**Participants:**

Holly Carmichael

Michael Murray

Ashley Mathy

Dr. Allison Hall

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**Introduction:**

A garrison is a safe place where an army gathers. In the same way, the *Disability Garrison Podcast* is a place for the army of disability rights advocates to gather and discuss complex issues. We are unafraid to identify problems in our world and have difficult conversations about them. But we are not just here to complain. We spend our time brainstorming solutions with generals in the disability rights movement. Together, we take action to make positive change and lead the fight for justice and equality.

**Holly Carmichael:**

My name is Holly Carmichael.

**Michael Murray:**

My name is Michael Murray. This is the Disability Garrison.

**Holly Carmichael:**

Welcome Disability Garrison listeners. Today we are going to be discussing and talking about guardianship, more specifically alternatives to guardianship. First, we're going to listen in and hear from Ashley, an advocate from the state of Wisconsin. And she's going to share about what her experience was under guardianship. So let's listen in.

**Ashley Mathy:**

Hi, I'm Ashley Mathy. I'm 26 and I'm a self-advocate and I live in Wisconsin. I've actually spoken around the state, and I'm a professional public speaker. I've been speaking for about five years. I graduated from Partners in Policymaking in Wisconsin. And I think speaking is probably my favorite thing to do because you get the energy and the crowd. And you can totally tell when you use an enthusiastic voice. And when someone talks monotone, everybody's ready to sleep. So it's like the whole crowd. It's so energizing. That's my favorite thing to do. But I had an opportunity a couple of years ago, an agency that I was actually a client. And said, Ashley, you’d be really good as a mentor. So then I started working for them, and now I'm a mentor for the Youth Voice Youth Choice Group.

I was at an event where some boys were interested in me, and someone came up to my mom and told them that I needed guardianship. So then they were very scared about that. So they ended up getting SSI and guardianship, and I didn't know much about any of it. And I had just gotten my first job, so I kind of just went along with it. But I never knew the restrictions that guardianship would have given me. Because choice matters when you have a disability or you don't have a disability. Choice making is so important, and you just need to be taught the right decision-making skills. And then you can make choices on your own, and then ask other people for help. It's so dehumanizing to be under guardianship, so I don't want anyone else to be under it. And I want to show people that they can do their own decisions by themselves, and I want to show them that I'm under guardianship, so don't get guardianship. So I guess that's me kind of living through them kind of thing and showing them before they go into something that's not good.

I can't hunt because you can't have a firearm when you're under guardianship, and your parents have to decide if you get married or what kind of boyfriend you have kind of thing because the court says you're incompetent to make those decisions for yourself. I thought that it was just going to be just like had a few things made for me and that it wouldn’t be like all my life and stuff like that. It wasn't like a set in stone thing. But as soon as you are actually in it, you understand that it is more of a restriction thing. You know what I mean? Like when you want to date someone, you have to go to your parents and say, Can I date someone or can I marry someone? I mean, obviously some people want to ask their opinion about it. But when you're in guardianship, it's more of a restriction measure than a oh, I'm going to ask this person, I ask this person, I ask this person. I mean, I want to be able to do things like my family does and not like be restricted and stuff like that. I know I'm going to make mistakes along the way, but I mean, I don't know anybody who's not made mistakes.

I guess neither one of us, me and my mom, both didn't know when we went into it that it was going to be so restrictive. And I mean, my mom's a great mom. She is supportive. She drives me to speaking events. She's supportive and stuff like that. But I think that we both didn't know what we were getting into because she kept reassuring me. She said, Ashley, I have guardianship, but you know that we'll help you make your own decisions and stuff like that. But I don't think neither of us really knew what we were actually saying yes to. And now that I am 26, and now it's a long process to turn this around now. But people need to be very matter of fact on what they're getting into with guardianship. You know what I mean? Don’t get it. It makes you feel like you're locked up in a box, that you're not going to get out of it for a long time, and that you can't make your own decisions and that you feel so little of yourself like all the time. And you don't want to be restricted. You want your kid to live a full life. And she's probably or he is going to like live a life that they want to, but it's not going to keep them safe by being on guardianship. So just don't get guardianship.

**Holly Carmichael:**

I think this is a critical and timely topic. I know for me, I'm working on some long term planning in terms of what happens for Maggie after I die. I know talking about death is somewhat morbid. But it's an important topic when we discuss in terms of people with disabilities and what that looks like for them. So our guest today, Allison, we'll let her give a little introduction of herself. But today's topic is alternatives to guardianship. So, Allison, why don't you tell our listeners a little bit about who you are and kind of how you came to be a guest on our podcast because of this topic.

**Dr. Allison Hall:**

Sure. My name is Allison Hall, and I'm a researcher at the Institute for Community Inclusion at the University of Massachusetts - Boston. And I think the way that we all got connected was through one of our project officers who funds a particular project that we're going to be talking about today. So the project is funded by the Administration on Community Living, and it really gives us an opportunity to highlight the voice of youth, youth with intellectual and developmental disabilities. So a lot of my work has been around supporting youth and families to identify alternatives to guardianship. And what I mean by that is really just decision making, helping youth and adults seek the support they need to make decisions about their lives. Because we all seek support. I'm not going to buy a car by myself. I'm going to ask a lot of people for their opinions. So we need to be thinking about people with disabilities as needing the same type of support or sometimes more intensive, but it could look different. But that people with disabilities could just use the same kinds of supports that we all use.

**Michael Murray:**

I love it. I love it. And as GT, we are always talking about your life, your choice. It's at the bottom of our logo, and it is a firm belief that we have. So we just heard from Ashley, who had such a powerful, powerful story to kick off this podcast. Truly impactful. I would love for you to just spend a minute and frame up the issue. Why are we talking about guardianship?

**Dr. Allison Hall:**

So this is really a critical issue that I became acquainted with. I've been in the field about 22 years now working around community inclusion and community integration for people with intellectual and developmental disabilities. And I think that a lot of families think the idea of guardianship is just a natural progression of them advocating for their children all throughout their lives and in the education system. And then a lot of families believe when their youth is approaching age 18, that they need to think about the future. And of course, they do. But often that can be from people telling them that you need to get guardianship for your youth or the parents talk to other parents. The parents might talk to their pediatrician who says you need to get guardianship in order to stay engaged with medical decisions. They might talk to school personnel, and they say, you need to be involved. You need to be a guardian in order to make educational decisions or to stay engaged. But that's not true, because there are a lot of other ways that family members can stay engaged and support their family members without resorting to guardianship, which families don't even realize sometimes how that can strip away an individual's rights and autonomy and how hard it is to reverse.

**Holly Carmichael:**

Yeah, yeah. Maybe talk about that a little bit for our listeners of like what does guardianship mean? What does that entail? What does it strip away? And how would you, if you wanted to reverse it, what does that process look like in terms of somebody reversing it?

**Dr. Allison Hall:**

Well, as I said, guardianship has always been a way that family members can try to protect people with disabilities. But there are just so many rights that people lose when they are under guardianship. In many states, they lose the right to vote. They can't decide who they live with. They can't decide who to marry. They don't make decisions about their healthcare anymore. And it really compromises their self-determination in terms of trying to terminate a guardianship or to reverse a guardianship or restore someone's rights, it is a very, very challenging process. There are what's called P&A's, protection and advocacy agencies, in every state, also funded through the Administration on Community Living. And a lot of the work goes to them in some cases when somebody wants their guardianship reversed. But it is so complicated. We have stories on our partners’ websites about how long it takes to reverse a guardianship, the paperwork, going to court.

It is a very complicated process. And I think sometimes family members, and I know this from research that I've done with parents, sometimes family members who are so interested in community inclusion and future outcomes and deployment in the community, they don't think guardianship impedes that. And if you look at the research, it actually counts. And I think parents also feel like, oh, my kid is turning 18, he needs a couple more years of decision-making experience under his belt before I will let him loose in the world. But guardianships, very often, I mean, very often they don't get reversed and they are permanent and they're very hard to change. So I think parents might see them as more of a temporary option when really it can be much more long term and have important long term negative implications.

**Michael Murray:**

And I think it's really important for all of the folks in the Disability Garrison to realize that families are trying to make their best decisions based off of the information that they had. And Allison, you really helped us also view this in this perspective of where we have no criticism for anybody, whether you're you make a different decision or what decision you make as it relates to guardianship. But we firmly believe that everyone, everyone deserves the right to understand the decision that is being made and that if there's one thing that we want to fight for right now is that all of you at the end of this podcast would understand the impact that this decision can have, and also, that you have alternatives to that decision. What are those alternatives and how can they have a positive impact? But I think before we get into that, I do think it's worth us just diving in a little bit, because there are some stories of people who have had really negative experiences with having a guardianship and how that impacted, like you said, their self-determination. I wonder if, Allison, can just talk about that a little bit.

**Dr. Allison Hall:**

I would like to share one story about Jordan. He's one of our youth ambassadors for one of our projects, civic projects in Youth Voice Youth Choice. And he had never heard of alternatives to guardianship. And his guardianship hearing was the next day. He was at a self-determination conference, and he learned about alternatives to guardianship. And he went home and spoke to his parents and he said, I don't think I need guardianship. And his parents that night became educated and thought, huh, look at all the rights that will be taken away if you're not your own guardian. So they went to the hearing the next day, and they did not pursue guardianship. And now he's using supported decision making, which I'll talk a little bit about. And he is just, I mean, he's working. He's so busy. He's doing so many things. But he really took the time to learn about what's available for him and so did his parents. And his parents were open to it.

Another situation, another colleague I have, she had tried to talk to her mother about alternatives to guardianship, especially supported decision making. And what's really interesting here is supported decision making sometimes can involve a lot of different people because you ask different people for help in different areas. So here's one young woman who wanted to pursue supported decision making, and her mother didn't really have her head around it yet. And her mother didn't really understand the idea of asking others for support. So this woman enlisted her aunt and said, Hey, I really need you to talk to mom and explain that these are the supports that I need. So this young woman was so resourceful, and she put together a team where she has supporters who help her make healthcare decisions, who will help her with her college schedule and identify what classes she wants to take. So I just think that when people have access to the information they need about options, it can really open up their whole world.

**Holly Carmichael:**

I love-love that. She used supported decision making to explain to her mom what supported decision making is.

**Dr. Allison Hall:**

Exactly, exactly.

**Holly Carmichael:**

Yeah, yeah. I think, Allison, you really hit the nail on the head when you talked about it's really a lack of information out there in terms of—and there are these I would say even not so subtle pressures for parents with disabilities or for parents of children with disabilities to pursue guardianship. I know for my own daughter, Maggie, she's eight. She's only eight. And I've been approached about what are you going to do when she turns 18 in terms of pursuing guardianship, whether that's through lawyers, in terms of doing end of life planning for ourselves, and kind of who's going to be the alternate guardian and setting all this up just as an assumption of because she has a developmental disability, that that's what you naturally do. And I brought up supported decision making. And I'll tell you, the attorney I worked with had never heard of it, had never heard of it. And even I think at the judicial system level, when we look at these judges who are granting guardianship, I remember looking at the cases of a particular judge in our county working with individuals, they always only did full guardianship. And what are the odds? What are the odds tell me that every single guardianship case that this judge has seen always only needed full guardianship? There was never a limited guardianship.

And so I think in this case, there needs to be a massive information campaign in terms of, of course, the self-advocacy information is the most powerful, educating individuals on what their options and rights are, but also from the legal and judicial side of we shouldn't just be blanketing. And I know there was a lot of press that was gained with the Britney Spears case, which wasn't necessarily guardianship, but conservatorship. And I know you also talked about supported decision making, too, in your examples. So maybe walking through what are some of the differences between full and limited guardianship, conservatorship, supported decision making? Just kind of what are these differences, nuances between these options and how do they better, in your mind, support somebody to maintain their rights, support their ability to self-determine their own lives and destiny like we all want to?

**Dr. Allison Hall:**

I think that concept of self-determination is probably the most important one. And the idea, it's kind of like on a continuum of to supporting self-determination and limiting self-determination. And full guardianship would be all the way on one side in terms of limiting self-determination. Full guardianship means that the person doesn't have control over all aspects of their life. Limited guardianship means that the person relinquishes control of some aspects of their life. Maybe it's financial decisions or maybe it's healthcare decisions. But if you look at research, more often than not, full guardianship is being granted as opposed to partial or limited guardianship. So very often, as you said, judges are making the decisions around full guardianship. There is work being done, one of our partners, the Center for Public Representation in Massachusetts, they do work training judges. And so there is a lot of work being done with the legal system. Another part of our project—

**Michael Murray:**

Can you say that partner one more time so that our listeners can check that out?

**Dr. Allison Hall:**

Yes. The Center for Public Representation in Massachusetts and their website is www.SupportedDecisionMaking.org. That's great.

**Michael Murray:**

And we'll put it on to our website as well. But man, what an awesome work that they're educating judges.

**Dr. Allison Hall:**

Yeah. And they're attorneys, and they're really a key partner in our center. So I was talking a little bit about the differences between full guardianship and limited guardianship. But then there are alternatives to guardianship. Supported decision making is a really great one because no rights are taken away from a person with disabilities when they're using supported decision making. I think in about 13 or so states, there's formal legislation around supported decision making. But you can use supported decision making in any state. You don't need to have a formal policy. It's great to write things down in a plan, but really, it's just a person's plan regarding who is going to be supporting them and in what circumstances of their lives. So even with healthcare proxy and power of attorney, you are moving decision making power from the individual to another person. And in some cases, that may make sense. But supported decision making, you're there as a supporter, and you are not saying that the person is out on their own and is making their own decisions. Because, again, what I said in the beginning is no one makes decisions in isolation. We have family. We have friends. And that's really an important piece of what supported decision making is. And I think sometimes it can be hard for professionals, for attorneys, for doctors, others in the healthcare field to wrap their head around what that means, especially when they're used to seeing guardianship in place.

Another thing I wanted to comment on is that idea, Holly, I think you said about assuming that guardianship is the next step. And you encountered that. Some of the self-advocates that we work with talk about the issue of presumed incompetence and that that's what they deal with and that that's what youth with disabilities deal with in a lot of these conversations about turning 18. And sometimes we refer to this time as the transfer of rights. That's more of an educational term where the decision-making authority around the IEP transfers from the peer to the student because the student became an adult. But the transfer of rights time is the turning 18 time. And it's a challenge when youth can go up against that presumed incompetence.

**Holly Carmichael:**

Yeah, you are so right, Allison. And I think in addition to presumed incompetence, we hold, as a country, we hold people with disabilities to a higher standard to essentially earn privileges we all automatically get. So even my daughter, Maggie, of trying to get her, we had to work really hard to get her into a typical classroom. And they said, well, she has to prove that she can handle all day first. Well, did any other student have to prove that? Or when we look at adults getting spending on a card, did you or I have to prove anything before they granted us a credit card or a bank account? There's this bar that’s set of well, we have to show that they're ready first. And we should not be holding them to a different standard. Part of self-determination is involving freedom. And that's freedom to take risk, that's freedom to fail, that is freedom to do things, make a different choice than you or I would make. And everybody, everybody, all of our listeners, you all have you supported decision making yourselves. You have gotten advice. You have gotten feedback on how to do things. This is about treating people like people, having dignity and respect that everybody has this inalienable right to make choices and have control over how they live their own life.

**Dr. Allison Hall:**

And allowing people to make mistakes. I mean, we all have that right to make mistakes. And I think that sometimes parents feel—and this was in a video of another self-advocate who had his rights restored. He said that sometimes parents can feel that guardianship is a magic shield to protect their children so they won't get in trouble or they won't see any harm. But there's no studies or anything that shows that guardianship is that kind of magic bullet that will protect people from harm. And sometimes there's actually some negative things associated with guardianship.

**Michael Murray:**

I think as a person with the disability myself, the desire to be able to step out there and to try things and that dignity of risk, that willingness to be able to fail is so important because if you don't fail, you're not going to learn. And so I think we all deserve that right. I just want to come back really quick. You said there are 13 states that are putting in legislation to try to outline what does supported decision making look like. And as the Disability Garrison, one of the things that we love to do is give people actions that they can take in order to have an impact on an issue. I just wonder if you could tell us a little bit about that legislation or some of those things that exist out there.

**Dr. Allison Hall:**

Yes. So some states, as I said, some states have legislation. And some states have very robust supported decision-making initiatives and grassroots efforts, and they haven't made it to the legislature yet. And some states have their legislation from 2015 and haven't really made all that many strides with respect to sharing information about alternatives to guardianship. So certainly that is one way. I mean, your listeners could, again, at SupportedDecisionMaking.org, I believe is a list of states that have legislation. And what's nice about those states is that they'll have forms, so something tangible that families can look at and say, okay, here is my supported decision-making plan, and I'm going to bring it with me. I'm going to print it out, and I'm going to bring it with me and take it to the doctor and I'm going to explain it to the doctor so the doctor knows that here's the person who supports my kid in terms of these decisions. But the decisions are still his own.

**Michael Murray:**

So good.

**Holly Carmichael:**

Does that mean you could never, now you're turning off your option of guardianship down the road? Like that you can never pursue that option?

**Dr. Allison Hall:**

No. And I think supported decision making is probably—one of the most positive things about it is it can evolve, and people’s support needs change, and thus, their supported decision-making agreements and plans and supporters can change. So I think it's probably one of the most flexible options that people can go with as opposed to guardianship, which, as we said earlier, is super hard to reverse. So I think—

**Michael Murray:**

And it just makes sense, right? Because I have supported decision making in my life as I think we've established that we all do. And those people change throughout my life. And so if I had one person that was there to make all of those decisions, that would be helpful. Yeah.

**Dr. Allison Hall:**

That gives somebody too much power I think.

**Michael Murray:**

It does.

**Holly Carmichael:**

Yeah, yeah.

**Holly Carmichael:**

Well, one thing I wanted to comment on, Michael, you talked about your right to fail. And what's also really important is supporting kids to be able to learn how to make choices early because having the right to fail is important for all of us. But we need practice. We need practice to understand how to make decisions. And even typically developing 17, 18, 19-year-old kids are going to make some poor decisions. So we need to support our kids to be thinking about making—how do we support them to make decisions? And again, Holly, your daughter's only eight, and it's something to be thinking about now. How do I make sure she has the skills she needs for when she does turn 18 and is in control of her own life?

**Holly Carmichael:**

Yeah. And you even alluded to earlier that sometimes the school system can be one of those subtle pressures in terms of encouraging guardianship. And I think it really does start at the level of the IEP. First of all, I strongly believe that if it's somebody's IEP, they're the I in IEP. They have to be at the meeting and need to be at the table regardless of their age. I know for my own daughter, Maggie, who's eight, we're scheduling the meeting, and they're shocked that she's there and I'm referring questions to her and talking with her. And is she always engaged in participating? No. Sometimes it's coloring on the IEP. But it's a matter of starting at that basic piece of nothing about us without us. And in terms of, like you said, we have to practice decision making. We all get that chance. And so if you're a parent of a child with a disability, including them at the start and discussing those things at age appropriate level and supporting them along the way as they grow to be good self-advocates can help set you up in the long run in terms of hopefully you are blessed enough to have your children outlive you so you want them to learn those skills and grow.

**Michael Murray:**

And same thing, my father invited me into my IEP meeting in third grade, and it was incredibly influential because I got to make decisions about my life. I got to see what was happening. I had an understanding of this process. And it was so incredibly valuable. And I think that choice is something that we all inherently want. If I tell my son—I have a four year old—if I tell my son what to do, he will most likely automatically buck me even if he wants to do it. If I give him an option, like he's going to share the cupcake with his sister, are we going to cut the cupcake this way or are we going to cut it up and down or left or right? You get to pick which way we want to cut it. And now all of a sudden, I've got a choice, I've got a decision. And so I think, again, just we do this in so many ways, and it's just good practice regardless. We all want choice in our lives, and making sure that that is an opportunity for all of us is so vital.

**Dr. Allison Hall:**

Another thing I just wanted to talk briefly about is being invited to your IEP meeting in third grade, that's setting some high expectations early. That was your father setting the expectation that my kid can participate, and it's going to be a difference in his planning. And parental expectation is such an important predictor for post-school outcomes for you including around decision making. And we need family members to think, yep, my kid can do it. And I think as a parent myself, it's hard. It can be hard to like shift into the mindset of my kid, with the right supports and the skills and experiences, my kid can make decisions. That can be really hard. But I think as a disability community, we all need to start there.

**Michael Murray:**

Yes.

**Holly Carmichael:**

And I think we all need to— you're right. Even as parents, so I myself feel like I strongly see Maggie as capable in fact for her IEP. This one pager, I put a picture of one word, capable. I wanted them to pull away from her. And I like to think, I most definitely see and champion Maggie as capable. And my son Dexter who is on the autism spectrum, he has an IEP himself, and he's very thoughtful and insightful. He was sitting down with me at breakfast the other day, and I was working. And he said, Mom, who do you think is going to be the CEO at GT Independence once you retire? And I said, I don't know. What do you mean? He's like, well, I think it should be Maggie. And I just realized, it just really touched me so much that he sees her as capable. And I had to check my own self because, I mean, she's certainly could be CEO. And here I was probably limiting that in my own mind to some extent. And so I think you're right. Parental expectation can be a huge factor. And I think that information campaign and working on helping educate parents at the very early stages is crucial.

**Michael Murray:**

I love it.

**Dr. Allison Hall:**

And not just educate so much as—certainly educating parents is really important, but some of the work we do is targeted at youth and we train youth ambassadors. Right now, we're working in eight states, and we're training youth ambassadors. And there is this one young man who's been participating with us. And his mother, we do it over Zoom and usually his mother sits to the side. You can't see her. But towards the end of the training, she kind of came in and said, This has changed me. And she has experienced her son's goals and expectations for him so differently because he has become such an advocate and is able to use supported decision making to just advance his life and things that he thinks are really important, like the right to vote. And he's an incredible advocate for voting in Georgia, and he's also an artist. So if you go to our website, you can see some of his advocacy through his comic strips. And I mean, it's so amazing just to see how his voice has really been held up through his artwork and now he's able to advocate for issues that are really important to him. And his mom was able to recognize that and say, Yeah, I really learned something different here.

**Michael Murray:**

If you could give one sentence to teachers, lawyers, medical professionals as they are figuring out or deciding what do I say in those things? And maybe they've pushed for it, and they don't necessarily believe you or believe what we're saying today. Do we have a parting word for them?

**Dr. Allison Hall:**

Guardianship should be a last resort. And there are so many other avenues to go down in terms of supporting youth and young adults to make decisions and live their lives.

**Michael Murray:**

That’s so good, so good. Allison, thank you so much for joining us and being a part of the Disability Garrison in our fight for justice and equality and self-determination. It was truly educational and inspiring, and I am stoked to ensure that everyone has the right to make those decisions about their lives. Thank you.

**Holly Carmichael:**

Wow. What an amazing discussion with Allison. Just so many things to think about. I hope that this episode gives you some thoughts into alternatives to guardianship, and I encourage you. We always want to close out our podcast with actions that you can actually take. And so our first action is to make sure you are aware of alternatives that are available in your state, to make sure if you are a person with a disability, share your wishes with your family. Guardianship is not the only option. If you're a parent like myself, make sure you are becoming aware and encouraging your child as they grow and develop and become adults, that you know what the options are, and that you're informed. There is a website we want you to visit called SupportedDecisionMaking.org. This lists each state and what the laws are, and you can go through that website with your family member and determine what the best option for your life is. And just know that guardianship isn't the only option.

A second action in terms of a really state specific and legislative action in Massachusetts. If you are a person who lives in Massachusetts or you have friends who live in Massachusetts, friends or family, there is legislation pending a bill that would allow people with disabilities and those that are elderly to enter into supported decision making. This helps them go with people that they trust and know to help them make decisions just like you or I do and use every day. The bill has safeguards against abuse, and if it's passed, what it would do is require that supported decision making is considered first before just establishing guardianship. It would make sure that youth that are turning 18 are aware of supported decision-making options at their IEP meetings. There are some great resources linked on our website that you can see from the Arc of Massachusetts. So if you go to GTIndependence.com and find our Disability Garrison podcast episode, you can find that information there. Just a great piece of legislation. And it could be if you're not from Massachusetts, a great piece of legislation to potentially model it in your own state and advocate for.

And then lastly, there is a great organization that we want to support for this episode called Self Advocates Becoming Empowered. Their mission is to help ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up and empower themselves, that they have opportunities to make new friends and learn from their mistakes, just like we all do. They are working hard to eliminate institutions across the United States, working hard to achieve national healthcare for all among many other things. Feel free to check them out. Self Advocates Becoming Empowered at SABEUSA.org. Thanks for listening in.

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