The Wayne RESA Roundtable Podcast S1.E4: Least Restrictive First: Rethinking Guardianship in Michigan with Representative Sharon MacDonell

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SPEAKERS
Sharon MacDonell , Beth Santer

Beth Santer 00:14
Welcome to the Wayne RESA Round Table podcast, a space dedicated to sharing valuable resources and insights with our educators and families. I'm Beth Santer, one of the Wayne RESA facilitators, who will be joining you for this conversation. Today, I'm excited to be joined by Michigan State Representative Sharon MacDonell, who has been a strong advocate for protecting the rights and dignity of people with developmental disabilities. Representative MacDonell recently introduced House Bill 4676. It's legislation that amends Michigan's public health code to ensure that when guardianship is considered for an adult with a developmental disability, courts first look at the least restrictive alternatives. This bill emphasizes alternatives such as supported decision making, trusts, representative payees and limited guardianships, ensuring that guardianship is only used when truly necessary and only to the extent needed. The goal is to strike a balance between protecting individuals and preserving their independence, autonomy and voice in their own lives. Today, we'll talk with Representative MacDonell about the motivation behind this legislation, the changes it would bring to Michigan's guardianship system, and what it could mean for families and individuals navigating these deeply personal decisions. Welcome to the program, Representative MacDonell.

Representative MacDonell 01:37
Thank you so much. Beth. I'm really happy to be here.

Beth Santer 01:43
So guardianship, power of attorney, guardianship, all of these issues have been a hot topic for a while. I know that I recently did a different podcast with Eileen Brandt where she talked about guardianship and power of attorney. So this segues very nicely this house bill. So what led you to become interested in this topic?

Representative MacDonell 02:03
You know, just to go a little bit backwards in history, which is about two years ago, when I was elected, I decided one of the things that I wanted to talk about, I wanted to be part of the legislation that I work

on, is about disability issues, because at the time, I was thinking, because I grew up with a disability, I have rheumatoid arthritis from four years old, and although that doesn't sound very bad, and I'm very lucky, I've been able to do everything in life I've wanted to do, but I have lived in that world of being bullied for what I couldn't do and not getting accommodations I needed, and it was a long time ago, so that was at a time when there just it was unheard of to ask for accommodations. It was just the beginning of what we called at that time, mainstreaming in public schools. So I thought I knew a lot about disability issues, and every day I learned how little I know and how much I want to know more and how much need there is for better representation of people with disabilities. So when I got into office, we decided to start the Michigan Legislative Disability Caucus, and the people who I work with on that caucus were one of their top subjects, and their interest in legislation moving forward was supported decision making and hoping that we could get it done and get it passed. And another office had those bills at the time, but they decided to give them to us. They thought maybe we could put some more energy into them. And then I met Linda Vanwormer and her sister, Amy Pekinpaugh, and they're kind of the great evangelists in Michigan for supported decision making. There was a channel news story about them that is really wonderful. If anyone can find it. I could give that link to you if you'd like to share it in the notes, but it just showed exactly the problem people have sometimes with guardianships, where they can lose all of their rights and not get to make any decisions. And in Michigan, as your other guests said, you know, we have, I think, too many guardianships. So it was a very powerful story, and Linda is the first person in Michigan who was placed under what's called supported decision making arrangement in probate court, and now she and Amy, her sister, are fighting to give all Michiganders with IDD's and their loved ones this option. So I'm just so impressed by them, and so honored to be a partner in their effort to make this more available to Michiganders.

Beth Santer 04:43
Well, thank you so much for sharing your personal story with what led you to this, but…, and we would absolutely love to have the link you spoke of. We would definitely push that out. And you're right, supporting decision making and least restrictive environment, not just in this arena, but least restrictive environment in general, gets a lot of conversation and discussion as we make sure that we have the appropriate access for our students and adults with disabilities. So can you explain, in plain language, what House Bill 4676 is, and why is it important?

Representative MacDonell 05:18
Well, we're all familiar with the idea of guardianship, a lot of us in our families, it's it's the seniors in our family who face that. So when someone is no longer able to take care of themselves, physically and or intellectually, they may need a guardian to make important life decisions for them, and that can be someone they know, or even a professional chosen through the probate court system. Often that might be appropriate for someone with, say, dementia, when their abilities are getting progressively worse and it's known that they will not get better. But a guardianship is really, usually, an all or nothing proposition. The Guardian assumes all the power from the individual, and the individual ends up with little to no say in legal matters. So, adults with intellectual and developmental disabilities or IDD's have a range of abilities and competencies. But today, when a judge considers a guardianship for a person with an IDD, the court doesn't have to consider that. They don't have to consider whether less restrictive options might be better for them, even though, of course, no two people with IDD's have the same needs. So the philosophy behind supported decision making is that people with IDD's need different degrees of assistance to live safely, and therefore the courts should consider their individual needs. It's a very… it's a very simple idea and a very fair and it's about individual freedom too. So perhaps some people may need a full guardianship, but others may not need that much. And like you, I believe that people should have the greatest degree of freedom possible to make their own choices while still staying physically and financially safe. So my bill does two main things. First, it requires probate courts to consider a variety of other less restrictive options before assigning a person with an IDD to a guardianship. And these, as you said, can include attorney trusts, representative payees and

other options. And to put someone under a guardianship, the court would first have to affirmatively consider these other options and actively rule them out. That's kind of the point that it's not just they get to, you know, they talk to them, as your guest said, for three minutes, and decide the rest of their life. But they have to get to know them a little bit and understand what this individual needs. The second thing the bill does is add the term “supported decision making” to Michigan law as one of these options, and in supported decision making or SDM, people with IDD’s work with loved ones and professionals to understand the choices they need to make, but they ultimately are the ones making the choices. So, no one has the right to make choices for them under this formal agreement. So you can think of it as the least restrictive of all the alternatives to guardianships, at least that go through the court. So if this bill is made law, Michigan will join 29 other states that currently recognize SDM in some form.

Beth Santer 08:21
I definitely appreciate that it seems like a more inclusive and comprehensive process than like what you were referring to when Eileen talked about that three minutes of just getting the basics before you make that decision. So, let's talk about gaps or problems. So what gaps or problems in Michigan's current guardianship process does this bill aim to fix?

Representative MacDonell 08:46
And it's really very simply… that we have this problem that courts today do not have to consider each individual's needs. Instead, they treat all people with IDD as if they're a single entity, and that just doesn't reflect the reality of people's lives. So in states that require a discussion of other options at courts, the really good news is fewer people with IDD end up assigned to restrictive guardianships. These individuals can have more freedom to make their own decisions, and that's what we hope for Michiganders with disabilities, that they too can have as much freedom as legally possible,

Beth Santer 09:24
Absolutely. So, this bill emphasizes using the least restrictive alternative, and you spoke about what that meant. But why is that significant for individuals with developmental disabilities?

Representative MacDonell 09:38
While people with IDD often need the support of others to be physically or financially safe, there are degrees to it sounds like I keep saying the same thing, but that's because that's the point. Not everyone needs a guardianship where people lose most or all of their ability to make decisions for themselves. So if someone is placed under guardianship, when a less restrictive option would work fine. They're really being deprived of their freedom for no good reason. They should have as few restrictions placed on them as possible to promote their safety. And our court system needs to maybe modernize a little bit here in Michigan and recognize that IDD is not a singular diagnosis, it is a spectrum, and that we need to find the best option for each person, one person at a time.

Beth Santer 10:27
Yeah, that's like a that uh… That's a thinking that all people that work in special education have is that individualization, for every decision, because everybody is different and unique in terms of what their needs are. So what are some of the alternative supports, like supported decision making trusts or representative payees that courts must now consider before appointing a guardian?

Representative MacDonell 10:54
And again, what's amazing is now they don't have to consider anything else.

Beth Santer 10:59
Hm..

Representative MacDonell 11:00
It tends to be either zero or 100. It's either no guardianship or a guardianship

Beth Santer 11:06
Hm…

Representative MacDonell 11:07
So courts today in Michigan do not have to consider any of those options before appointing a guardian. Under my bill, courts would have to consider these options. They would have to in addition to guardianships, attorneys, in fact, trustees, representative payees, assistive technology and supported decision making. But right now, unfortunately, they don't have to do any of that.

Beth Santer 11:31
Hm., so, we know that when we're talking about something that can look a little different in practice. So can you explain how supported decision making works in practice and how it differs from guardianship?

Representative MacDonell 11:43
Yes, supported decision making is very different from guardianships. And also that's I'll put in another plug for the news story we're going to share with people about Linda Vanwormer and her story. But under a guardianship, you fully lose all or some rights to make decisions for yourself. Your guardian might control how you spend your money, whether you can start a romantic relationship where you live and more and there are some cases in Michigan, I mean, in the last five years, where people actually have someone swoop in, take their house away from them and just and just take everything away from them, because we have so few regulations for…for guardianships. But if your guardianship has the right to make decisions about a given area of your life, your input is considered pretty irrelevant. So compare that to supported decision making, where at the very beginning, the person chooses their support team, it might be made up of a sibling or two and some friends, maybe, who have some professional experience, and even professionals who they trust, who they can go to to get help, understanding the decisions they have to make. And they can consult with their team on an as needed basis. And after gathering input from their support team, they get to call the shots, and no one is making the decisions for them. The exact level of formality in SDM arrangements varies by states, with some requiring formal paperwork to be drawn up and submitted to the court stating who is on someone's support team, while others don't require any documentation. And my bill has no paperwork requirements to minimize the administrative burden.

Beth Santer 13:25
Hm, so any decision that parents with children with disabilities make is always something that they have to balance independence but also a fear for their safety and well being. So how does this legislation protect the rights and independence of adults with developmental disabilities while still ensuring their safety and well being?

Representative MacDonell 13:49
And yeah, again, it's the very essence of what the bill is. It ensures that courts work to find the best balance between protection and freedom for every person with IDD by treating them like the unique individuals they are, which is so important to all of us. So depending on every individual, strengths, needs, capacities, et cetera, they will fall somewhere on the spectrum of DD and certain support systems will just work better for them than others. So some might be restrictive and others too permissive, but my bill neither sacrifices safety for the sake of freedom or vice versa. It just aims to maximize both.

Beth Santer 14:27
Sounds like it's just making sure that we consider everything

Representative MacDonell 14:32
Yes.

Beth Santer 14:33
So what does this bill mean for families who might be considering guardianship for their loved ones? How might their process change?

Representative MacDonell 14:40
If you believe that guardianship is appropriate for your loved one, you can still petition for guardianship. That won't change. All that's going to be different from current law is that during the hearing, the different options that we're talking about will have to be considered in addition to guardianship. If the court believes that guardianship is best, they will still be appointed a guardian. It will not change any of the authority that the probate judge judges have. It will just require them to consider a little more broadly how to best help this individual.

Beth Santer 15:15
So it doesn't close off options,

Representative MacDonell 15:17
Not at all.

Beth Santer 15:18
If the spill becomes law, what additional steps do you think Michigan should take to continue improving how we support adults with developmental disabilities and living independently and with dignity?

Representative MacDonell 15:29
That's a great question. There's a lot going on. I'll put in a little plug for my MLDC meetings. They're monthly, and we bring in people with disabilities and professionals and everybody wants to talk about ways that we can make individuals with IDD’s and disabilities have more independent lives and more dignity in what they do. One example of that is actually a parent group. I know one of the parents out of Troy is working a pilot program right now called Tech First. And I don't know if you've heard of that, but Tech First is an idea to create, like a smart home, which can be an apartment too, where one or two people with any kind of disability could live, but they'd have some technology in there to make sure that they're living safely. And when people start talking about this, they think, oh, no, that means cameras and somebody watching. But what it is is if, if you forget to close the door when you come inside, or you forget to lock the door, an alarm goes off to remind you so you don't have a person who has to be there to lock the door behind you, you get a reminder, or, you know, it safety in what you're doing on your computer, or safety in how you're cooking in the kitchen, just different forms of alarms and information that can be helpful to the people. Right now, obviously we have a lot of trouble with having enough people working in the field, having enough workforce to be supporting people who are trying to live independently, and this is a way to make it more possible and less expensive, because you might have one or two people who can be watching alarms and things going on in different different apartments, and they could be helping 20 people instead of one or two people at a different location, but it's just a way to get people out in the community and find ways that they can live safely without having to pay a full time person to live with them.

Beth Santer 17:41
That's a great example of how technology can give access to our population with disabilities even after they exit school. So, you mentioned the Michigan Disability Caucus, and so I'd like to segue to that, because you are the lead of that. And so, can you share what the Michigan Disability Caucus is, and why is it such an important voice for people with disabilities across the state?

Representative MacDonell 18:06
It's interesting because I started off and there was a group that kind of loosely existed already, and it was mostly self advocates with disabilities who were meeting on a regular basis talking about issues. And usually a legislative caucus like this is only legislators get together to meet to talk about possible legislation. But what we're doing is we are throwing the doors wide open so the members of the Michigan legislative disability caucus are legislators, but also parents who are concerned about issues for their adult children, or their children who are going to school and need more help with their special education. We have people in advocacy groups. We have people from nonprofits, all kinds of experts. So every meeting, it's virtual on the second Monday of every month, and we have between 30 and 80 people in every meeting, and we share a single topic each meeting, and people ask questions, and we're just trying to, you know, make sure everybody has the information. There's always somebody who's saying they're surprised, they heard somebody, they heard something brand new, even if they've been working in the field for decades. So it's a great place to share information, but also look for opportunities for legislation to assist people with disabilities in living independently and with dignity.

Beth Santer 19:39
Yeah, that’s so important. What are some of the key priorities or initiatives the caucus is focusing on right now, and how can community members get involved?

Representative MacDonell 19:48
Well, that's um, we have a brand new email address that we can also share, and anybody just writes to us, we'll end up talking with my wonderful legislative director, Matt Dargay, and he can get people on our invitation list so they know these meetings are coming up every second Monday, but we talk about a lot of different things right now. There are a lot of concerns about Medicaid cuts and what's happening in the state of Michigan, the budgets that are not going through and need to be negotiated on and passed. There's a concern right now that both the federal government and the state government could shut down on October 1, so things are not feeling very stable right now.

Beth Santer 20:35
Yeah

Representative MacDonell 20:36
For people and families, that's pretty, pretty scary. There's also in the middle of that in the state of Michigan, there are some efforts toward PIHP and CMH reform. I'm sure a lot of your listeners understand that alphabet soup, but the people that are passing through the Medicaid dollars to the nonprofits who help people with everything from caring for them in their homes or transportation, and we're trying to get rid of some of the the conflicts of interest in the system, but it's kind of a rough time to be doing reform with all of these cuts and all of the uncertainty that's happening right now in the state and the country. And we're also, you know, looking for ways to push the rest of the legislature to really understand the concerns of people with disabilities, period.

Beth Santer 21:31
Yeah, I appreciate you lifting all of the moving parts, because you can't ever have one thing that happens that isn't impacted by something else. And you're right, there's a lot going on right now that

can impact and influence all of this. I want to thank you for joining us today and for sharing your insight on House Bill, 4676 and the future of guardianship in Michigan. This conversation reminds us of how important it is to protect safety and independence for adults with developmental disabilities and how laws can evolve to better reflect dignity and choice. I also want to say that I have seen Representative Sharon MacDonell be a consistent voice and advocate for our students and adults with disabilities, and we appreciate that very much. We hope this episode has given our listeners a clearer understanding of what guardianship reform means and why it matters. If you'd like to learn more about House Bill, 4676 or follow its progress, we'll include resources in the show notes, and we're going to include the links and anything you send us to make sure that our listeners have that. Thanks to all of our listeners, we hope that you would join us again for the Wayne Resa Round Table podcast. Thanks so much for joining us.

Representative MacDonell 22:45
Thank you Beth