June

June, June MSW, LICSW, ACHP-SW, and mother of Alissa (24) and Katie (28). Katie is medically complex and likely has Rett Syndrome but that is not definite.

1 TITLE: Undiagnosed: "28 years and we still don't know exactly"

https://courageousparentsnetwork.org/videos/undiagnosed-28-years-and-we-still-dont-know-exactly/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes living in the not-quite-certain-what-it-is-space, not knowing the prognosis. "If you don't know what it is, where do you go? Early on, I thought, if we knew what it was, we could do a better job of caring for her. .. And then I adapted to not having a label." How do parents plan ahead? When to plan ahead? Living with unpredictability.

Transcript:

June: Katie has a number of diagnoses, and they're --- the doctors are not always in agreement. When she was younger, she was just diagnosed with developmental disabilities and seizure disorder, but she has some of the hallmark characteristics of Rett Syndrome like holding her hands at midline, heavy breathing and breathing abnormalities. So we thought for a while there that she had Rett Syndrome. The doctors did the genetic testing and nothing came up. So they said no, she doesn't have it. But it's always been the diagnosis that most closely fits her set of symptoms. So we've always found contact and information from that group most helpful. We recently moved to Massachusetts from California. The doctors at BCH say for sure, she has Rett Syndrome. So despite what the genetic testing says. So 28 years and we still don't know exactly, but that does seem to be the diagnosis that most fits her.

Early on, that was really difficult because you want to know what it is to treat it most effectively. If you don't know what it is, where do you go? You can do symptom management, but we always kind of feel or I always felt --- God, if we knew what it was, we could do a better job of caring for her. But then at a certain point, it just became this is what it is and I'm just doing the best I can and she is who she is. I guess I no longer thought like the perfect treatment was going to come along. So we just settled in and accepted that this ---we were living without a diagnosis for a while. We knew certain aspects of her but we

still didn't have a label.

When she was first hospitalized when the first crisis hit and she was having uncontrolled seizures, she was about nine months old and they told us she wouldn't make the week. She survived that. They told us that she wouldn't make the year, so that's kind of what we had in mind. Then it was she is not likely to see five years. So when she made it to five years, we had this huge party, because we were so proud that we flew in the face of their prognosis. It was ever constant there that I was worried about her passing. Then one day I woke up and she was ten. We were celebrating her tenth birthday and I looked at my husband. I said oh my God, we have to prepare for adulthood. We have never done any planning because we never thought she was going to survive that long. Then at 10, it was like I think she is going to make it, we have got to plan ahead. Now I think she probably has a limited lifespan, probably 40s and 50s in the best guess for most of the girls with Rett Syndrome. But I also know that a seizure could take her this afternoon. There is a level of unpredictability there, so you never know.

TITLE: UNDIAGNOSED "You realize you can't put your life on hold until this resolves because this may never resolve"

https://courageousparentsnetwork.org/videos/adapting-you-cant-put-your-life-e-on-hold-until-this-resolves-because-this-may-never-resolve/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, talks about the early years when everything felt so critical and intense, and then how one adapts and begins making plans for the rest of your life too.

Transcript:

June: Early on it was so difficult because of the uncertainty about her diagnosis and her prognosis. It was so new to us. It was such a learning curve. The medical field, the different treatments, the different medications, the special ed system. All of that was absolutely overwhelming and you had the impression of or at least I did that every decision you make is so critical. Some of them were life and death decisions that we were making. The pressure and the fear of misstepping were so great. Then I guess as time goes on and we survive one crisis after another, it's not that that disappears but it becomes less intense and a little bit easier to navigate. You realize you can't put your life on hold until this resolves because this may never resolve or it may not resolve in the way

you planned, but you do get to a point where you have to go on making plans for other parts of your life at least. Are you going to have other children, or are you going to stay here, or move closer to hospitals or what not. You realize that as much as you want to make your child the full focus, you still need to deal with the rest of reality and the rest of life.

TITLE: "It showed me that there was hope -- there were people in the world who would love her and care for her."

https://courageousparentsnetwork.org/videos/finding-support-other-parents-showed-me-that-there-was-hope/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes how she found support in the early years to cope and have hope, especially from fellow parents. "Other parents get it."

Transcript:

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June: There were times when I did seek out counseling. Some of it was more effective than others. I do remember feeling at times that I was talking to people who had no idea what it was like to raise a child with special needs and how their advice I kind of dismissed because I didn't feel like they really understood what was going on and how critical some of the decisions were or how intense some of the emotions were around the situation. But I also had some good experiences and some wonderful guides along the way. I would say many of them were other parents. I was lucky enough to be connected through a mentor parent program with a wonderful woman, Trudy Grable, who still works with Parents Helping Parents in San Jose. I remember two things. I was feeling so upset about the diagnosis and Katie's future and not knowing what her life would be like and realizing she probably wouldn't go to college, get married, have grandchildren, any of those things. Would there be even people in the world who would love her and care for her like we would? Trudy came to the house one day to meet with us and she brought her daughter Lauren who was older and similar in that she was developmentally disabled, but of course her own unique person. Lauren gave --- we had a nice talk and then Lauren gave Trudy so much trouble when it was time to leave, she didn't want to get in the car. Trudy grabbed one of the car mats and said to Lauren --- hop on, this is your magic carpet ride and pulled her to the curb using that car mat. I was so impressed with her creativity and her resourcefulness. I can't explain why, but it touched me and it showed me that there was hope, that there was a way to

make this work, and that yes there were people in the world who would love her and care for her and know how to work with her. That was like pivotal to me. Other parents along the way have taught me about the special ed system and held trainings or provided on the phone support when things were going wrong. Other parents who have children with seizures – I was part of the Seizure Network and I could call them for if not guidance at least a listening ear. Somebody who got it and could say yeah, that really sucks and listen, where doctors and teachers and even family members sometimes don't have that time, but other parents got it and would help me out at those moments.

4 TITLE: "Where I got support varied depending on the time and situation"

https://courageousparentsnetwork.org/videos/where-i-got-support-varied-depending-on-the-time-and-situation/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes the various sources of support -- when it can come from family, when it can come from friends, from a support group, from medical providers. "You find the people you feel comfortable with who will listen while you process."

Transcript:

June: You know, where I got support varied depending on the time and situation. My family has been really supportive over the years but there were some discussions I found difficult to have with them so I might have them with a girlfriend instead. I was involved in some support groups early on...in some educational groups that ended up being supportive and I made some friends with other parents and found a few that I could really open up to and that was helpful. We were really lucky to have some fantastic healthcare providers early on that I really felt guided us with some of the decisions we had to make so you kind of -- it's not always the same person. It's not always the same avenue over and over again but you find the people that you feel comfortable with, the people that will listen while you process and figure out for yourself how you feel about things and how to cope.

TITLE: Becoming a social worker: "If I needed to work outside the home, it had to be something meaningful."

https://courageousparentsnetwork.org/videos/becoming-a-social-worker-if-i-needed-to-work-outside-the-home-it-had-to-be-something-meaningful/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, shares how her experience as Katie's mother influenced her professional choices. "Some of the things I had

learned - advocacy, listening, adversity -- would translate well into social work. ... I wanted to pay back to other families."

Transcript

June: When Katie was born, I was in my final semester of business school. So I was going to work in marketing and do some research and things like that. Then she surprised us and her care kind of stalled both my degree and my career for a while. Then years later, when I needed to return to work, I kind of felt like the work I had done with Katie was so important, caring for her that if I needed to work outside the home, it had to be something meaningful. Otherwise, it wasn't worth not being with her. So I searched high and low for things I was interested in. I was working in a family resource center at that point and I really enjoyed the direct contact with other parents and decided that social work was probably the way to go.

I realized that some of the things I had learnt, the advocacy, perseverance, letter writing, listening were skills that would really translate well into social work. So that was part of what led me there. Also having experienced so many challenges, difficulties, frustrations along the way, I realized there was a lot of work that could be done to improve our systems of care for people with special needs; medical system, special ed system. Even if I alone couldn't make a difference, maybe advocacy with other parents could. I think I'm so grateful for the parents who went before me and paved the way and did some great advocacy in the 60s and 70s on disability rights and obtaining special ed services and things like that. I felt like I needed to pay back or I wanted to pay back to help other families if I could.

So I do work with other families with children with special needs. I'm a palliative care social worker for the pediatric palliative care network here in Massachusetts.

Going back to school to become a social worker happened much later. Early on, I could not have done that. I marvel at working moms who are able to be there for their child, be up to date on the child's care and still have a full-time job. I know at that point I was so overwhelmed by my own grief and Katie's care needs, medical needs, educational needs that I didn't have the bandwidth to do that. There were times when I was working at the Family Resource Center where the other families' stories would touch me so deeply that I felt like I wasn't being of service to them because it was bringing up so much of my own

issues. It wasn't until much later that I felt like I had the composure, the experience to not --- to maintain my professionalism and not devolve into ineffective social work with them.

TITLE: Finding the right fit: "Finding a spot that still valued our participation in her life."

https://courageousparentsnetwork.org/videos/considering-options-for-out-of-home-placement-finding-the-right-fit/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes the awakening that eventually Katie's care would too much for them alone at home, exploring all the options, eventually finding the right place, and transitioning to the new home. It was like respite.

Transcript:

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June: I think it was a real eye opener when she turned 10 and then so much of our focus had been on keeping her alive, you know, and helping her to see another year, and when she turned 10 and we realized that we might have her for longer than we thought, we realized we had to start doing some planning. And, it was no urgent need but a couple of years later we thought well let's look around, you know, she was about 13, let's look around and see what the adult options are so that we can plan ahead for transition, know what kind of -decide for ourselves what our goals for her were, what the optimal solution would be.

And so we spoke with the DDS case manager and she showed us several group homes and none of them were anywhere I'd want to leave my plants let alone my precious kid, you know, so we were like, "Okay that's not an option." We kind of put that aside and said, well then we have to get serious about planning for a home of her own or live-in care. So, we started having those conversations, not everyday at the table but occasionally throughout the year like, what are you thinking about this or I just heard about supportive living, do you think that's something that we could consider? So we kind of started having the conversations probably when she was about 12, 13.

And it really didn't go anywhere, we didn't have any concrete plans yet, but then her case manager called us a year later and said, "We just got an opening in this great group home, you have to see it." And we went. Nah we saw some we're not taking that route. Thanks but no thanks. And she says, "No really. This is one of our premier group homes in the area. They have stable staff, the home is beautiful, the makeup of the other children in the home is great. You really need to go see this." And I am like, "Nah." And she's like, "No really."

So we did, we went. And everything she said was true. Stable staff, the home had been open for seven years, all the residents, the other five residents were there for those whole seven years. The staff was very capable and kind and compassionate with the kids, there were activities for them. I spoke to some of the other parents that had children in the home and they all raved about it and we went, "Huhhh. Well maybe we need to do -- we really have to think about this. Do we want to wait until she is 18 which was kind of our plan, you know, kind of adult normal transition age or -- and not know what options exist or not have this option because this was the first opening in that home for seven years, or do we want to make the move now where we've got an amazing setup, you know, where this group home is so well established and well run?" And after some hemming and hawing, I would say I was like 70% no, I want her home for a long time.

And then we found out -- and this may not be true everywhere or in Massachusetts but it was true in California at that time, that Katie could be home with us for up to like 14 days a month and still retain that placement. And that just flipped the odds and now I was feeling like, well shoot. If I can still have her half the time, half the month -- it's just like getting a really good respite, you know. And that was the clincher for me. And so we decided to give it a try. We figured we'd give it six months to see how it works out.

So we were lucky in that they were accommodating and so we started to slowly transition her into the group home. We would bring her over -- bring her over to meet the other kids and the staff, next time she stayed for dinner. Then she would go for one weekend day and then the next week she'd go and spend an overnight and all along we'd be providing guidance to the group home about who Katie is, how best to meet her needs, what her subtle communication was like, because Katie doesn't have words, or at that point she didn't even have signs or gestures, so you really had to watch her closely to kind of figure out what she needed and warn them about the things she gets into.

So by the time she actually was kind of residing there, they already had all this knowledge about her. And I did continue to have her home. She would be with us from -- in general from Friday night till Tuesday morning and then she's like after school go back to the group home for those few days and that gave me the opportunity to participate in Allisa's classroom and to have some downtime, to sleep, because sleep was a biggie; we were sleep deprived for years. Katie's seizures are worse at night and so it wasn't uncommon that we would only get three, four or five hours sleep. That takes a real toll. And that was one of the contributing factors that kind of helped us decide on the group home.

TITLE: Out-of-home placement for our medically complex child gave us more time for our other child. "We talked to Alissa: this is your turn to have us alone for a while."

https://courageousparentsnetwork.org/videos/out-of-home-placement-for-our-medically-complex-child-gave-us-more-time-for-our-other-child/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes the transition of Katie to a group home and how it gave them respite and more time for their other daughter Alissa.

Transcript:

June: There was certainly a period of adjustment for all of us. I do remember early on like the first week or two, Allisa climbing into her bed at night, kind of -- because she was scared. She couldn't hear Katie. Katie breathes heavy and snores and all sorts of noises so those noises weren't happening and that was disconcerting. But she would come visit us, she would come or visit Katie, she would come with us when we picked Katie up and got her home. So she got to know the staff and the people, the home, and felt more comfortable.

We had always made it a priority to have Allisa time even when Katie was around, either one-on-one with her dad or myself but also we used out-of-home respite option that we had in California which was like one weekend away, a month or a quarter and we had always used that as our Allisa time. We'd take her to the beach or do some of the things that were more difficult to do with Katie along or that Katie wouldn't really enjoy or would be hazardous for her, we would do those things with Allisa when Katie was at respite. So she had that experience and so it was kind of more just like expanding on the previous respite experiences.

We also talked to Allisa about, you know, Katie had us alone for five years and this is your turn to have us alone for a while. We weren't sure if it was going to last a month at that point or six months or what not. It ended up working out beautifully. And Katie did remain in the group home. We did continue to have her home, you know, 10 to 13 days a month so I mean she was still an integral part of the family, barely time to think of her as gone or what not. And she saw Katie having fun, you know.

TITLE: Moving to a new state. Finding a new place again.

https://courageousparentsnetwork.org/videos/group-housing-for-a-medically-complex-child-moving-to-a-new-state-finding-a-new-group-home/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, talks about the long term impact on the marriage, which ended in divorce and prompted a new job, moving to a new state and starting all over, including finding a new group

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home.

Transcript:

June: Another factor in choosing the out of home placement was the strain on our marriage and the family with Katie's needs over such a long period of time had taken its toll. So we felt like if we had a chance to get some sleep, catch our breath, maybe we could firm up our marriage and unfortunately that didn't happen. And we ended up divorced. So, I needed to go back to work, I needed to finish my schooling, get my degree, get back to work, and was lucky enough to there came a point of time where my folks here in Massachusetts were elderly and starting to struggle, and where it made sense that I come back home to Massachusetts.

And so I -- with her dad's permission, packed up Katie and we moved back home to Massachusetts and started all over, all over with Special Ed services -actually not Special Ed because she was already an adult, so a day hab services, DDS, all those applications, applying for mass health and you know medicaid her all over again. It was quite an undertaking but we have created a great life for ourselves. Katie was home with me for the first year until a series of seizures and broken bones made living in an non modified home really challenging. And so once more we -- I looked around for a group home for her.

She was lucky enough in the sense to get priority rating from DDS and so it was possible to get her into a group home. And we -- the first one we tried here wasn't a good fit for her so we continued looking and right now she is in a group home with four other adults. I keep calling them kids because Katie is always a kid but they are adults, really close by, you know, within just 10 minutes, I continue to see her every weekend and have my Katie time.

9 TITLE: Advice for families: "You may not know why you are reacting to something but you are probably picking up on something, so trust your gut."

> https://courageousparentsnetwork.org/videos/a-parents-tips-for-finding-grou p-housing-for-a-medically-complex-child-adult/

> Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, tells parents to be picky about finding just the right group home for their medically complex child. Go for visits and see if the other kids are the right mix for your child. What's the schedule? How accommodating is the staff?

Transcript:

June: You know I would tell parents the same things I told them when they were looking for nursing care, like be picky, you know, it's okay to interview 5,

10, 15 until you find the person you think is going to be a fit. You know take the best of the crop, give them a chance, and guide them, educate them, inform them about your child's needs, so that they can rise to the occasion. We saw -- we looked at a number of group homes out here.

We look a lot at the staff and especially the management because the management tends to be a little more long term than some of the direct providers, where these people that we felt we could talk to resolve conflicts with, were they -- how did they interact with Katie? Were they welcoming or did they want clear visits at certain times? Or did they not care about drop-in visits? What did the environment look like? We found faces -- people told us the staff was great. And then we felt the house was really dreary and it's like, no I want a better environment for her, you know.

Look at the -- there's a limit to what you can learn about the other residents but if you go for visits, you will see and interact with them and is it the right mix for your child? What's their schedule like? Are they available during the day if Katie has a seizure in the morning and needs to stay home, is that going to be something they can accommodate or does everybody leave during the day and there are only staff from 3:00 to 7:00 or whatever. There are some great guides online that other parents have written and so different checklists and things you can use for guidance as well. I would say a lot of it comes down to how comfortable you feel in the environment and with the people who are going to be working with your child. And don't dismiss those parental instincts. You may not know why you are reacting to something but you are probably picking up on something, so trust your gut.

TITLE: Parent Worries: "I feel more comfortable knowing that there are two or three caregivers in the home and they can trade off if they need to"

https://courageousparentsnetwork.org/videos/more-parent-perspective-tips-about-finding-out-of-home-placement-for-a-medically-complex-child/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, talks about the range of options available for out-of-home placement and encourages parents to explore all of it. She addresses general concerns about neglect and how she thinks about it -- for her, the number of caregivers in the home is an important factor.

Transcript:

June: Well Katie's placement at the group home worked out really well for us. I am not naïve, I know things can happen and I also know that there are other options and so I encourage families to look at all the options. That includes things like adult family care, adult foster care where they are paired with a

single provider and living in the community or supported living where the supports are beefed up but again they are in their own apartment or what not.

There's also for kids who are more complex, their own medical group homes that provide a higher level of care that Katie gets at her community group home. And all these options exist because kids are different, families are different, needs are different. So it's for the whole gamut of things. My friend Trudy I talked about before was -- it was very important for her to have Loren with an active social life, so she didn't want to do a group day hab program during the day so she's created a wonderful individualized program for her daughter using agency of choice or there's different words for the programs, but where they decide how the money is spent.

And Loren has an activity set for her every day of the week, Monday may be shopping, Tuesday may be bowling, Wednesday she goes to the senior center, what not, and they have really personalized a program for her, and it works beautifully; it's not without its challenges as well, any option is. But it's up to parents to weigh the pros and cons and figure out what's best for them. I just hate to hear group homes not being considered because I really feel like they do serve -- they are a wonderful resource and can be the right option for some families. I know for us, it's allowed us to have a bit of a more typical life and activities which were very difficult to achieve with Katie's intense needs.

Obviously one of the big concerns with anyone as vulnerable as Katie is, or people with disabilities who may not have the language or the wherewithal to protect themselves, is that there would be some kind of neglect or abuse and I've always felt like the group home with several staff present might make that a little bit less likely than if she were with one care provider. I also know how much energy it takes to care for Katie as much as I love her, she is -- when she is awake and alert, she is a ball of fire. And I know how tiring that can be and so I feel more comfortable knowing that there are two or three caregivers in the home and they can trade off if they need to take a break, that the burden is not just on one person. So I worry a little bit less about that. Do I know it's an issue? Do I take it lightly? No. But, you know, I feel like there is more oversight in a group home.

TITLE: There is room for change along the way. "I might choose a different option in the future."

https://courageousparentsnetwork.org/videos/group-housing-for-a-medically-complex-child-each-family-has-to-make-its-own-decision/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, shares that every parent has to make the decision that is right for them regarding out-of-home placement.

Transcript:

June: I think every parent has to decide for themselves what they think is the right decision. This was the right decision for us, the two times we've made that decision. And that's not to say I might not choose a different option in the future. I think my hope is that someday we'd have a lovely little duplex of Katie next door and me right there so I can go over anytime I want. Luckily, they have an open door policy at the group home, so I do still visit her quite a bit. But that was the right decision for us and has worked out well so far. It wasn't a decision we took lightly. It was a decision that had significant ramifications I think. Although we -- you know, Allisa -- weathered it well with Allisa and all, there were people that weren't in agreement with that decision.

TITLE: When your community doesn't understand. "There is a lot of pressure on parents to provide homecare."

https://courageousparentsnetwork.org/videos/when-your-community-doesnt-understand-there-is-a-lot-of-pressure-on-parents-to-provide-homecare/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, shares openly the blowback she got when they chose group housing for Katie. "They thought we were giving up on her. I saw it as doing what was best for our family and for Katie." There is so much pressure for parents to provide homecare and it can be perceived as being about parents' values or capabilities. For June, it was an evolution that took into consideration the entire family.

Transcript:

June: I actually lost some friends over it; they felt that we were giving up on Katie or institutionalizing her. And, I lost those friendships and that really hurt. I did not see it that way. I saw it as, you know, doing what was best for the overall family and getting Katie -- broadening Katie's horizons, activities, and her circle of support. I was lucky in that my immediate family supported the decision. And you know we would talk -- I was able to talk with them about it, they were supportive --

There is a lot of pressure on parents to provide homecare. And I think it's wonderful that those supports exist and that's the default. I don't think this is a decision -- using a group home is a decision that anyone would take lightly. But maybe there is an element there of not wanting to acknowledge other options because it makes you question your values or your capabilities. You know we all have different values and base our decisions on them, different belief systems, and I obviously respect other parents' decision to make whatever

decision they make for their children.

I know early on in my experience when people had suggested we consider that, it horrified me, like, "No. This is my daughter and I am going to do whatever it takes to care for her at home and I don't want to be separated from her." But eventually I realized that there are some advantages, not only for us, but for Katie, for Allisa, and as a mom I felt like it was my responsibility to weigh the situation for all the family, not just what's best for Katie but what's the best solution out of some very difficult solutions for the entire family.

TITLE: "It was a shock to learn there weren't necessarily medical professionals trained to care for adults with disabilities."

https://courageousparentsnetwork.org/videos/a-medically-complex-child-age s-out-the-disheartening-challenge-of-transitioning-to-adult-services/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes her disheartening surprise at discovering how few options there were for her daughter when she transitioned to adult services. It took years to get connected to the right people; luckily she had time to figure it out.

Transcript:

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June: I think it was eye opening when she became older and transitioned into adult services to realize the dearth of options that were available. She certainly wasn't on a vocational tracker, college track. So basically we were looking at day hab services. Some of them were better than others. I started looking around when she was about 18 even though I had intended her to stay in special ed through 21, just to see what was out there. It was kind of surprising the lack of attention to continuing her education. The goals become a lot more about maintenance and less about learning. That was a shock. To find out that there weren't necessarily medical professionals trained to care for adults with disabilities or children with the extent of her disabilities was surprising. We'd had the blessing of many really good developmental pediatricians along the way and to find out that there were very few adult options or few adult providers who really purposely chose that field was surprising. It took us a while to get her connected to the right people. But I guess the good part is you have a few years to make those transitions whereas when you're in early intervention and transitioning into special ed, I think those are a little more jarring because the, because they happen so quickly and you're in such a tight timeframe. I had been warned about some of the difficulties with adult

transition. In some ways, it wasn't as difficult as I expected but it was a little bit disheartening.

TITLE: Guardianship: "It was surprising to learn that I wouldn't have the authority to make all the decisions I had before."

https://courageousparentsnetwork.org/videos/when-a-medically-complex-child-ages-out-guardianship-and-medical-decision-making/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, describes the complicated and cumbersome process of getting guardianship when her daughter transitioned to adulthood. So much paperwork, notifications, legal bits. Also -- Guardianship doesn't automatically cover critical decisions such as medical orders. "It was surprising and upsetting to learn that I wouldn't have the authority to make all the decisions I had before. I was flabbergasted and angry. I know her best."

Transcript:

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June: I think one of the challenges --- one of the immediate challenges is getting guardianship for Katie, who is severely disabled, we knew she would qualify for guardianship, but it's still a complicated process. A Lot of paperwork, a lot of getting other people to sign off on --- you know have to notify the immediate family and they have to agree or they have an opportunity to testify against the guardianship, that can be a little nerve-wracking. Just tracking all the paperwork that's needed, getting the clinical team report done, finding out who is going to do it, will school assist or do I have to find my own people, that can be a cumbersome process. It was also surprising to me to learn that even though I was becoming Katie's guardian, I wouldn't have the ability, the authority to make all the decisions I had before she was under 18. For instance, there was no question when she was growing up, if there were critical medical decisions, I could make that as her parent, but after she turned 18, we have guardianship. The guardianship only covers ordinary medical decision making and so if there were a life threatening illness or decision to make about treatments in a life threatening situation, I might not have the authority to make that. I might have to go to court to do that. That was surprising to realize that those critical decisions for somebody that I had cared for so long might rest in somebody else's hands who knew nothing about her and her journey or our family values. So it was kind of upsetting reaching the transition age or going for guardianship.

Interviewer: How upsetting was it when you first understood that to be the case and how are you with that now?

June: I think I was just astonished at first when I learned. It just didn't make any sense to me that a court would have more say about my child's care than I would.-So I was just flabbergasted I think at the beginning. I do have respect for the fact that you don't want to limit anyone's rights. The disabled population has had such a struggle to get some of those rights. I do appreciate that we don't want to take those away too easily, but it still kind of makes me angry. I'm the one who knows her best. I've cared for her all these years. I think I have the best idea of what's in her best interest.

TITLE: Guardianship and Co-Parenting: "Because her dad is a co guardian, I have to consult with him on all those major decisions."

https://courageousparentsnetwork.org/videos/co-parenting-a-medically-complex-child-and-guardianship/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, explains how she and her ex-husband share guardianship now that Katie has transitioned to adulthood. "I have to consult with him on all those major decisions." They process things differently but they usually see eye to eye.

Transcript:

June: So for married couples when their child turns 18, they have the option of one parent or both becoming guardians and there is an advantage to having only one in that it leaves them open to having the other parent designated as adult. Family provider adult, caregiver adult, foster care parent. I didn't -- as a single mom I didn't have that option. In fact I still share guardianship with Katie's dad.

And so that brings up -- number one, because there was not another adult in the household, I wasn't eligible for the adult family care program but other parents might find themselves that that's an option for them and that is a wonderful way of still having the child under your roof. I didn't have that option and in fact because her dad is a co guardian, I have to consult with him on all those major decisions. We luckily have similar views and values, so it hasn't been a major concern. As a matter of fact I think it's a bit of a relief because I don't have to do that constant negotiation or compromise too.

So then I can be much more direct and clear about my hopes and wishes for

Katie. So I think it's simplified in some ways, the decision-making process because I am the primary parent involved. But there are still instances where he does need to be involved in certain decisions and I kind of let him know what's going on on a day-to-day basis, what the options are and what my opinion is and why. And I've been fortunate that we usually see eye to eye and so it's just a formality of signing whatever paperwork needs to be signed to proceed.

Female Speaker: Have you and he ever been on a different side of an issue about Katie.

June: No, little things here and there but nothing critical. Even when we were together, I often had the sense that the decision -- the final decision was up to me. We all process information and make decisions differently and he would kind of state what he felt was right and be done with it and not want to revisit and I would be kind of hemming and hawing and thinking it over and looking at different viewpoints here and there and ultimately I felt like it was my decision anyways, so now it's just kind of recognized more that that is the case.

16 TITLE: "It took us five years before we decided to have another child. I still say it was the most courageous decision I've ever made."

> https://courageousparentsnetwork.org/videos/parenting-a-medically-comple x-child-and-deciding-to-have-another-child/

> Description: June MSW, LICSW, ACHP-SW, mother of Katie (28) -- who is medically complex and likely has Rett Syndrome -- and Alissa (23) -- speaks about how consuming Katie's early care was and how it took a lot of courage to have another child in the absence of knowing whether Katie's condition was genetic. "The only way I got through the pregnancy was by not entertaining thoughts of 'What if.'"

Transcript:

June: Katie was my first. Her care kept us so busy for the first, kind of the efforts to keep her alive, get the treatments she needed. I don't know that we thought about having another child but after a couple of years went by when it was the time we were expected to do that, we started talking about it. There were times when I thought I might want to try and my husband was not in the same place. Then there were times when he wanted to try and I thought --- oh gosh, I don't know if I can handle anymore. So it took us five years before we decided, really decided, to have another child. I still say it was the most courageous decision I've ever made. It took a lot of courage to do it because at

that point we weren't really sure, and we still aren't to some extent, about what her diagnosis was and what the chances are for having another child. Yes, we did go to the genetic testing. We did hear some information but it still felt like a crap shoot to us. It wasn't really clear guidance. But they were suspecting Rett Syndrome, so we --- and I was older. We had amnio done and found out she was a girl. At that point, they did not have a genetic test for Rett's. They hadn't determined ---- done the chromosomal workups and known what caused it. So we just knew that the risk was higher if we were to have another girl. So they offered us the opportunity to terminate the pregnancy and try for a boy which would have a lower risk of having Rett Syndrome. We weren't really sure that Rett Syndrome was what Katie had. As a feminist, I felt like I couldn't terminate that pregnancy because she was a female. So I decided to go ahead, but like I said it was a really hard decision to make. Probably one of the hardest decisions in my life. It took a lot of courage. I was fortunate that I had a relatively easy pregnancy. I think the only way I got through the pregnancy was just not even entertaining thoughts about what if. Certainly, they would flitter across my mind, but I just wouldn't allow myself to go there because I couldn't. It would have immobilized me. We were fortunate enough that she was born healthy and actually every developmental milestone she made, I felt another ton of bricks leave my shoulder. Now she is a thriving independent young woman. I'm very proud of her. For different reasons, I'm proud of Katie. But they're both remarkable women.

TITLE: "Around four, five, six, she started asking questions: how come Katie can't talk? Why does she have seizures and I don't?"

https://courageousparentsnetwork.org/videos/medically-complex-children-and-siblings-a-mother-shares-her-daughters-early-and-evolving-relationship-and-how-she-parents/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28) -- who is medically complex and likely has Rett Syndrome -- and Alissa (age 24), describes how her typical daughter evolved her understanding and questions about her sister, and how she parented her through that. "Around four, five, six, she started asking questions: How come Katie can't talk? why does she have seizures and I don't? ... It presents different challenges at different times and I'm open and honest with her and reassuring."

Transcript:

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June: I was lucky. Katie didn't show much sibling jealousy. I often had both of

them in my arms. Katie in one, five years and Allisa in the other. Allisa grew up not knowing any different, so the first few years, not that we didn't talk about it because it was ever present, but it wasn't much of a concern. Children just accept everybody. They're not making judgments yet about people and who they are and what they look like and things like that. She was close to Katie. They would snuggle. One of my favorite pictures is of them taking naps together and they are both sucking their thumbs with their pinky fingers entwined. They just grew up side by side. As Allisa made developmental progress, she kind of would naturally --- just never asked about Katie's development. I don't know that she could have at that stage, but she just naturally did things for Katie that she saw us doing. So I remember putting them in the bath and Allisa at two and a half picking up the face cloth and washing Katie's back because that's what she had seen us do. She didn't think anything of it. She used to help Katie tie her shoes. Katie can't do that. It wasn't something we asked her to do; it came naturally to her, because that's how she saw us working with Katie. But of course, as she grew up, there are different levels of awareness that happen. So I'd say probably around four, five, six maybe she started asking questions about how come Katie can't talk, why Katie does this, why does she have seizures and I don't. We always welcomed the questions and spoke about it. Hopefully, in ways that were developmentally appropriate for her in simple terms. Katie's brain doesn't work as well as yours. We don't know why she has seizures but we give her the medications to make it less. We always tried to put somewhat of a hopeful spin on it. So she just sticks up to those. Later on during grammar school, there are more detailed questions. Will this happen to me? How come Susie is like this or whatever? We tried to answer them honestly to the best of our ability. Encourage her to keep asking the questions. It was always right there. We gave her the tools to explain. By us explaining to her in a developmentally appropriate way, she had the tools to explain to other people. I remember being in TJ Maxx or Marshalls something and running into another family. We get a lot of stares because Katie isn't typical. I think they had a four year old who did ask a question. Before I could even answer, Allisa answered for me because we're used to that. So it doesn't --- it presents different challenges at different times, but just being open and honest with her about what's going on, reassuring that it wasn't going to happen to her I think was important. Not all parents have that comfort of knowing that, but we were fortunate to some extent that we did. Their relationship now is somewhat similar in that Allisa is very protective of Katie. Even little slights, gets the fur on her neck up. If she feels like somebody is staring or something or whatever, she will go out of her way to show them that Katie is loved and pull Katie close

and give her a kiss or a snuggle or talk to her. Something to kind of get the message across that this is Katie and she is loved and she is part of our family. She always asks about her. Allisa is living out of state right now. So never fails to ask. When she is here, they spend a lot of quiet time together. Katie is a big snuggler, so we all love our Katie snuggles.

18 | TITLE: Alissa, the sister, is part of the decision making.

https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-and-keeping-the-adult-age-sister-involved/

Description: June MSW, LICSW, ACHP-SW -- mother of Katie (28), who is medically complex and likely has Rett Syndrome -- and Alissa (23), talks about how she is introducing Alissa to some of Katie's systems of care and legal documents because she is an integral part of Katie's life.. "though I don't want her to ever feel responsible for Katie's care."

Transcript:

June: We've made it clear to Allisa that it's not required that she have responsibility for Katie after I might be gone. But now that Allisa is an adult, we have started to introduce her to some of the systems of care and the processes we go through as parents or as guardians of adults. She has come to DDS meetings with me. She has come to evaluate day hab programs with me. She helped pick Katie's new group home. I need Allisa's seal of approval before I make the final decision, not because I'm putting all that burden on her, but because she is an integral part of Katie's life and I want her to have some base understanding. My hope is that she is always overseeing care. I don't expect that --- I don't want her to necessarily have all the day to day responsibilities. If she were to make that choice, we'd have a long conversation about that, but I do suspect and hope and have reason to believe that she will always be involved in Katie's life in some way or another.

Interviewer: If Allisa was here, I would ask her this directly, but she is not, but has she expressed worries or concerns to you about if she were the only living family member of her sister.

June: More like she has given reassurances that she is up for the task. Then me trying to say --- wait a minute, you have a life to live too. I don't want you to have that day to day responsibility, but I'll be thrilled if you could stay involved at least overseeing care. I don't ever want Allisa to feel like she doesn't have

that option. I also show her that she wouldn't be in it alone, that there are people out there who will support her. We have some friends who she could call for guidance. She knows who those people are and not afraid to reach out if she needed to.

We talk about this just like we talked about all the other issues along the way. She knows where the legal documents are and what the trust says and what the wills say. Also knows about Katie's circle of support and who to seek out and who the important contacts are whether it be DDS, day hab, or group home or whatnot.

TITLE: "As a single parent, you are responsible for all those daily care and that can be tiring and exhausting"

https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-as-a-single-parent-the-positives-and-negatives/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, shares some of the positives and negatives of parenting Katie as a single parent. The decision making is easier but it can be tiring and exhausting.

Transcript:

June: Certainly there are times when it would be helpful or you'd want input from your partner or the other parent, and that's a little harder to come by or it's fraught with a lot of emotional baggage at times. But, you know, for me personally I think it's been a little bit easier because I already had that responsibility anyways. With families I work with, I've seen some difficulties when an absent or not-as-involved parent may try to -- may want to have input into critical decisions but then they don't have the base understanding of the day-to-day challenges. And that can be a point of contention. It can also -- as a single parent, one of the disadvantages is you are responsible for all those daily care and that can be tiring and exhausting.

TITLE: Adjusting Expectations-- maybe it's not so critical that we push everything; maybe we set less stressful priorities.

https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-letting-go-of-the-push-and-the-expectations/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, discusses how hard they would work and hope in the early years for progress and a change, how overwhelming the To-Do list was from specialists, and the pressure she felt to be a good parent. And how she had to shift her expectations and give herself

permission to set her own priorities.

Transcript:

June: It's so fraught with like -- what's not being captured is like we would hope for a change and then we'd plan and we'd work so hard on it whether it was OT/PT speech and then it wouldn't happen and the devastation you feel. And at some point you -- whether it's acceptance or whether it's resignation, I don't know but it just -- do you stop trying? It's not you stop trying because you're still doing all the caring, you are still trying to do all the supports but I guess there's a realization that you may not achieve that. And while there is a huge letdown and it can be demoralizing to have that realization, there's also a freeing, a sense of...maybe it's not so critical that we push everything and maybe we are able to set a little bit less stressful priorities.

I remember when Katie was little and, you know, I would come and the OT would work with her and say, "No I want you to do just these two things, this and this, and tell me how it goes next week." And I'd go, "Oh okay, you know," and -- and the teacher would come and say, "Make sure you're trying doing this during feeding." Oh okay. And then who else? Speech or somebody would say -- and give another little homework. And each one was very reasonable. But by the end of the week, I had 12 things I needed to try in addition to giving her, you know, 14 medications, four times a day and remembering the timing of which one goes where and it's like it became absolutely overwhelming and yeah I felt like I had to do everyone of those things to be a good parent and eventually you realize you just actually can't.

I mean maybe some women in families can but I couldn't and so I had to kind of start taking that information in, not just regarding it but using it to figure out what my priorities are for Katie and what, you know, my partners priorities were for Katie and put the most attention to those. Even that had meant that some days I had to say, "We didn't try that this week" or "No I didn't get to that."

TITLE: Finding balance: "I think some of the peril that parents feel is that every decision you make is the critical decision."

https://courageousparentsnetwork.org/videos/parenting-a-medically-complex-child-and-finding-balance-not-every-decision-is-critical/

Description: June MSW, LICSW, ACHP-SW, mother of Katie (28), who is medically complex and likely has Rett Syndrome, shares the peril that parents feel that every decision they make is a critical decision and that there is always more medical consults they could do. "I encourage families to think about who their most trusted providers are who they feel will help them make the best decisions."

Transcript:

June: I think some of the perils of parenting is feeling those pressures that every decision you make is the critical decision. Sometimes they are critical decisions and sometimes there are other options to be considered. And sometimes that option is, you know, allowing things to be. It's not pursuing additional treatments or interventions. I know as a young mom I felt a lot of pressure to make the right decisions and I guess with time you kind of learn that you make the right decisions or the best decision you can at the time and you just adjust to the ramifications of those decisions, you know, and in most decisions many decisions can be changed if they don't work out.

And so that brought me some comfort over time. I think somebody told me if you see a surgeon you know they are going to recommend surgery because that's what they do is cut, and I think one of the perils is see another doctor, falling into the trap of wanting to see another doctor or get another specialist involved and certainly that has value at times but at other times it's just complicating the situation by getting another three sets of opinions to consider. So I encourage families to, you know, think about who are the most trusted providers? Who are the ones that have the best sense of not only the child but the overall family situation that you feel will help you make the best decisions possible without running into that trap of having to seek second third, fourth, fifth opinions, and -- because that can be so draining and so confusing.