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**ORAL HISTORY VIDEO INTERVIEW WITH
DR. MARY CICCARELLI
MAY 10, 2018
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 119-DO**

MC: MARY CICCARELLI

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

JT: So, my name's Jennie Todd. We're here in Indianapolis today. It's May 10th. And, we're with Doctor Mary Ciccarelli. So, we're going to start with you introducing yourself, your name, where we are, and your title, or what you do. So.

MC: Hi. My name is Mary Ciccarelli. I'm a professor of clinical medicine and clinical pediatrics at Indiana University School of Medicine, and I'm here today which is May 10th of 2018, to talk a little bit about the history of disability in Indiana.

JT: How did you happen to get into this field?

[00:00:44]

MC: It's an interesting question to ask how I got interested in the field of disability services. I have been a primary care doc for over 30 years now, and I gradually-- because of the type of doctor I am, I do both internal medicine and pediatrics. My friends who were pediatricians who took care of children with complicated illnesses found me to be the right person to transfer people to. And so, I started to accumulate attract, a group of patients who had significant disabilities. And, as that started to increase in number in my practice, the ability for us to accommodate those patients in a busy practice became more difficult. Because they take, in general, a longer period of time per patient, I was starting to be more and more behind schedule, because of that patient group. Therefore, I started looking for ways that we could build some different way of doing this.

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[00:01:50]

I was working on a project with the School of Medicine pediatric residency on improving training of pediatric residents in working within their communities. And, as a consequence of that, we were partnering with a variety of organizations, one of whom, at the time was IPIN, Indiana Parent Information Network, now ASK, About Special Kids. And, as a consequence of that pairing with that organization, we started talking about family-centered care, and transition needs, and the specific needs of people with disabilities. And, we realized that that organization and my organization were both interested in thinking about how to improve certain services for transitioning youth with disabilities. So, we learned that Maternal Child Health Bureau federally, as well as Title 5, were interested in this as a project. They had started funding that now 17, I guess, years ago. And, they were ready to start a second round of thinking about improvements at a state level, and we got involved, IPIN and me, got involved talking to Maternal Child Health here in Indiana.

And, they funded us to do a little bit of pilot work in terms of thinking about what do we need? And, we went around and talked to a number of the centers for independent living about what the needs were in our state. So, as a consequence of that, we were able to put in a pilot funding requisition to Title 5 here in Indiana, and we were funded to start building transition services. When we started building transition services, we thought people would come to see us with a variety of different types of health care needs. But, in fact, sometimes when you build things, you don't know who will come. And, when we built this, the people who actually came were people with signif-- in much higher proportion to their representation in the population, people with intellectual disabilities, and physical disabilities. And so, then just by happenstance, I started doing more and more of that work.

[00:03:56]

JT: OK. Good.

PH: That was good to hear about how you're talking about taking longer because that's a big issue that we're trying to talk with, just, people with disabilities. It's your right to ask questions, and--

MC: Yes.

PH: Tell them that you need-- they need to slow down.

MC: Yes.

PH: So, that was great to hear.

JT: Alright. OK. Yes, I was trying to decide if I want to hop into transition or just, kind of, stick with the script. I think I'll kind of stick with this, and we'll go to transition a little bit later.

MC: OK

[00:04:23]

JT: So, were you trained anywhere along the line specifically on people with disabilities?

[00:04:30]

MC: I think that that's-- the question of how do we train physicians today to do disability services is an interesting question. And, I trained in the late '70's, early '80's. And so, there was very little specific attention to the actual work I end up doing in my career. We did a lot of training in the hospital on people who were very sick at bedside, which is very different than caring people in home and in community. And, most of that, I found I had to learn myself by being thoughtful about my approach and reading what literature there was, and I guess I would describe that as self-taught process. I think there's better methods today than there were in the late '70's, but that was the truth then. That you kind of had to figure it out.

JT: That's kind of what I thought. So-- and we're going to delve into that a little bit more later on. So, can you talk about the medical issues facing people with disabilities today, and how they've changed? For instance, people with Down syndrome are living longer. People are healthier now. And, what's brought that about? And just, what's caused the changes, and the changes you've seen?

[00:05:42]

MC: It is interesting to look how services and life expectancies have changed for people with disabilities over the span of my career so far. When I was in training, it was common to think about people with spina bifida, or Down syndrome, particularly those with heart disease, dying prematurely in life. It was also common for people with cystic fibrosis to die before reaching adulthood. And, that has evolved over the last 35 years to now a point where we see adult life expectancies for people with significant cerebral palsy, for people with cystic fibrosis, Down syndrome. And, for each of those diagnoses there are some specific interventions that probably have changed their life expectancies significantly. The ability to offer good treatment for congenital heart disease for people with Down syndrome greatly changed the curve of their life expectancies.

The ability to do better respiratory breathing, eating, and seizure management for people with cerebral palsy changes their life expectancies. And so, I think we could pick through each diagnosis, and notice that there were evolutions in health services that improved outcomes from a staying alive point of view. One of my favorite, and favorite is probably the wrong word. One of my most disappointing graphs that I like to use is how much we've improved in the life expectancy for spina bifida, yet the participation of that part population in employment remains a flat line. So, they're alive, but are they actually experiencing the fullest life in terms of community participation? I think we know they aren't, and so, we've done part of the job, and we have another whole portion to still do.

[00:07:45]

JT: Yes, it's interesting. I worked as a social worker for many years. And, back in the '80's, I remember many moms telling me, moms of children with Down syndrome, who were in their 20's and 30's-- they were still kind of waiting for them to die, because they weren't supposed to live past 5. And, you know, we would be talking about finding jobs and these sorts of things, and the mom was like, well, the community's not a good place. You know. Or had told to institutionalize their child. And, that was very common with many of the folks that I met back in the '70's [inaudible].

[00:08:13]

MC: You know, we were still de-institutionalizing the state, you know, when I was already practicing here, right? So, that was still a real entity, I think. You know, and that's-- we didn't talk about that as a reason why there is increased life expectancy, but certainly institutions weren't the best place to have prolonged life. And so, our de-institutionalization as a state might have-- I can't show you data to that end, but it did happen concurrently with these other things, so maybe it did have an impact in life expectancy as well.

JT: That's good. So, you run a program called the CYACC program. Can you briefly tell me what CYACC stands for, describe the program, when it started, the services, the geographic area, that sort of thing?

MC: I had the privilege of starting and now running a program called the Center for Youth and Adults with Conditions of Childhood. And, we call that "kayak," or CYACC. And, we know it's phonetically incorrect, but you'll give us that license, please. And, its mission is to steer youth and young adults towards successful adult life. Youth in particular, who have special health care needs. And, it was created through funding through the State Department of Health, Maternal Child Health, Title 5 funds. And, we are a team currently of three doctors, two nurses, two social workers, a couple of administrative and research assistants, who try to approach planning for adult life in a comprehensive life course manner. And so, individuals who are ages 11 to 22 and perceive that they have a higher need in their transition to adult life than the services they're currently getting can support them in, come to us for consultation.

[00:10:03]

And, that consultation means that you meet with, usually it's about a 2 hour visit with a doctor, a nurse, a social worker, to think about what are your health needs? What are your life and environmental needs? What are your supports that you're receiving and eligible for that we might actuate? And, from that whole visit, we create a list of actionable goals, or a transition-ship plan of care, where we think about maybe, well, maybe you're not on a waiver yet, and those services are going to be very important to you in the future. Or, maybe you are not yet fully aware of what opportunity school can offer you in the 12 plus programming of special education. What kind of decision-making supports might you need? Those are all the types of things that we work on as examples of goals. We have served about 2,000 people since April of 2007 when we started. And, about 90% of our patients have neurocognitive disabilities. So, it's interesting.

[00:11:04]

When we opened, we didn't know exactly what mix of patients would come to see us, and you know, 10 years later it's interesting to see how the team has evolved in their skill. I'm proud to be part of this team. We're really a group of people who work collectively in a very trans-disciplinary manner, and all seem to have the passion of figuring out how to help people out by getting out of the box. And, thinking about what does it take to help this person, not what are the rules. Because sometimes finding an Eagle Scout who's willing to build a ramp for a family, you know, is salvation to that family. And, finding a program that will help with hearing aid batteries when you're not eligible to get refills yet from Medicaid

opens a big door for someone. And, it's those kinds of things that the people I get to work with are very creative in finding and doing and make me enjoy particularly working with them all.

[00:11:59]

JT: Great. So, how do people find out about this program, and is it-- maybe you answered this-- is it just primarily people from Indianapolis and geographically close that can come? Or, who-- how do you promote this program?

MC: So, CYACC is a state-wide program, by funding. And, we care for-- I just did an analysis of last year's, of patients and we took care of patients, I think I'll get this approximately right. Let's say 30% were from Marion County, 40% from the doughnut counties, and then another 40%-- well, now over 100% aren't I? Another 30% from all of the surrounding counties. So, we in a typical year, we see people from 75% of the counties in Indiana. So, it is state-wide. We are, of course, because of just population density, better at knowing things about the center of the state where we are more population-dense than the rural areas. Because we just have more experience with those, but we are funded to take care of people across the state. We aren't in the business of trying to market our program, because we barely keep up with the volume we get. We're funded to have the number of people we have, and we function at maximum capacity all the time. So, we try to never say no.

[00:13:14]

We get about 250 new patients a year. We probably get 300 consults a year, and see about 250 of those, just because some of those families just choose not to seek that service further. And, that-- without further funding we couldn't expand to be bigger than that.

JT: OK. And, I think you answered this, but I'm going to give you a chance if there's something else you want to say about this particular question, is why is CYACC important for children and youth with special health care needs with their families?

[00:13:43]

MC: I think the goal of the CYACC program is to support people who are having trouble navigating the system. And, people might have trouble navigating the system for a variety of reasons. Because an individual's health care needs are very complex because an individual's combination of health and social needs are very complex. I'd like to say that navigating disability services is easily usable in this state, but I'd have to put my tongue very deeply in my cheek to say that with a straight face. And so, I think that lots of families who have significant social determinants of health are as a family, have disabilities across generations in particular, find a hard time navigating the different services that might make their lives improved. And, accessing paratransit with the right forms, and prior authorizing the right equipment, and figuring out what services to use to their best advantage from home- and community-based services supports. All of that feels daunting and complex to many families.

[00:14:47]

And so, the service that we offer tries to help sort and prioritize that. Because sometimes you just have to do things in the right order to get them right. I think I could use voc rehab as an example. If you knock on voc rehab's door and say I need help. They ask what do you want? And, if you can't formulate the answer to what you want, you have a hard time getting services. So, you have to pre-form the question before you get to the door, perhaps, for some services. Or, when people apply for adult SSI, if they're in the business of being very strengths-based and being positive about what they can do, they tend to sometimes not be good at explaining what they can't do, and therefore why they need social security insurance. And, helping people understand that you can't get SSI if you can't explain what you can't do. And, families are very used to, in childhood, building strengths. And, sometimes you have to help reframe that for people to be eligible appropriately for things that they really are eligible for.

JT: That was really good. OK. So-- you OK?

MC: Yes, I'm good.

JT: You need drink or anything?

MC: Yes. I'll take a sip.

[00:16:04]

JT: So, what are the issues facing youth and their family as they transition from pediatric care to adult care? What's the most common? What's the most challenging? And, how are we dealing with that?

MC: There are lots of challenges that families face when they're moving from pediatric to adult care. I'll focus first on the issues around health care, and then maybe around issues in more of a comprehensive life frame. So, in terms of health care, parents have to move from being the managers in charge of their child, to gently stepping back in a way that doesn't create danger. To still provide a safety net while youth are rising up in their self-management skills. So, as the parent steps back, that feels very frightening to parents of children with special health care needs in particular, because they have to figure out how do I keep this person still well, who I've invested so hard in keeping them well because of their health complexities. And, they-- letting go isn't easy. And then, children have, have to figure out how to step up in their self-management skills to become an activated, autonomous person.

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They also have to learn how to use their social supports effectively in life, their natural supports. And, the crisscross of those two changes are often not as smooth as they could be. In addition, the average pediatric health provider of any sort is used to working in a model of care that we could call the best interest of the child. And, people act upon the child in their best interest. Whereas in the adult world, we have an autonomous model of care where people make choices based on information, and reasoning, and choose what they want for self. And, moving from this to that in terms of a model is not easy for everybody. So, the pediatrician is comfortable with their model of care, because it fits them. It fits what they're doing, but they have to start introducing this new concept, because you can't flip a

switch the day you turn 18 to 22, and move into the other model seamlessly. You have to practice those skills and trip and fall a little bit to learn how to care for self.

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And so, the on-ramp from pediatrics is introducing some of these self-managing skills. And, the off-ramp as you're moving into adult services, after the transfer from one to the other, requires that the adult side gets that you're new to this, and that in fact this might not be as easy as the book says it is. If there is such a book. And, the persons have to, kind of, be acclimated, or helped, accommodated into the adult world. And, I kind of think of this as having some scaffolding built around you that you can gradually take down as the person reaches autonomy. There is certainly some people with various types of disability, let's pick in particular people with intellectual disabilities, who might not get to what we would call full autonomy, because they need supports. And so, then in the adult world, for young adults, we don't often think about that model. It's a small percentage of the whole. And so, the adult health care system might be able to recognize that people with geriatric needs and Alzheimer's dementia, for example, need supports in a different way, but they don't often extrapolate that as easily back to the person-- the young adult with autism, the young adult with serious mental illness who is having similar needs.

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And so, all of those issues can play a role in the work that people perceive as they move from pediatric to adult health services. In addition, people often don't need the exact same replica of the care team they had in childhood in adulthood. Because the scopes of practice of different providers changes. And so, redefining what does your care team need to look like in the adult world requires an understanding of the adult health care system, and a synthesis of what your needs are, and how do we deliver them in adult health care, as compared to how we delivered them in pediatric care. And so, it requires a little bit of shifting of understanding of who does which service in the adult world compared to who does which service in the pediatric world. In addition, people have issues related to eligibility for services. So, the language we use around mental health services in pediatrics uses different billing codes and diagnosis names than it does in the adult world.

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And so then, making sure the person fits into the services in the adult world based on now they don't yet have their adult diagnosis clarified might make things difficult. There aren't the same types of providers for intellectual disability in pediatrics as adult care. There isn't anything currently that we would call a "developmentalist" in adult medicine, whereas many people with intellectual disability receive services from that group of individuals in the pediatric world. So, there are gaps. There are difficulty with eligibility, changing from disability, eligibility in pediatrics to adult world has a different book, nationally, in terms of how you define that. And, people sometimes get lost in between the move from one to the other. So, all of that is just kind of based in health care. And then, the other issues that are interesting when we think from a more comprehensive life course view of what's hard about moving from pediatric to adult care. Let's say you're a person with physical disabilities, and your parents did things for you as a child, but now you want more independence.

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You have to figure out, well, what equipment accommodations do I need? Who do I need to help me as a support person? How do I find them? Hire them? Train them? Work with them? Be the leader of this team rather than the recipient of this care? And, that's a complex issue. How do I use paratransit appropriately, and is there paratransit available? We're a state that has a mix of urban and rural environments. And, in rural environments, there's often not paratransit resources. And, there's often a lesser number of available slots in, with different agencies, to receive special care from caregivers. And so, there's a paucity of availability of services in the adult world that will slow people's ability to progress towards the level of independence that they might want.

JT: Do you have a sense-- and, I guess because one of the things, not being in the medical field, in thinking about this is, I thought, OK, pediatrics are used to being with the family for, maybe 18 years. It's the same doctor. They've built a rapport; they've built a history. And they also-- it's a sweet little child. So, then they move away from their pediatric care to an adult physician who comes from a different perspective, who hasn't known-- this is just a new patient coming in. And so, it's the whole starting over again, and not the same sort of "this is a sweet child that I'm going to get to know and I'm going to invest the next 20 years." If that sort of--

MC: Well, they might be invested in them for 40 years, but--

JT: Right.

[00:23:30]

MC: Seventy.

JT: Right. And, that's what you hope they're thinking. This could be a patient for 70 more years. But, do you think that the attitude or just--

[00:23:38]

MC: So, I think that people notice that the difference when they move from pediatric to adult care is another fascinating issue for families. When you're comfortable with the person who took care of your child as a parent, you are used to a nurturing and somewhat prescriptive environment, and that feels comfortable. And, most people when they are asked about making a change to adult services when they are in their teen years, they and their parents balk. Because they say, "I don't want to change, I like where I am. These people love me. I want to stay with them." And so, the initial reaction by nearly everybody is "I don't want the change you're forcing upon me." As humans, we generally don't like change that's forced upon us. And then, they might get introduced to the adult world. Then they'll say this adult world is different than the world I'm used to. I'm not encouraged to bring my guitar and play it in the waiting room anymore. I'm in fact told that's not allowed. And so, my initial reaction to that is, gee, this is different and I'm not really liking it. But, if you wait just a little bit longer, the person's recognized, wait a minute, I'm being treated like an adult.

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I don't have to sit on baby chairs, and there aren't elephants on the walls anymore. You know, this is the grown-up place, and I am a grown-up. And, I like being a grown-up. But, we have to actually let people go through those moments of discomfort to realize I do actually want to be treated like an adult. And, I am being treated like an adult, and that is good. But, there's turmoil in the changing phase because we all react to change with less embrace than fear, as a general rule.

JT: Right. And, I think that's some of the feedback that we get from young adults, and even middle aged adults, where they don't get enough time. Or, the doctor might talk to someone who's with them instead of them. And, they're not used to speaking up or saying I don't understand what you mean by that. Or, I want to be part of this decision. Can you tell me more? So, I think that's--

MC: When I talk about that acclimation zone between being a young-- a youth, teen, and then a young adult emerging in your adulthood, and then actually an adult, the learning how to be an activated patient who actually has voice and power in that conversation is something you have to practice. And, that's why people need scaffolding during this time period to help them with that. It is-- if you practice the skill it's not as hard as if you've never tried it and all of a sudden the world is passing you by and you're not doing it. And so, I think that's an important piece of appropriate transition readiness, assessments and preparedness training. To help people begin to use their voice in clinical care.

[00:26:30]

JT: Very good. Thank you. Basically, if you could briefly describe some of the changes over time in the U.S. and more specifically in Indiana.

MC: Let me clarify the question first. You mean--

JT: That the challenges with transferring-- transitioning from pediatric to adult care.

PH: I think it'd also just be important just to look at not just transition, but how the challenges have changed over time. I mean, you sort of talked about that, but--

[00:26:59]

MC: Alright. I think it's interesting to look historically at how our services have changed over time. We-- it really is probably 20 years in the literature now, that we talk about the transition of youth with disabilities into adult care. And, I think-- are we 30 years post Americans with Disabilities Act? -- Ish? Since that passed as well. And, that changed our approach to thinking about services for adults with disabilities. And, and as a consequence of those, we both think about people's rights with disabilities, to be persons first, and to have the appropriate accommodations so that they have the rights to the same services. Simple as getting an ASL interpreter for somebody who needs it. You know, those are all changes that have happened since I've been a clinician, because ADA came forward, and made us stop and think about those kinds of things, and required us to act upon those things. I think that the life expectancy changes in pediatrics for people with serious disabilities of childhood certainly brought a different awareness to everyone of having patients who were needing transition.

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Or, the volume of patients who were needing transition. That's been a change, not just nationally, but internationally as well. So, there's organizations that look at this internationally. We have a-- I get to participate in a group called the International Health Care Transition Research Consortium. And, we have folks from Australia, and England, and Sweden, and Switzerland, and Canada of course, and the U.S. talking about the similarities that we're facing in terms of the issues of promoting youth with special health care needs as adults, as emerging adults. I think that in Indiana, our sustained support from the state Department of Health to continue to build a transition program, and collaboration across primary care, and specialists in the state have created forward momentum.

Not yet enough to call us successful in terms of this. When we look at national statistics for how good are we at preparing youth to enter adult life, we still don't score very well as a nation, and in Indiana, you know, we're slightly above the national average, maybe. And, you know, and I like to pretend that just because I work in this area. But, you know, I think we're pretty close to the national average in terms of how we do helping people successfully move. And, we have all the services technically that we should have. We don't afford everyone who needs them access to them easily and deliver services to them easily, currently.

[00:30:11]

JT: Thank you. Is there anything else you'd like to say that just talks about the differences of transitioning for youth with disabilities versus a general population?

MC: Sure. So, there are differences that happen when a youth has significant special health care needs, and they need to move from pediatrics to adult life than if you were a garden-variety teenager. You know, 82% of youth don't have any serious chronic illness, in Indiana, and that's approximately the same number, maybe give or take 1 or 2% nationally. And so, that 82%, when they move from pediatric to adult care need maybe 3 or 4 things. They need to have a point of contact in the health system that is something other than an emergency department. So, ideally a primary care provider of some sort. They need sustainable health care financing, which means they have to change out of one plan into another, typically. They need to know when they're signing the forms instead of somebody who is doing it for them as a proxy. And, they need to have enough information about what does it take for me to be a healthy person, to be able to manage their own self. So, what does it mean to be fit, to eat healthy, to sleep enough, to be attentive to your body's needs, and get help when you need it.

[00:31:23]

So, everybody needs that. And then, the 18% of youth who have special health care needs, I actually tend to divide into 4 major categories. Youth who have a chronic disease that doesn't give them either a visible physical or intellectual disability. And so, let's pick diabetes, inflammatory bowel disease, sickle cell anemia, cystic fibrosis, we could name 50 others. But, those are good examples of that group. And then, there's a group that have physical disabilities. So, let's pick muscular dystrophy, or someone who's had a traumatic amputation as good examples there. And then, there are people that have intellectual disabilities. And, we could pick people with autism, or someone with Down syndrome, as an example

there. And then there are people with serious mental illness. And, we could pick bipolar disorder, or schizophrenia as examples there. And, each of those groups of individuals actually have some slightly different needs in transition. People with chronic disease need to know not just the things I described for the typical population, but they also need to know who else do I need on my care team besides a primary care provider?

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And, they need to know enough about their own health management to be able to truly take care of themselves, which has to be more than being given a medical-- medicine reconciliation page at the doctor's office. You need to know, what do I do to stay well, and how do I feel when I'm well. What does a flare of my illness feel like? What am I supposed to do then? What's an emergency, and what do I do then? And so, you really have to have this scope of understanding of what's happening in your body, and what are you supposed to be looking for? People with physical disabilities probably need to do everything I just said, and then they also need to know what equipment do I need? What new services am I eligible for, and do I have to apply for? How do I get assistance from other people in a dormitory if I'm going to university? If I move into my own apartment, how do I find the right one? And so, their home living needs are quite different than a youth who doesn't have any serious illness. And then, people with intellectual disabilities need help in maybe two main ways.

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They need additional help with what level of decision-making supports will they need. So, are they a person who can be their own advocate with informal supports? Or, do they need something all the way up to a level of formality that would be legal guardianship? They also need help with accommodation in learning how to live an adult life. Enough education, done in an acclimated way, so that they move into an adult life safely. And that means usually caregivers giving them the right balance of safety and freedom. And, that's a tenuous, wobbly balance for lots of families and service providers. And, they may also need help learning how to manage their own health habits. People with intellectual disabilities may or may not be good at reading their own body cues. And, they might not be attentive to how to problem-solve around them, and might need supports.

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So, at the simplest level, they might need someone to remind them, if you don't get 8 hours of sleep, you're no good tomorrow. And, if you don't go to bed now, you're not going to get 8 hours. You know, and that's a mathematical calculation that might be beyond the skill of some people with intellectual disabilities. At a much more complicated level, some people who are, who have-- are more profoundly affected by their intellectual disabilities might not be able to pay attention to what their body's doing, might not be able to express what they're feeling, might need somebody else to help manage at a much more complex level. And so, those are the added services that people with intellectual disabilities need. And then, people with serious mental illness have-- I sometimes find maybe the most difficult for me at this point, still, having done this work for about 10 years, in that they, when they are not experiencing a flare of their illness, they need everything I just described for a person with chronic disease. When they

are having a significant flare of their illness, and they are slipping in their own capacity to self-regulate and make decisions for themselves, they need someone else to step in and help them.

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And, making that springing power of attorney, springing support person, actually be present, giving the person autonomy when they should have it, and then stepping in when there's a flare is a very complicated process. Particularly if you have mental illness that might also bring along with it some paranoia about this. And then, fear in letting someone else step in. And so, it can be a very complicated event.

JT: Perfect. Thank you very much. Do you want another drink or anything?

MC: Yes. Sure.

JT: OK. Well, next we're going to talk about Special Olympics.

MC: OK.

[00:36:07]

JT: So, I know you've been involved with them and their health screening and that sort of thing. So, do you want to talk about your role, Special Olympics, the Games, and the booth, and then, the follow up, and your role in Special Olympics.

MC: OK. I've had the privilege of being able to work with Special Olympics Indiana now for a couple of years. Our Indiana organization received a Golisano Foundation grant to work on healthy communities. And so, we're just rolling up our sleeves in terms of thinking about what that might look like, and how do we improve healthy opportunities for persons with disabilities in our state? And, the health promotion process that they use is-- has focused very much in its early years on collecting data to show that there are disparities of care in the population of people with intellectual disabilities. And, I think we have solid data that affirms that that's true. And so, our next step is to think about what the solution to that is, and to think about how do we improve health habits day to day by education of self-advocates as well as their caregivers?

[00:37:26]

How do we improve the screening and evaluations that happen for people with intellectual disabilities in the medical environment? And so, we're trying to think about that as a state, as a national and international organization. There's some recommendations in terms of thinking about when you care for medically, people with intellectual disabilities, how do you think about the particular co-morbidities that they might be at risk for? Such as choking, seizures that are not adequately managed, not maintaining their hydration adequately, not having adequate nutrition or being over-nourished, and constipation as kind of the "biggies" of common co-morbidities in that population. And so, thinking about how to preventatively help families, caregivers, and self-advocates not get into trouble with these issues. And then, how to also recognize them with early warning signs rather than at a point of more potentially fatal crisis.

[00:38:39]

JT: OK. Well, this is a little off-subject, but Peggy and I get to work with Special Olympics too, and we rolled out this workshop with Clinton County last-- two weeks ago. And, we're going to do another one in Crawford County, or Crawfordsville, Montgomery County. And, we did a two-day workshop basically with broad strokes on My Healthy Life, and talked about keeping yourself healthy. What does that mean? Health literacy, going to the doctor, partnering with your health care professionals. Lot of role-play with talking to your doctor. Talked about nutrition, talked about exercise, hydration. What happens when you go to the doctor? What you should be getting. Male, female sorts of visits. And, it was really interesting because, even-- we had people partners. So, we had a family member or a support person come with them. And, the support person seemed to be just as engaged, and felt like they learned almost as much [inaudible] particularly with the relationship with the health care providers. It was really interesting because most of them, when [inaudible] said they did not talk to their doctors.

MC: Right.

JT: That they just either were afraid--

MC: Were passive. Rather than activated. And, you get better health care if you're an activated patient. Absolutely, it's an autonomous model of care. And so, if you don't go, you're not going to get the care. And, if you don't ask questions you're not going to understand what you were told.

[00:40:02]

JT: Right.

MC: And that's-- could we circumvent that by better education and more time for everybody? Sure, but we'd have to redesign the whole health care system for that to happen, and pay for it adequately, which we're not doing either, so.

JT: Well, and I agree with you. I think we also need to educate the athletes, need to educate the patients on what to expect, what your responsibility is when you go to the doctor, what's their responsibility, how you work together, that sort of thing.

MC: And, how you use your social supports to help you. Your natural and paid supports to help you. So, if you can't remember when you pooped last, who's going to remember for you? Because the doctor needs to know that.

JT: That's right. That's right. Here's what you need to know. Anyway. Alright. Sorry. [inaudible]

[00:40:43]

MC: Yes.

[00:40:44]

JT: Anyway. Anything else you want to say about Special Olympics? The base-- the exams that went through, the follow up that might or might not have happened? Because I think there were six stations that said they went through. The ears, the eyes, the teeth, the feet--

PH: Right. They talked about referral.

MC: Special Olympics Indiana is working on improving the follow up care for people who receive screening at events like the state Games. So, last year at the state Games, we had optometrists, audiologists, dentists, physical therapists, a variety of other health professionals. Dietitians, nurses, physicians, including people in training across all of those. Podiatrists. And so, there was two benefits to the process of doing this health promotion work, or this healthy athlete screening work. It is both to educate the patients that they have a need for some kind of care, to identify those who are at more emergent risk to need something. So, if you already have hearing loss, if you already have a need for glasses that you don't have, that's a more significant need. And then, to train individuals who are entering those six fields in how to interact with Special Olympics athletes, with persons with intellectual disabilities.

[00:42:11]

How to accommodate your care to simpler health literacy, interactive language that affords the athlete themselves to speak for themselves first-- as a person first-- are, I think, a very rich part of this program. And, we are working on developing more interdisciplinary training for people in training in the health professions to experience this kind of health care and these accommodations. So that they are activated to recognize it later. It's easy sometimes in practice for people with intellectual disabilities to pass for someone with typical intelligence. And, therefore not get their care accommodated. Patients don't come in to the doctor's office and say, Reading is hard for me. Talk slower, I don't understand this. I'm not sure I've ever had someone say that to me. And, I care for this population quite frequently.

And so, then you have to actually figure that out. If the person doesn't volunteer it. And so, I think the experience of these students in the Healthy Athletes program is really formative to helping them begin to think differently about how do they go looking for this need to accommodate care.

JT: That's wonderful. OK.

PH: We should mention that one of them came in the second day with this plate that you had given them, the plates?

MC: Yes.

[00:45:17]

[Multiple Speakers] [Laughing]

[00:43:39]

MC: And so, you're not-- we actually tried to experiment with that, which was hilarious. So, we have these divided plates, right? And, we didn't recognize that you could also mound things on them. So, we had to actually teach that the plate shouldn't be mounded so that you could barely carry it. Because, like, they-- I had one guy who, like, put potato salad, then like three biscuits in the carbohydrate square. I'm like, no, no, no that's a little-- overdoing it.

PH: [inaudible] remember that.

JT: That is funny.

MC: That's right. That's right. It should-- we should have a shelf that it has to slide under to still be acceptable.

JT: We showed them Michelle Obama, and she [inaudible] plate.

MC: Yes.

[00:44:15]

JT: And so, the next day he brought in, and he goes, Well, I got this from Doctor Ciccarelli. And, it was really great, because he hadn't talked at all the first day. Super quiet. And, you know, we tried to engage him some.

MC: Yes.

JT: And, talk a little bit. But, the next day he came in and he stood in front of the whole group, and we, you know, said, well tell me about the plate.

MC: Yes.

JT: How does that work?

MC: Yes.

JT: And, he did!

MC: Yes. Good. That's good. And so, and it's interesting to think about what giveaways catch people, right? Because I think the plates are very useful as an educational tool because they can apply it, right? Which is different than the ChapStick to protect yourself from the sun, or other things that are some of the common giveaways that are just advertising almost.

[00:44:56]

JT: Yes, that was really [inaudible].

[00:44:57]

MC: Cool. Very cool.

JT: OK. So, you kind of talked a little bit about this, but the next question is, is people with disabilities are having a hard time finding medical providers that are competent in working with them, take the time, you know, have effective communication, and that sort of thing. So, we're curious about the training for medical doctors. So, in terms of disability issues, attitudes, communication, plain language, all that sort of thing, what do you think is happening now, so the students are getting more training? And, you gave us a really nice example. But, are there other examples that you can think of that are happening?

MC: It's an interesting question to think about what training do health professionals need still in their schools to help them improve their services for people with disabilities? Indiana University School of Medicine is in, now, the beginning of year 3 of launching a new curriculum that integrates different parts of science together in efforts to improve the learning experience for future physicians. Part of that new curriculum has an interprofessional education curriculum, so that people are working together with people who are also entering the field in other professions, so that's one of many enhancements. A second is that we are creating a thread of disability education through the 4-year medical school training. That starts with the culture of disability, and the rights of a person with disability on to how do you actually apply that into your clinical service delivery. And, I think we'll see evolution and improvement, I hope, in the readiness of our graduates in caring for people with disabilities.

[00:46:41]

There are still small organizations, nationally in the U.S., that are trying to work on improvements in both medical and dental training around people with disabilities. And so, I think we have some forward momentum in the last 10 years, in this area. But, still plenty of room for improvement.

JT: Perfect. Let's see. Have a couple of random questions for you.

MC: Sure.

JT: Let's see. Let's see.

PH: Something that just popped into my head. You were talking about rural areas--

MC: Yes.

PH: And I didn't know, you're seeing more telemedicine? And I didn't know if that's something that could, help those areas, in the rural areas?

[00:47:25]

MC: Well, I'd love to-- number 1, I'd love to talk about why people in the adult world have trouble getting services, because Medicaid pays so poorly, so we need to talk about that, because that's a real--

[00:47:34]

JT: [inaudible]

MC: Well, you know, if you have a choice between-- I'll say this live, right? So, I'll go back to-- there are other issues that impact the ability for patients to find the services they need in our health care system. Comparatively, patients who are-- have disability, and therefore have their healthcare financing funded by Medicaid, are at a disadvantage across our state, because the payment per dollar for Medicaid is much reduced compared to what the payment per dollar charged for Medicare, or other private insurance. And, therefore, practices decide what percentage of Medicaid patients they can afford to take within the business model they're using. And, medicine has been, much more in my career-- medicine is much more of a business than it was, perhaps 35 years ago.

We are-- we have accountants, and the Masters of Business Administration running medicine in a way that maybe wasn't as prominent 35 years ago. As a consequence of that, our service delivery is timed in a much tighter way than it was when I started in medicine. And, the way we bill is measured in a much tighter way. And, all of that was created for reasons, not just business reasons, but to prevent fraud, et cetera. But, it has altered the relational aspects of medicine in many ways. If you're on a clock, and get 10 to 15 minutes to do what you have to get done, you-- and all of that happens at a computer screen, that changes your ability to be relational with your patients. And, 40 years ago, people who were physicians ran their own businesses.

[00:49:42]

Now, physicians work for organizations. And, aren't the decision-makers. They don't drive the decision about how long are my appointments? I'm told how long my appointments are. And, that's a substantive difference. And so, we really need a-- if we want to equalize healthcare for people who are funded through disability services, we have to equalize the payment. We have to equalize the model. So, in our state, we have a reasonable network of community health centers, and those centers take all Medicaid patients. And so, we focus a lot of our attention there right now, in the current billing environment to focus on those physicians as the physicians that we might want to help expand their abilities to serve people with disabilities, because they're, kind of, the obvious target because of funding streams.

JT: Well, out of all of the athletes, we talked with only one had private insurance, and it was because he was still on his parent's insurance. So, everyone else, as most of the athletes, I'm sure will run into--

MC: Right. Absolutely. Right. I mean, there might be dual-- there might be people who are dually insured, but you will certainly meet mostly Medicaid. The patients we serve in CYACC are, I think they're over 70-- it might be over 80% have Medicaid plus or minus private insurance.

[00:51:13]

JT: OK. And then, let's see. Cultural competency. Is that something that was talked about much in the field? In terms of thinking about it for people with disability?

[00:51:29]

MC: So, there's this interesting-- so, health care disparities are a-- are something we talk about in health care in the United States. And, health care disparities based on race and ethnicity, and gender have been a common part of the dialog, and a common part of the work done at the federal level, and state level. To think about how to equalize, or promote health equity. The disability population has had a hard time getting their foot in the door as one of the disparity groups. And, it's, best I understand it, it's a political problem. Because the lobbying power of those other groups don't want to necessarily make room for another group to be lobbying for equity for themselves as well. Because the pie doesn't feel like it's big enough to accommodate all of those needs. But, certainly we know there are disparities for people with disabilities. And, the culture of being aged, or gendered, or--

-- from this race or ethnicity versus the other. All are an important part of learning how to address the care that people need. And so, we talk a lot in medicine-- maybe a lot is a wrong word, but we certainly train people and talk about cultural competence, and what that means. It is an important piece of the communication skills that we build in trainees, and that we expect of providers. But, it's, you know, as a nation we don't do great with this in all walks of life. And, I think that medicine has plenty of room, or health care has plenty of room to improve its cultural competence. But, it's a rubric we are at least conversant in at this point.

[00:53:19]

JT: OK. That's great. And then, my last random question. People that use wheelchairs. When they want a mammogram, and they cannot transfer very easily, or they are particularly large, what, you know, what's happening in terms of like, with in a dental chair? Or, with a mammogram? Or, different procedures that it's really hard to evaluate someone who is physically limited to the chair?

MC: There are-- the question of how do we use appropriate accommodations or equipment for people who have disabilities and can't get services in a typical manner is an interesting one. There are the average-- we'll use mammogram, mammography as an example. The average mammogram machine requires you be able to stand. There are mammogram machines that afford people the same services sitting. Every hospital system doesn't necessarily have those. And so then, one of the care coordination jobs that our CYACC team does is figure out where this person can get what they need. And, it becomes interesting to think about who could help us with that? Who could help us advertise, like, that Eskenazi has a-- at the Saint Margaret Center-- has a good mammography ability for people who are in wheelchairs.

[00:54:48]

Whereas every other system in the city, I'm not sure we-- and I honestly have not recently investigated this, so I can't speak with confidence, but don't definitively have that ability. There are high/low tables that you can use to help people transfer more easily. They're-- they cost 5 or more times what an average exam room table is, so every exam room isn't going to have one, but which exam rooms have them? People who need help with an adult changing table. Where are those available in your facility? And, making sure that a facility is using a universal design approach to building, and then good information at their information desks about how do you do the things you need that are common

accommodations? I think we can see some people who-- some systems that do that really well around our state, and some that are still early in developing their ability to do that well.

[00:55:43]

JT: OK. It's just a random thought. Is there anything else that you want to talk about? That you think we might not have touched upon? Or, you want to go back and say more? Peggy, anything you can think of?

MC: We have not talked about waivers at all, or how-- and our ability as a state to keep up with what the demands are. You know, we're really in a bad spot right now about that. So maybe that would be worth talking about?

JT: OK. Can you think of-- [inaudible].

[00:56:14]

MC: So, home- and community-based waivers programming is an important resource for people with disabilities. And, right now the way we render those services in Indiana, they're carved into an aged and disabled pot, and a developmental disability pot. And, you can't have both, even if you have both needs. And so, you have to decide which fits you best at which time, and you can't flip back and forth willy-nilly. And, the-- I don't remember exactly what year we changed our home- and community-based waiver program through developmental disabilities, but let's say it was maybe 5-ish years ago, where we greatly changed the certification process, or the eligibility process so that many more people received waiver services. And, we went from having a waitlist that was 10 to 13 years long, to now, under a year in most circumstances. And, now that we have this much shorter waitlist, we have many more-- we have a lot more people who are receiving services, and our state service providers haven't been able to keep up pace in their growth with the difference in number.

And so now, we have families who struggle, even though they have waiver eligibility, not being able to get the services they want. Particularly in rural areas, but it's not exclusively a problem there. It's also a problem in urban areas. And, that's been a recent change. And, probably, it's a good thing that we got thousands of people off the waitlist, but now we're still in a catch up phase getting them the services they need. We also, when we made this change, altered the size of the budget that was available to people, so people are having to re-acclimate to how to use a smaller pot of money individually to meet their needs, and learning how to spread your money out, so that you get the different things you might need. And, where to compromise, because you can't have everything you want. You have to find a way to balance that. And, that's been a-- that's a process that's in evolution, I think, in our state, as we're trying to right-size that, that workforce. We still, of course, pay direct service providers poorly across the country.

[00:58:33]

And so, that population has a very high turnover rate, and not a highly sophisticated education rate in terms of being able to help as caregivers of people with disabilities. And so, that's another substantive problem that we're dealing with as a state at this point.

[00:58:51]

JT: Right. We're from Bloomington and we work with a couple of the large organizations there. And, that's a constant. It's just-- I mean, they can't keep DSP's.

MC: I think the national turnover rate is something like 50% in those organizations.

JT: It's very high.

MC: You know, it's 30 to 70% so, you know-- and then different ones of them. And then, when you look at that, how can you-- you can't keep people trained. And so then, you know-- and if it's, it's-- so, as a health care provider, you know, when I have somebody brought to the doctor by a caregiver, a paid caregiver, who has no idea who this person is, and met them under 2 weeks ago, how do they help that person supplement the history that that person has trouble providing on their own? They can't. And so then, you can't provide health care without a history. I might say history is more important than physical exam. Yes, I'm pretty convinced I can say that, yes. From my experience. And so, that's an interesting ongoing problem, that paid caregivers have such a high turnover rate, they don't know their clients.

JT: And, typically if they do know them, they might not even be the one that goes with them. It's the sub that drives them there.

[01:00:06]

MC: Yes, I'm just the transportation, and I met them last week, once.

JT: Right. And, oh, I forgot their folder that has their health care information [inaudible].

MC: Well, but their health care information in their folder is so rarely organized in a way that has any utility for me. It's hard to read, it's not organized, it doesn't have historical information. It's really, really a gap still in our state.

PH: I don't know if you've met some agencies that they have a staff person that's just basically what they call a health advocate?

MC: So, their wellness coordinators that are paid through waiver are few and far between because the regulations cr-- as I understand it, because the regulations created for that make it onerous to do that work because of the way you have to visit with families with the person, with the person you're an advocate for. So that it isn't-- I haven't seen it reap the benefits we had hoped it would when we created those-- as a state, when we created those wellness coordinator positions.

JT: And, depending on your level of care, it depends on the wellness attention you even get.

[01:01:13]

MC: Right.

[01:01:14]

JT: So, and that's--

MC: It's a Catch-22, isn't it?

JT: It's a mess.

MC: Yes. The-- we didn't talk at all about telehealth, and it might be worth talking about that. We kind of-- we, we-- that might be another thing we talk about. I mean, I often get asked how we might be able to use telehealth to improve the care across the state, across the urban and rural differences. And, we're early, in the health systems I work in, experimenting with telehealth, so we're using is some. And, I think that it has potential. I've tried it to a limited extent myself to date, and I think it-- I feel that I lose some of the information I can gather when I'm in the same room with somebody. So, I haven't quite acclimated myself to the compromise it takes to do telehealth. I-- when I can touch you, I know a lot more about your health than when I can't. Now, I think I earlier today said that the history is a very important piece, and more important than the physical exam. But, it doesn't mean I don't need physical exams to do good health care.

[01:02:21]

And so, I think the telehealth has room to grow, and services for everyone in our state, and particularly perhaps for people with disabilities. Not exactly sure where that's going to move to. For mental health it might be more clearly, obviously, a good addition. Because our mental health task force is probably even a bigger deficit state-wide for people with disabilities than our medical health care task force. And so, I think we should play with telehealth more, and learn to use it better. And, we hope to try playing with that ourselves.

JT: If you had a pot of money, and--

MC: And a magic wand?

JT: And, given your experience, primarily with thinking about people with intellectual disabilities, what sorts of programs, services, help would move them along into having better health? Better connectivity with their doctors? Overall, just wellness? What sort of things?

MC: This is a hard question.

JT: Where would you throw your money?

[01:03:41]

MC: If I had, if I suddenly came into a pot of money that I could use to improve health care for people with intellectual disabilities or other disabilities in our state, I think I would focus on individual and caregiver training as the least common denominator. Changing the workforce alone of health care providers mean-- are people who touch individuals with disability twice a year? Sometimes only once a year. And, that isn't going to make as big a difference as if every day you're adequately hydrated, and eating healthy foods, and sleeping enough, and being physically active, and know your own health care plan,

and know how to recognize seizures, or other potential risks. Take good care of your skin. Do all of those other pieces. If we could get that happening in homes, in group homes.

[01:04:45]

If natural and paid caregivers were at a higher level of ability as advocates for people, I think that would make a bigger difference than if we were doing better physical exams once a year. I think we could certainly stand to do both. But, I think that if I was going to focus, I would probably focus on that first piece.

JT: Do you think, would you focus also on educating people with disabilities themselves as well as the caregivers and families?

MC: Oh yes, I hope I said the initially that training of people in their homes, training of self-advocates and their caregivers is a critical piece to helping people live healthier lives. If you think it's healthy to eat a McDonald's Happy Meal every day for dinner, you're at a disadvantage. And, lots of people in our communities across our state still think that a piece of fried chicken, and french fries, and a Coke are a good, healthy meal. And, they're not. And, think that watching television is a good activity, as compared to being active. And, it's not.

[01:05:57]

PH: That's what we've talked about, is the training needs to happen with the staff and the people with disabilities, because the people with disabilities are saying, you know, I don't want to eat the McDonald's every day, but their staff people [inaudible].

MC: But, they're also funded to have, you know, to be on a SNAP-level budget, right? And a SNAP-level budget doesn't buy arugula every day. And so, how then do you eat healthy on a low income? It's feasible.

JT: It is feasible.

MC: You can eat healthy. And so, how do we teach people how to eat healthy on a low income?

JT: And, that's the whole thing. I mean, the staff have to buy in to it too, but you also, you can't just say it. I have to show you how you can have a fish taco instead of a hamburger taco for the same dollar.

MC: Right.

JT: And, I can make it--

[01:06:46]

MC: I like to try to help focus people that at every fast-food restaurant, there are healthier choices, and there are less healthy choices. And so, you can go there and make some healthy choices. And, you can get apple slices instead of french fries. And, you can-- not to drink a sugared beverage. And, that makes the meal significantly healthier. And, there are sandwiches that come with multiple vegetables on them, compared to the ones that don't. And, all of those are choices people can be encouraged to make.

And so, I think we have a lot of room to improve that. And, that can't be about your once a year physical exam. That has to happen in a different place than that, I think.

[01:07:28]

JT: Right.

MC: I don't mean to underplay that we need to teach health providers how to do a better job, too. But, if I had to pick where the first place to go, I'd probably pick individual and caregiver training. Well, and I think we could go all the way back to health education in special education. And, how are we helping families think about-- at this formative age-- what does it mean to be in charge of being a healthy person? The health education for typical students in our state doesn't necessarily get everybody to the mark we want, in terms of understanding health habits. And, I think we probably don't actually get to as even high a mark with what we do in special education health education. And, I think that maybe that's another interesting area to think about creating improvements, really, at that early, formative level.

[01:08:25]

PH: Yes, that is where it needs to start. Definitely.

MC: If you, you know, right from the time you're eating lunch at school, if you're not buying a Coke and fries and a pretzel as your whole lunch, you know, and if there's ever a vegetable.

JT: And, it's not ketchup.

[01:08:41]

MC: Yes, because that's too far of a stretch for me to call that a vegetable, right? Right?

[End of interview]