting can be done differently.

I'm your host Marjorie Aunos.
And today my guest is Tammy Bachrach. I met Tammy a few years back and I knew her voice needed to be shared. Tammy's doctoral thesis is about stories shared by adult children of parents with intellectual or developmental disabilities. As a child Tammy saw how her mom, who has an intellectual disability, was treated differently, yet to her, she was the most loving person in her life. In her research, Tammy wanted to showcase positive stories of families headed by parents with intellectual disabilities, to counteract all the negative things that are said about these families. I started the conversation by asking about her family?

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Tammy (01:29):
I have a brother and my parents, and as a child, even though my mom, dad, and brother all have various degrees of learning challenges,the disability part wasn't something that was for in the forefront of my mind, particularly as a child. You have no concept of that at all. You just know that, oh, mom doesn't read very well, she can't help me with homework, that sort of thing. But, um, their formal diagnosis, you know, now I know what that is. It was learning disability or at the time mental retardation. Now it's intellectual disability. My parents lived in a time where institutionalization was still a thing. Um, thank goodness they kind of were under the radar, um, at the time. And then my brother's life and our life together expands sort of the beginning of the rights of people with disabilities to even be educated. And so we sort of like lived this change, hopefully a positive change. Although it's still not necessarily where we would like it to be for people with developmental disabilities. So it's been really fun in that way to look back at what we live now. I'm like, Oh, okay, that's why that happened, or whatever. But as a child, it's just mom, dad, and Tim. It's very ordinary and boring. And so when people became interested in it, I thought, Well, why are they interested? I didn't even get it. It was like, there's really not a story here. It's only after I realized that people thought it was odd that you start to beginning to wonder. But what is unique about our family, they would see it as a negative or a problem. But the only thing I did realize was that we, I had an aunt who was very involved and, um, involved to the extent, supportive in a lot of ways, but controlling in a lot of ways as well. And so my parents had lost their rights to maybe the decision making parent for us. And so that was unusual. I didn't question it at the time, but, you know, looking back, I realized that took a toll on my family, my parents' relationship and kind of our, um, I don't think necessarily the way I saw my mom, but I ended up kind of playing a protective role because she would, she was not always treated well by her older sister, um, in a, in a rather demeaning way.

Um, and it wasn't until I was older that I realized it was because of my mom's intellectual disability, that she could do that to her, that she could kind of be victimized in that way. And it's kind of weird cuz this is someone I love, you know, loved and supported us, and yet there was this tension between being kind of unkind based on my mom's struggles in some ways. But so ordinary, really ordinary childhood in many, many ways. But had that extra layer of, um, kind of contention in a way about who's in charge or who's in control. And my mom having to play a more, more passive role.

Marjorie (04:50):

Okay. Do you wanna share a little bit about like, specific stories maybe that, you think are, would be interesting to us?

Tammy (05:05):

One is as I got older, like a teenager, then you kind of become more aware of the social norms around things, right? And you begin to evaluate your family against other families that you visit and that sort of thing. And it was about that point that I realized, oh, my, my aunt is rather ashamed of, or maybe I, we shouldn't, was told not to invite people over to the house. So there was this feeling of like, it's not okay, or you should not invite people over. And at first I thought, Well, my mom's not the best housekeeper, <laugh>, maybe it was that. Um, but now I think there was, there was more to it. In high school you're trying to kind of fit in and all, but so we just didn't have people over that was discouraged and, and we didn't.

All along though, I realized that there's a sense of protection for my mom and I always, I loved her. She was probably the most loving, nurturing mom you could want, which was really interesting because I have these two kinds of moms, you know, I had my mom who, you know, would just do the world for you and for anybody. And then I had my aunt who was also very kind of loving, but she had a pretty big temper and she was, you know, more volatile and a little more unpredictable actually. Um, but highly intellectual. So it was like, you could kind of see the comparison. And then I remember thinking, you know, when you become a mom yourself, you know, which mom are you gonna emulate? And I kind of absorb both moms. But my parenting style, I hope my children think is more like their nana, which they, you know, of course I have four kids and, and grandchildren now. So they all, Nana's a big central part of their life.

Marjorie (07:02):

It's very interesting to hear from the child and to sort of say like, you know, my mom gave me a lot and gave me like, you know, warmth and kindness and love mm-hmm. <affirmative>. And a lot of qualities that I wanna emulate in my own parenting, which I think is a beautiful message.

So do you wanna expand a little bit, uh, more in terms of that relationship between your aunt and your mom and how that played out in reality? Like how did your parents, for example, lose custody?

Tammy (07:33):

Yeah, that's, that's an interesting story and there's some mystery around a little bit. My mom as a girl there, she, gosh, this would've been in the fifties went to a class for the, the title for the class, we even have a little paperwork on it is the, the Class for Retarded Children. That was the name of the class last. And my mom reflects back that they didn't teach me anything, they just let us color all day, you know. And then you fast forwarded my mom's mom died. My grandmother died when she was 12. And so then she goes to a new place, and lives with a sister and in Colorado, and they have no special education, nothing. So she just started in junior high and high school, and it's a disaster. Disaster, you know? So she, but she loses her label at that point.

There is no label. And then somehow she moved, she ends up moving to Washington with another sister who's a little bit, um, just a little bit older than she is. And they end up finding, um, and enrolling her in a work program with Goodwill. And that's where she met my dad. And she did that for a little while, and then she began a family. And so she stopped doing that, and again, and she stopped having a label again once she moved away. There weren't any kind of social workers that kind of carry your case like they do now. Um, so again, she was just a woman in the community having children, <laugh>, you know, um, probably thankfully, right? Yeah. But without any sort of support. She ended up having some medical problems, and my family, of course, wasn't very well to do. So really having good doctors and people to take a look at and good medical care was a challenge. She ended up getting ill and, it was in a thyroid condition and being hospitalized. And, my mom and dad's relationship was a bit rocky at that time, and she had two little kids. My brother was just, I wanna say nine months old, and I was three. So in, you know, became my aunt to kind of save the day. And my mom's in the hospital. She was there for three months, and my aunt came in, um, from California and basically took us. She kidnapped us, really. And she'll even say that I kidnapped you guys and took you to California. And my dad was like, You know, what happened? Where are my, where's my kids? And my mom, my grand, my aunt went to, um, the courts and said, My sister's ill. She's in the hospital. She got temporary guardianship without my parents ever being talked to, called no signatures, no showing up at court, No nothing. She was just given guardianship of, um, my brother and I, and one thing.

I think now looking back at all of that and looking at some of the documents they were, it was called temporary guardianship, but I don't, it never became temporary. It became permanent. And I don't know, my parents probably didn't realize they could even contest that. And I don't know if they, if that would've worked or not, if they had, but it, in effect, operated as losing all parental rights and decision making. She had papers the whole time she would give them to the courts and doctors, um, had full rights as our parent. Um, and my parents didn't. And they never went to court.

There was never an allegation of anything, um, against them, except my mom was hospitalized for that time period. And then when she came back out of the hospital, um, she moved to California to be with her children, <laugh>. And so she sacrificed a lot of what she wanted to do in her ability to make any sort of decisions or live an adult life, kind of, because she wanted to keep her kids and family intact to the best of her ability.

Marjorie (11:58):

Yeah. That's a pretty big, um, show of love right there and there, right?

Tammy (11:59):

Mm-hmm. <affirmative> mm-hmm. <affirmative>

Marjorie (11:60):

To be able to sort of say like, I don't have many choices, um, but I'll make sure that I'm there for, for my kids in the best way that I know how. It's a great representation of a lot of things that we've seen in research also in terms of, you know, um, parents with disabilities, not, not knowing that they have rights or how to fight for their rights, or how to go to court or, or the mm-hmm. <affirmative>, the unfairness that can be just in the context of sort of, um, understanding just how the legal system works.

Tammy (12:33):

Yeah. It's definitely not accessible for many, for many reasons. One, economically. You have to have resources, or at least that's the, the view that most people see is, Well, I don't have the resources and the money to take anyone into court or to file anything or hire an attorney to be an advocate for me. Um, and not being able to navigate or read that sort of information, I know what your rights are, was a huge, huge disadvantage. My mom and dad feel like, well, she was able to provide these economic things for you, and so we appreciate that. And and maybe in the long run it was okay and it was worth it. (Yeah) But it did, it was a cost to them (Yeah) To have that kinda support. Yeah.

Marjorie (13:25):

I was wondering also, like in terms of, of, you know, sort of that relationship, um, your, your mom and, and your aunt, how did it look like, day to day? Were you living with your parents? Were you in the same house as them? Were you living with your aunt and they would come and visit, or can you describe a little bit what that looked like?

Tammy (13:45):

So for the majority of my life, I lived with my mom in a home, um, that was owned by my aunt, and my parents lived in that home for a few years, and then they separated. So my parents end up getting a divorce. They will both say significantly because of the loss of control over their family and being able to make decisions. And these are decisions, like, can we go camping next weekend? No, because the children will miss church, and that's not allowed. And so even those simple kind of things. So we all lived in the same community. And I lived with my parents, or then my mom and my aunt and uncle lived, uh, a couple miles away, but they would check in on how we were doing, and often they would also provide transportation, particularly after my dad was no longer living in the home. My mom didn't drive. And so if we needed transportation to church or to school or that sort of thing, then it would be my, um, aunt or uncle who would provide that transportation.

So simple decisions about clothing I could wear, what school I went to, if we could miss church or not miss church we'd have to get permission to go visit. You know, any sort of thing was really controlled by my aunt. And then she provided financial resources to us and, and kind of paid the bills for my mom, who would struggle with that kind of thing. At that time, again, she was a relatively young woman at that point, and there were no support agencies. My mom didn't have those kind of supports, so she was only relying on an aunt to do that kind of thing if she needed it. Now we know that she really probably didn't need it. You could, you know, she kinda goes to pay her bills, you know, now, you know, she just goes there and does it and it's fine. And she's gained a lot more confidence now that she's kind of out of under that protection of my aunt in a way. She's learned a lot of, and she's very capable woman in so many, in so many ways. And then she works around her areas of weakness, just like we all do. Right we just kind of figure out how to get around that thing. Um, but yeah, that was kind of their relationship.

Um, even now, I think my mom holds a lot of the negative feelings about her sister. She's passed several years ago now, but, um, yeah, it was a stressful, stressful time, but that was our kind of day to day Yeah. Was mostly mom. And if something happened, um, where we thought, um, mom was going to get into trouble because something happened, like if we got injured, then my aunt would just come unglued. It was always gonna be my mom's fault, even if it was, we were playing and we're kids you know, <laugh> my brother one time, he, you know, had the skateboard in the house and it went through this sliding glass window and chattered the window, and he wasn't really hurt, but it was a thing. And then we would kind of conspire to hide certain things from my aunt, because we just knew my mom would get it. <laugh>. Yes. We were co-conspirators in some ways, so.

Marjorie (17:03):

I could see that <laugh> mm-hmm. <affirmative>, I could see how that could happen.

In your story, what I find amazing, which I think also is, is unfortunately happens often or too often still now, is that your parents didn't sort of like lose guardianship or their, the control you know, over, over you and your brother because of the disability. It was something else. Your aunt was awarded temporary custody or guardianship, and then it was never returned. And we've seen that also in research where, you know a mom would lose temporary custody and then she could never sort of be good enough in, um, Yeah. You know, as an example to, to have the children return. To me, that's something that's very striking that we've seen in research and that's highlighted in your story.

Tammy (18:07):

Yeah. I, I think, I guess my comment to that would be, it seems unfortunate it's still the case that a label of intellectual disability trumps everything else. It's like, people kind of just fixate on that and what they think that means for the person. And until the person can prove all of their stereotypes wrong, they aren't seen as anything else but intellectually impaired. And I think that, wow, are we missing out on so much of humanity. And, really those relationships with, with the people and maybe over provide support, over control, over, minimize their capacity when we stereotype folks and just pigeonhole. Um, and most of the time that is based on what, you know, special educators or other people have written, psychologists have written about intellectual disability, not really through relationships with people with dis, intellectual disabilities either. So that medicalization of the category becomes, uh, hyper focused on, you know, versus who they are and what their gifts are.

Marjorie (19:21):

So you have had those lived experiences, obviously, like all your life mm-hmm. <affirmative>, how did you end up sort of like doing the auto-ethnography and then you also met other children of parents mm-hmm. <affirmative> with, uh, intellectual disabilities, and how did you meet them and how those conversations were, uh, when you actually met them and, and interviewed them?

Tammy (19:48):

So I, I, as I mentioned, it was through my PhD program that I began reading literature. And some of the literature was old, or was about the time that I grew up. And so it was, there was really not the voice of the children present. It was really just the authorities talking about the risk factors for children in those kind of things. Um, there wasn't some of that there wasn't really even an advocacy for parents. It was just kind of, you know, written in a very negative tone. But as I began reading, I thought, well, this has been my experience and it's different than what I'm seeing in the literature, but is our family, just kind of the odd one <laugh>, you know, is, is, or, and I didn't know other people, who were raised, by parents with intellectual disabilities. I knew one other woman who worked for an agency that I did and, and her experience was more similar to mine. So I thought, well, that would be an interesting research project to take a look at. Maybe our family is unique.

So I reached out to our regional center, which is the case managers, and asked if they could help me find families, and adults cuz I originally wanted to look at, kind of that retrospective looking back. Now that they were adults, How did they view their childhood? How did they view their relationship with their parent and the support they received and all of the things that we just talked about.

I was able to find, um, four other individuals who agreed to do, you know, many, many, you know, interviews with me, um, and share. And it was so much fun. I've always loved to hear other people's stories. They varied in age range because, you know, still in the US at least, I read things in other countries and it appears as though there is more freedom for people with intellectual disabilities to have children. It's still pretty rare in the US to even think about people with intellectual disabilities getting married or having a family is almost this taboo terrible thing to even mention cuz goodness, how do we do that? Each of them talked about their moms as moms, not really as people with intellectual disabilities. I mean, they obviously saw their parents' limitations and many of them knew, that they had these supports and they needed some supports.

And it was interesting to find the common thread that we all had was that the relationship sort of trumped that label, that sense of protectiveness of, you know, we're gonna be there for our moms. We look forward to our moms being grandmas and relying on them as grandma. And they, they all had a view of a long term relationship that was really positive with their parent. And didn't give mom any slack for her disability either, you know, so, which is great. Yeah. But, um, you, you saw some common threads of the support was important, appropriate support. They all had some sort of scare about custody. Each of them had a sense of resiliency as well. Like they saw something about their life experience as being positive, sometimes hard, sometimes stressful, but making them better people in a way.

So their outlook was very interesting to me. And I loved the, their quotes, which are in the article. it's my desire to put forth their words as much as possible because I think you can't, you can't even do it justice otherwise, it just, when you summarize, you don't get it. But, some of the things that I've seen about this, the study that I did that's different though from some other studies is where there was support, it was consistent support. It was family, it was either family driven or it was family centered. And the two participants who worked with the same agency talked about the same actual direct service staff being consistent for long periods of their life, which isn't always the case in that field, often there's a high turnover.

Marjorie (24:32):
So in all of those, you started by saying like, I wanted to know if my family was unique in comparison to what you had read mm-hmm. <affirmative>. What would be your answer now that you've done this?

Tammy (24:40):

I don't think it was very unique. I don't. I don't. I mean, at least the other four participants shared a lot of the same experiences that I shared. And a lot of the danger and anxiety wasn't based on the parents' intellectual disability, It was a reaction to that. Or the custody issues or the, you know, And even when they talked about, well, we ended up having to step up and, and be more responsible, um, in some ways, cuz I think there's a theme of that where the children take on a little more responsibility. Not that they become the parent, cuz I didn't see that in any of our stories, but they take on, oh, they can drive now, so they're gonna drive the family around. They can be ex go to the doctor and kind of explain things or go to the school if they have younger children or younger siblings, that kind of thing. They saw that not as a negative Right. At the time. It might have been a bummer <laugh> when they were kids, but looking back reflectively, they think, no, that, that kind of kept me on track, that taught me how to be an adult and give me confidence in my ability to, to do things, um, and not, you know, fool around and get into trouble.

Marjorie (25:50):

Yeah And I think also what's important is to always sort of put it in context. I think that depending on our circumstances, we have to step up or, or not, you know, at different times because of our living circumstances, because we're a family and as a family members, you know, sometimes we all need to chip in.

Tammy (26:27):

Yep. Right. And even, even like being kind of a, um, when we talk about sometimes I would make phone calls from my mom and get the information from a doctor or, you know, send that prescription over to the pharmacy or whatever, that's not any different than some of our, families who come where the kids speak English and the parents don't, and the child becomes the translator kind of, or that go between, for second language families. So it dawned on me like that's pretty much the same, you know, as my experience. it doesn't carry the same stigma though, um, as an intellectual disability does, but it's similar.

Marjorie (26:59):

So if we were to turn to the future a little bit, what is something that you would like to see happen or be done in research in this field in the next, let's say five to 10 years?

Tammy (27:11):

If I had a magic wand and could just change people's perceptions. It's not just with folks with intellectual disabilities or parents, but I think it even starts in our schools. We still hyper-focus on the label and medicalization, whether you're a doctor or you're a special education teacher or you're a social worker. And until we address the stigma around the label of disability, we need to shift our whole thinking in a way. And I know that that is gradually happening. I hope it's happening. That we begin to see people as people, not as separate people or semi people <laugh> because of some particular label or characteristic that they have. We value one kind of being, and quality of the being, versus recognizing, you know, the disposition of people. the most important characteristic of them. Not, you know, whether they can read Shakespeare or even help their children with homework. You know, like there, there should be and could be other people that can step into that role. so there's just a shift I guess in, in our, in our field we would call that the social model disability, right? Looking at really analyzing what we're doing. Not focusing only on the person, but, but what are the support doing to make their job harder, their life harder, their children's life harder? And what can we do to make it easier? <laugh> by asking them, by you know, being a partner with them, not superior to them.

And if that shift of thinking happens, I, it, it potentially could affect education, our legal system, our social workers' views. but to see families as an asset that needs to be supported, maybe, maybe not, maybe they're doing just fine, just leave them be. And be more of an advocate for them versus a control for them. Paperwork, You know, maybe that's not gonna be their thing. Or sometimes time management isn't their thing, you know. Like making, okay, you have to schedule an appointment that's three months out, that falls off my radar sometime, you know, <laugh>. So what, what can we do to support that, you know, and, and address some of the issues around poverty and, inequality in those areas as well, which obviously becomes a, a risk factor, in my opinion, greater than having intellectual disabilities or could, could, depending on, on your community And the supports that are there.

Marjorie (50:16):

In listening to you, I would add sometimes, you know, as professionals, as researchers, as people who do not have an intellectual disabilities to just be humble a little bit more. Cause we all struggle for different reasons. our intelligence doesn't protect us from making mistakes, for doubting ourselves, for struggling sometimes.

I loved listening to you, to your story. I felt, and I heard all the love that you have for your mom, for your dad, for you know, what they, they gave you and how they made you, you. I also felt the love from, from your aunt, even though, you know, it's a little bit more complex.

I really thank you for sharing this part of you, your research and, um, you know, I think that, um, this is how we, we hopefully change, opinions and, um, you know, by sharing stories like yours. So I really wanna thank you for the time.

Tammy (30:57):

Thank you. It's been a pleasure to share it.

New Speaker (31:02):

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