

## Episode 5 - It Takes A Village

Marjorie (0:07)

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 guests are Beth and Lily White.

Beth and Lily are 18 years old twins. They were raised by Amanda, a single mum with an intellectual disability. Talking with Beth and Lily has been a treat for me as I know how powerful their voices are and how precious their testimony will be to you. By sharing some of their thoughts, they are gifting us their perspective of being raised differently, or is it much different? They might actually be showing us how being raised within a community, where several adults gravitate to offer support, should be the norm. Enjoy! And don't forget, for more information about where to find the full recording and additional resources, check out the show notes!

Marjorie (1:29):

So today I'm really, really excited because I get to speak to Beth and Lily. And Beth and Lily are very important girls to one of my greatest friend that, um, I spoke to already on this podcast and that's Marg Spencer and they are an important part of her life. And so I hear about Beth and Lily all the time, but this is my first time that I actually get to have a conversation just with them. And, uh, that makes me very excited. And I'm also very excited because I think that's a great gift that they're giving us today by talking to us about their life and their family and what they like, and what's important to them. So Beth and Lily welcome. We are very, I am very excited to have you here and to have this time to be able to chat with you guys.

Twins (2:22):

Thank you for having us. Yeah.

Marjorie (2:26):

So we're gonna start, and it's gonna be easy. I'm just gonna ask you, who is your family and how would you describe your family?

Elizabeth ([02:34](#)):

Um, well, obviously I'm Elizabeth and Lily is my twin. Uh, we also then have our mum, our three aunts that we're very close to, and their kids, which I think we have eight cousins. And then we have Shelly and Nikki who looked after our mom when she was younger and her children, their, both their children. And then we have Margaret and all the Spencers and all that. We also have Susan Collings and then we have Marianne and well, we have two Marianne's and then, one of them has a partner called Normy. And then our friends <laugh>. It's a very supportive kind of group. Yeah. Yeah.

Marjorie ([03:48](#)):

Well, what's amazing to me is that, I mean, I know a bit about your life, obviously, through Margaret, but I had not realized how many people is sort of in your circle. Yeah.

Elizabeth ([04:04](#)):

And yeah there's a lot of us.

Marjorie ([04:05](#)):

people from your mom's world, from Margaret's world. Do you wanna tell me a little bit that you know, about who Marg is to you and, and which part, you know, does she play and which part each of them sort of play? Maybe not like each of them, but sort of like in general, how, what do they do for you or how do they help or what's their role in your lives?

Elizabeth ([04:27](#)):

Well, Margaret she's, she's kind of like, I guess our grandmother in a way, we, we like go to her when we can't like have help from our mom 'cause she doesn't understand like our school work. Yeah. So we always go to her, if we need help with any school work that we know our mom can't quite help us handle. With Susan she's, we actually grew up with some of, uh, her boys a little bit when we were younger.

Marjorie ([04:51](#)):

So each person sort of has like their, their role in a way

(Elizabeth and Lily): yeah.

Um, in your lives. Right. Yeah. And I guess whenever you need sort of help or, or just have fun, each of them sort of have, have

Twins ([05:06](#)):

Yeah

(Marjorie) That role.

(Elizabeth) Yeah. Yeah.

Marjorie ([05:05](#)):

That's pretty, uh, so that's something special because you know, um, yeah. Sort of like a big sort of village all around you guys and, and you get to have sort of the best of both worlds or of your life with your mom and then with everybody else.

Marjorie ([05:16](#)):

Can you tell me, um, what would be the thing that you love the most about your mom?

Elizabeth ([05:24](#)):

Um, well she always asks us if we need anything before she leaves, um, when she goes out,

um, she always asks how school was when she's home and always continues to check up on us.

Marjorie ([05:39](#)):

That's pretty awesome. Um, it's interesting that you're saying that 'cause you're both 18, so you're both now adults

Twins ([05:47](#)):

Yeah.

Marjorie ([05:48](#)):

Which is like, um, a big thing. And as you know, I have a son and my son is about to turn 12 and he's at that age where all of the things that you just mentioned is like horrible. Like he can't, you know, sort of fathom, oh my God, you're asking me again. And so it's funny that, uh, I don't know if you had that, that phase with your mom.

Twins ([06:08](#)):

We did, but yeah,

Marjorie ([06:10](#)):

But it gives me, um, hope. It gives me hope because I'm like, okay, well maybe in six years it's gonna come back.

Twins ([06:23](#)):

Yeah.

Marjorie ([06:25](#)):

So that's, uh, that's great. Are there things that are difficult with your mom?

Twins ([06:28](#)):

I think certain things we try to explain to her and if we can't explain it like again or properly, um, we just simplify, simplify it as much as we can and if she doesn't understand it, then we'll get someone else to explain to her. <affirmative> yeah, yeah. Yeah.

Marjorie ([06:45](#)):

That's a great way of doing that. And I guess that's how, you know, you'll, you'll get sort of other people from your network that you mentioned <Yeah.>. Sort of helps you out in that, uh, in that respect. <Yeah.> And I have to say, I mean, with anybody in terms of like kids and parents, you know, like Thomas sometimes goes to my mom and sort of said like, oh, can you like come down and help out with that? It's not as specific as someone might think in terms of like, this is the intellectual disabilities or their learning difficulties. <Yeah.> That create that. I think sometimes we all meet sort of, uh, a little sort of distance from, or, or someone else to sort of help out to understand what's going on.

Twins ([07:31](#)):

Yeah.

Marjorie ([07:32](#)):

So lately I've seen you guys being more vocal, um, in sharing about your family. <Yeah.>. And the last one that I saw, which is going to be in the show notes, because I think it's a, a very beautiful segment that you did, I believe for ABC.

Elizabeth ([07:48](#)):

Our mom did the ABC radio and then we did the project.

Marjorie ([07:58](#)):

Oh, the project. Yeah. That's the one. Exactly. Which I thought was like a beautiful segment. And it was really like the first time I think, where I really heard your voice through throughout 'cause often, like we've heard Marg, we've heard, um, Amanda, your mom's voice, but it was really the first time where I really clearly heard, um, your voice. Do you wanna tell us a little bit about that experience, uh, sharing for, for the project?

Elizabeth ([08:23](#)):

Well, it obviously was quite scary. Um, but we just took our time to like say everything. It was a new experience for sure. Yeah. 'Cause we are used to more about like being behind the camera instead of in front of it. But it was a great experience. Yeah.

Marjorie ([08:47](#)):

Yeah. What was scary for you guys?

Elizabeth ([08:48](#)):

Just being, I think vulnerable, like telling people a bit about our lives and what we do sometimes, yeah.

Marjorie ([09:00](#)):

Yeah. That's, that's pretty scary. I have to say. I don't think you need to add anything to that 'cause it's true. <Yeah.> I mean, and then it's sort of like putting out there to everybody 'cause it's sort of like

Elizabeth ([09:17](#)):

Yeah.

Marjorie ([09:18](#)):

On TV. So a lot of people and you never know, um, who could see it. Um, now in that show actually. Um, and I'm gonna put Lily a little bit on the spot you got emotional for for a little bit.

Elizabeth ([09:31](#)):

It was actually me. Yeah. Yeah.

Marjorie ([09:32](#)):

Okay. So it was Beth. So I'm putting Beth on those spots and so Beth you got a little emotional. Do you wanna tell us a bit about like why or how that got sort of out?

Elizabeth ([09:49](#)):

Um, so we were always like close with our like three cousins, Haley, Leonna, and Emily when we were younger. Um, so like when we started growing up, we kind of saw them quite often. As the older cousins, we kind of watched what they went through and all that and when they went into foster care, we knew we wouldn't be able to see them as much as we'd like to, which was kind of upsetting and kind of just like re-lived that a little bit in the, uh, project. We were never asked if we wanted to see them, like how often we wanted to see them when they were first taken away and stuff like that. So got a bit emotional about that. <laugh>

Marjorie ([10:41](#)):

Yeah, for sure. I know it's hard to talk about that or, you know, just like you said, it's like putting yourself out there and making yourself very vulnerable. Um, but I think it's also very powerful, certainly for someone like me or for anybody else who works in this system or works, you know, um, helping out kids and families who may need help to hear that. And that sometimes, you know, um, kids are being removed from, from their family of origin for different reasons. Um, but it's their whole network that gets sort of affected by that. It's not just those kids and those kids get affected by being away from their whole network. And just like you said, you know, like for you guys, it's like, nobody asked you: do you wanna stay in contact with your cousins? <Yeah.> And how often do you want to see them? And they probably weren't asked either in terms of how often do you wanna see your cousins, Beth and Lily, and, and all of that.

Elizabeth ([11:34](#)):

Yeah.

Marjorie ([11:35](#)):

So I think that that's very important, I think for anyone to, to understand that fear of being removed or having family sort of taken away from you.

Twins ([11:47](#)):

Yeah.

Marjorie ([11:48](#)):

'Cause I mean, just like you mentioned, you have, you know, such a huge sort of family or network around you guys, if you had been taken away at any point, it was sort of like all of them being affected and all of you being away from them as well.

Twins ([12:06](#)):

Yeah.

Marjorie ([12:07](#)):

Was there any moment where that might have been an option for you guys where, you know, um, because of your mom's sort of learning difficulties that you might be removed from her care?

Elizabeth ([12:20](#)):

Um, yeah. There was a moment in time. <Yeah.> Where we were like home a lot on our own. But we, we didn't find any, like we didn't find it hard 'cause in a way I think that experience helped us grow our independence.

Marjorie ([12:44](#)):

Well that too is sort of like very powerful actually because often, you know, we say, oh kids, you know, we need to protect them and we need to be there for them, which is true. But I remember sort of reacting when, as you know, I have, you know, yeah. I had an accident and so I raised my son now from a wheelchair and when he was little, uh, he learned to make his own breakfast very early, you know, at a time where other kids his age like were very far away from making him breakfast on their own. And for him it was sort of easy 'cause one, it was like everything was available to him at his level because it needed to be available at my level, so everything went down, you know, the bowls and stuff. Um, and you know, someone could have said, well, hold on a second, you know, as a parent you're supposed to make breakfast.

Um, and so it's interesting because for him it was sort of like fun 'cause he was like, you know, I'll do it. And sometimes he'll say I'll prepare breakfast for you, mama. You know, but it was sort of like his way of sort of being nice to me. Uh, it wasn't a very elaborate breakfast. I mean it was a bowl of Cheerios. Um, but it was sort of like the thought and for him it was like, he was proud of being able to say that. And so what I find, you know, in your answer, it's that, well, hold on a second, you know? Yes, maybe you could see this as, oh no, there's lack of supervision. <Yeah.> But you could also see that as well, they're actually learning something, um, on their own and they're learning to be independent. <yeah.> While still being safe because I'm pretty sure that all the people around you guys would not have let anything happen to you. So if you were unsafe somebody would've said something. <Yeah.> Right. So, thank you for that, cuz that I think gives us a, a great alternative perspective <yeah.>

Um, okay. Now you've lived 18 years with your mom and with your extended family. Um, this podcast is for, um, child welfare professionals, but it's also for, um, researchers and people who work in the field. If you could do research in the field, if parents and parenting with an intellectual disability or learning difficulties, what kind of questions would you ask or what kind of research would you wanna do?

Twins ([15:12](#)):

Um, we'd probably do an interview with kids. More like, like asking them like who's important in their lives and why to kind of like what we kind of just, um, mentioned. It could be like

their friends, cousins, um, grandparents, like anyone really.

Marjorie ([15:35](#)):

Yeah. And what would you wanna know in asking them about their families?

Twins ([15:43](#)):

Um, just like if they want to maybe like move out of the situation they're in, if they don't.

Yeah. How would they feel if they were removed in a situation? And couldn't see those people as often as they would've wanted to.

Marjorie ([16:08](#)):

So maybe even like talk to kids who have been removed versus kids who haven't.

Twins ([16:11](#)):

Yeah. Have been.

Marjorie ([16:12](#)):

Yeah. And try to see the difference in terms of their networks, that would be sort of like really awesome. Now with Marg, because of, you know, um, her, her relationship with your mom and with you guys and because of me being sort of a bit like your mom, I guess, you know, um, in my own situation where I also needed help from, from other people and, and that meant that Thomas needed help from other people. So I often ask my mom for example, and my dad was very involved as well. So Marg and I often talk about co-parenting. So if I were to talk to you about co-parenting, what do you think that means, and do you think that that's something that was used or that could relate to your family and your situation?

Twins ([17:07](#)):

Well I think it is, is, um, having maybe two people, figuring out, um, how to, um, help their children or child, um, equally like, have equal amount of time, equal amount of effort into helping your child, your child, stuff like that. And it has played a key role in our lives. When we can't go to our mom, we go to Margaret and if, um, our mom needs space. Like growing up, we would come to Margaret's every weekend. So our mom had space for herself and yeah. Have time to herself because of how often she was with us and helping us.

Marjorie ([17:56](#)):

Now, and, and your mom is, is a pretty great lady 'cause I'm raising one child and sometimes I'm like, oh my God, this is like really hard work. But for your mom, she got two for the price of one. Right. So, uh, raising twins is certainly sort of like double the work I'm sure <laugh> and I'm just like thinking of like some of my friends who are twins. Um, did you ever play tricks on your mom when you were younger?

Twins ([18:10](#)):

Um, not on our mom, but certainly to other people <laugh> yeah. Our mom kind of just knew which one was which so which really, she would sometimes mix us up, but, but most of the time she'd know which one's who and 'cause she gave us set colors, growing up for of clothing. <Yeah. Yeah.>

Marjorie ([18:32](#)):

And what was the tricks that you would do to, on other people?

Lily ([18:34](#)):

Well, in primary school, um, we had a canteen. We would both order at the same time 'cause there was two lines and um, once the lady who was, um, getting our food, we would switch spots. Um, and yeah. And she would get confused and sometimes when we didn't switch spots, she would swap like. 'Cause we had these little, um, money cards, things like token things. Yeah. I don't know lunch monitors I think for me. Yeah. So there's like money on it. Yeah. There's already money on it for you to use for food and she would swap ours around when we didn't switch. Yeah. Yeah. It was fun.

Marjorie ([19:18](#)):

That is fun. Yeah. And seriously, um, now that you're both like one beside the other I can see the difference. <Yeah.>

But if you weren't, I'm not sure <laugh> I'm not sure. I knew, I would know. And obviously I didn't because I thought it was sort of Beth and Lily in the project. Yes I, so you could play tricks on me. It would work probably.

Marjorie (19:41)

Okay. Now if you could organize services like child welfare services or talk to, to people who manage their, those types of programs, what would you want them to know or how would you organize services and maybe that's two questions. So we could ask, like what kind of programs would you like or how would you organize the services? We'll start with that.

Twins ([20:06](#)):

I think when they're considering taking the child away, they should have a talk with the child and ask them if they're comfortable with being removed from their family, and providing like services for them as well as, um, like for us, for example, um, our mom gets services for, for her disability so she can do things and we wouldn't be able to have those services if she wasn't around. So maybe having something for the kids as well, then just the person with the disability.

Marjorie ([20:46](#)):

Yeah. That is actually pretty smart.

Elizabeth ([20:51](#)):

Yeah.



Marjorie ([20:52](#)):

<laugh> yeah, you're right, right? Um, yeah, it makes me think actually of something I did after my accident, where I had asked for Thomas to get services because I felt that my accident had not only affected me, but it also had affected him even if he was very young. So you're basically sort of bringing up a similar situation where it's sort of like kids also need

Elizabeth ([21:16](#)):

The support

Marjorie ([21:20](#)):

support in different ways, than the support that their parents might be getting.

Elizabeth ([21:30](#)):

Yeah.

Marjorie ([21:31](#)):

And that's um, yeah, that's pretty powerful too, in terms of, of that.

So that's something that you would add, which I think is, is awesome. Now if you were to talk to workers. So the people who are social workers or educators in terms of how they act with parents with disabilities or with children and families, is there any, like, advice you would give them or any sort of, um, things you would want them to know to be doing a better job with them?

Twins ([22:09](#)):

I think just in general, um, just try not to assume about like what the child wants, what the child wants or what the, um, person with the disability wants. Just like ask them, I think, 'cause they might like know what they want, but they haven't had the chance to voice that. So yeah. Yeah.

Marjorie ([22:36](#)):

So what would you say if someone would say, okay, well I'm gonna ask them what they want, but I still feel that it's better, let's say for them to be removed or it's better to do whatever I think my, my recommendation is in terms of the service, for example. Is it really just about like what you want or is it also about what's better for you?

Lily ([23:04](#)):

Just, um, providing choices if there was like, if it is a serious thing, providing choices and alternatives so they can still have what they want, but also to make it sure. Um, that they're living a better life and it is safe for them.

Marjorie ([23:27](#)):

So it's what they want, but it's also, I guess, in a way what they need. <Yeah>. Is that what I'm

understanding? <Yeah>. And that's certainly like if we're not asking then we don't know. And um, we're making choices based on what we think is right. When for them it might be different.

Lily ([23:44](#)):

When you don't have all the information.

Marjorie ([23:50](#)):

Yeah. And do you think you would've known, you know, at age five or six, what you wanted or what was important to you?

Lily (24:00):

We definitely have different ways of worrying about things than I think parents do. For example, if the house is messy and all that or like, if there's a lot of stuff in one room or something, us, for example, we, um, didn't really worry about that. 'Cause we just like knew it was just stuff that we needed and all that it didn't have to be too organized and stuff like that.

Marjorie ([24:14](#)):

So you're basically saying that, um, that the preoccupations are different In a perspective of a child than of a worker than of a parent.

Elizabeth and Lily ([24:24](#)):

Whereas, um, if like maybe a social worker or just like, what's called anyone walking in and they like see mess, they constantly assume the worst. Yeah. They constantly think that they aren't fit to parent because it's so messy and stuff like that. But when it's just how families are. You have like messy houses sometimes and sometimes you don't, you know, it's just yeah.

Marjorie ([24:59](#)):

Yeah. 'Cause that makes me think also of like how we have sort of certain standards I guess, or certain ways that we imagine should be, you know, a family should look like and how a family should work. <Yeah>.

But then it's learning about that family before even sort of passing judgment, and you said it earlier, you know, it's about asking the kids, it's about asking the parent and that would be the case, you know, like if it's a parent from a different culture, right. Background, like we would ask or, or any type of parents we, we would wanna know or understand that they're going, um, or what they value most. <Yeah.> And you're right. I've seen that many times where we focused a lot about how the house is clean or not, or the cleanness of it when there might be other things that are way, much more important for the kids and for the parents for different reasons.

So I think that that's pretty amazing sort of advice that you're giving, uh, those workers certainly, uh, food for thought for me.

Marjorie (26:16):

I really thank you because with a little bit of a conversation like this, like I've learned personally a lot of things and it's definitely made me realize that there's a whole lot more factors than sometimes we take for granted. And that definitely sort of listening to children is an important one <mm-hmm> <affirmative> and that sometimes children know what's good for them and what they would like for them to happen. <Yeah>. And so for that, I think thank you for, for being a voice. Um, for all children, basically who, who might have to either, you know, do research or, or talk to social workers and other workers that come in their house and uh, thank you for taking the time.

Elizabeth and Lily ([27:05](#)):

<laugh> alright. It was nice. Nice talking to you. <laugh>

New Speaker ([27:07](#)):

This podcast was supported in part by a grant from the Minnesota Department of Human Services,  
Children and Family Services Division.