S3 E15 — Changing Clinical Care to Better Treat Pain for People with CP — With Dr. Amy Bailes and Dr. Mary Gannotti

**Dr. Marie McNeely** 00:02

Hello and welcome to Changing What's Possible: The Disability Innovation podcast brought to you by Cerebral Palsy Alliance Research Foundation or CPARF. I'm your host, Dr Marie McNeely, and this season, we are excited to bring you cutting-edge stories and insights on research, technology and innovation for people with CP and other disabilities.

Before we introduce you to today's guests, I'd like to take a moment to tell you about 3forCP, CPARF’s grassroots fundraising initiative for cerebral palsy research and disability innovation. Whether you level up a readathon, a sip and paint event, a comedy show, or something else that you love, 3forCP gives you the chance to make a difference in your own signature way. Head to 3forCP.org, to get started. That's the number 3, F, O, R, C, P, dot O, R, G.

And now we'll get started with today's episode. We have two guests whose research CPARF is currently funding — Dr Amy Bailes and Dr Mary Gannotti. Listeners, Amy is a physical therapist and associate professor in the Department of Allied Health at Cincinnati Children's Hospital Medical Center and the University of Cincinnati. She is also Director of Quality Improvement with the Cerebral Palsy Research Network. And Mary is a physical therapist and professor at the University of Hartford, who performs clinical research with the cerebral palsy Research Network and is Co-chair of their Adult Study Group. Today, we are excited to learn more about Mary and Amy, as well as their collaborative work investigating pain in people with cerebral palsy. So thank you both so much for joining us today. How are you?

**Dr. Amy Bailes** 01:40

Great — thank you so much for having us.

**Dr. Mary Gannotti** 01:42

Yes, this is wonderful. Thank you for this great opportunity.

**Dr. Marie McNeely** 01:45

Well, we are excited to chat with you and excited to learn about both of you, so we'll start with some background information. Amy, can you tell us a little bit more about yourself?

**Dr. Amy Bailes** 01:55

So yes, hi, I'm a physical therapist by training. I've been a pediatric physical therapist for about 39 years, and about 10 years ago, I got my PhD and started to be more interested in doing research, and got involved with the Cerebral Palsy Research Network, which we're here to talk to you about today. While I have worked mostly with children over the years, a lot of the children I've seen have gotten older and become adults, so that has sparked my interest in working with adults and the trajectory I've taken since then.

**Dr. Marie McNeely** 02:26

Wonderful. And Mary, can you tell us a little bit more about yourself and your background?

**Dr. Mary Gannotti** 02:30

Similar to Amy, I've been a physical therapist for about 39 years, and I actually started working with adults with cerebral palsy because I grew up next to an institution for people with physical and mental disabilities.

So I have been working with adults with CP, along with children with CP and other developmental disabilities, for most of my career, and I was very interested to see if the things that we were doing at the Shriners Hospital for Children, if the orthopedic interventions and some of the other work that we had done in early intervention programs in international countries made a difference in the long term. And then I was really excited to get affiliated with the Cerebral Palsy Research Network to sort of push this agenda forward.

**Dr. Marie McNeely** 03:22

Wonderful. And I'd love to get into some detail about the Cerebral Palsy Research Network. Amy, can you tell us briefly what this network is, and maybe share how you originally got involved with it?

**Dr. Amy Bailes** 03:32

Yes, I would love to. So in 2014, the NIH had a big meeting about the state of the science at cerebral palsy. I was at that meeting, and one of the things that was discussed at that meeting was that the US doesn't really have a network to do surveillance or research like other conditions have or like other countries have. So out of that meeting came the idea to create a network of institutions that work together to improve care, specifically for cerebral palsy, because nothing exists in our country.

So, in 2015 Paul Gross, who he's a parent of a child of cerebral palsy, who's a young man now — he had a background in developing a network for hydrocephalus, and spearheaded this effort to create the Cerebral Palsy Research Network, which has become a network of institutions — academic institutions and other hospitals and such that serve children and or adults with cerebral palsy, with the primary goal of improving care for those living with cerebral palsy through research, quality improvement, and educational activities.

At that meeting, at the NIH a piece of paper went around who wanted to be involved. And at that point, I was just completing my PhD in epidemiology, and was particularly interested in service utilization, in real world care. So becoming part of the network made a lot of sense to me, as well as it has become a real network of people that want to do the right thing at the point of care, which — who doesn't stand behind that?

**Dr. Marie McNeely** 05:07

Absolutely. And how did this ultimately lead to you, then, Amy studying pain in adults with CP?

**Dr. Amy Bailes** 05:14

Great question. So as part of the Cerebral Palsy Research Network and part of the leadership team, I then became the director of quality improvement activities for the network. I've been trained in quality improvement methods through the Anderson Center at Cincinnati Children's so a big part of learning health networks is doing quality improvement, which is a little bit different than traditional research in that we're testing ideas to change processes along the way.

We don't wait for all the data to be collected, and we want to change things at the point of care and the outcomes. So one of the groups that was working in quality improvement was adults, because one of the first projects CPRN did was to create a research agenda involving stakeholders, people with CP caregivers, clinicians. And one of the big topics was adults, because there are a lot of adults living with CP that have not been cared for as well as they could be. So because one of the quality improvement groups was working on adults, we identified the area to tackle pain in adults with CP.

So as the leader of the quality improvement group, that has led me to this project that CPARF has recently funded.

**Dr. Marie McNeely** 06:23

Very cool and Mary, you touched on it a little bit in your background to your introduction. But can you tell us a little bit more about how you got involved with the Cerebral Palsy Research Network, and perhaps how this helped shift your work from maybe focusing more on children with CP to also thinking more about adults?

**Dr. Mary Gannotti** 06:37

Yeah. So as I was saying that all of my work was really focusing on were the interventions that we were doing in childhood, working with the Shriners Children's Hospital, we had international and national sites — was it making a difference in the long term for adult outcomes?

And we were able to collect small samples of adults, but it was really difficult for case finding, and it required creating a network of hospitals to do that. And then we wanted to start a community registry, and I, too, was with Amy at that meeting in 2014 and not only did we need a clinical registry — we needed a population-based registry, a patient-reported registry, because adults with CP are not represented in national data sets appropriately that we could do clinical research that's meaningful. We need more data.

So along with Amy, she was in charge of quality improvement. I was part of the leadership that was around the adult initiatives, and that included both community registry and consulting with research, along with quality improvement that concerns adults. And as Amy says, pain and functional decline are priorities.

**Dr. Marie McNeely** 07:59

Absolutely. I think pain is a hot topic in a lot of populations, and particularly in people with cerebral palsy. So Mary, I'd love to get into some of the details. Can you tell us a little bit more about what is the state of the science surrounding pain in people with cerebral palsy?

**Dr. Mary Gannotti** 08:15

Well, a recent meta-analysis that looked at populations across the globe, has identified a prevalence of about 70% among adults with cerebral palsy. So that means not everybody gets pain, but many people do.

And among people with cerebral palsy, looking at pain severity in terms of doing match controls. We don't have those clear studies, but we do know that adults with cerebral palsy, when they do experience the pain, the pain interference, can have much more consequences on function than it can a typical person. In our registry, in the community-based registry, the patient=reported information shows the adults with CP do have more pain interference and intensity than peers from US norms on the PROMIS — the patient-reported information instruments from the NIH.

In our registry and in other reports, the low back seems to be the most common location, and that location usually indicates some sort of musculoskeletal dysfunction. But as with all pain over time, it can become centralized, which means that your brain just starts to perceive everything as very painful in that area.

So we're not quite sure in terms of the causes. Some people think that because people with CP have brain injury and damage to the central nervous system, they feel pain more severely anyways. We're not really clear, and this is more information that we need.

In terms of changes across the lifespan, we do see that even young children experience pain, and as one would expect, the longer that you have pain, it might get more severe over time. In our registry, half of them reported that their pain had stayed the same since last year, whereas 40% reported that it has gotten worse. So we still need more information on that.

It's not clear who's at greatest risk for pain, and that's something that we want to uncover more in terms of your functional level, people with high level of function and with less physical abilities still report the same amounts of pain as we can tell in our samples, although it is indicating that GMFCS I — the less severe — might report it more.

So the gross motor functional classification system (GMFCS) levels is a five level scale that indicates someone's ability to move, particularly locomotion. And for someone who is a level one, that means that you can move pretty much like everybody else, it just might look a little bit different. And then level two, it might look even more different, and you might have problems when you walk. And then level three is when you would use some sort of assistive device. And at level four would be that you primarily use a wheelchair, can't really walk community distances. And then five is you might have difficulty holding your head up.

So we're still trying to unpeel the onion in terms of the types and who have the greatest risk factors, and at what time in your lifespan it might occur. So those are things that we really need more information on. So we need to really count things better and classify things better and keep track of it better so that we can get that information. But some people might have headaches or stomachache pain. So there's lots of different types of pain to think about.

**Dr. Marie McNeely** 12:30

Absolutely, and I think you made a really important remark there, that pain can have even bigger functional impacts for people with CP. Can you maybe elaborate on this or give an example?

**Dr. Mary Gannotti** 12:39

For example, someone that I know just recently. She's a 42-year-old woman. She didn't even really consider herself as having CP. One leg is shorter than the other. The foot is a little deformed. She limps, and maybe her hand is a little bit weak. And she works in a gardening center, and she's an organic gardener, so she functioned quite well in a physically demanding job with her disability.

She had to give so much effort to function at this high capacity that having this pain really set her back so much that she wasn't able to function at all in her job.

**Dr. Amy Bailes** 13:29

I think another way of looking at that is that in people that have cerebral palsy, pain can limit their activities and change what they're able to do, especially as they get older. More so than people that don't have cerebral palsy. And in the past, that's really been overlooked, and people just say, “well, you have cerebral palsy,” and that's not the case. We need to treat it. We need to improve care so that people can continue functioning and doing what they want to do,

**Dr. Marie McNeely** 13:49

Absolutely. And I know Mary touched on this a little bit, but Amy, is there anything that you'd like to add on, from your perspective on what are some of the biggest gaps in pain research and related care for people with CP?

**Dr. Amy Bailes** 14:00

Well, I think Mary hit on all of them, with the exception of maybe talking about how we treat it and getting people the right treatment for their pain. So we think we know some things that might work, but we don't know for sure, because there's different types of pain, and we don't identify pain appropriately in the adults that are being seen. So I think Mary touched upon everything.

**Dr. Marie McNeely** 14:23

Absolutely, and I'd love to get into some of the details here about the process of improving the quality of care for pain for people with CP. So Amy, can you give us insight into what steps are involved in this process?

**Dr. Amy Bailes** 14:35

Like I said, quality improvement is a little bit different than research, in that we're looking at the process of care, what the clinician experiences and what they do with the visit, as well as the outcomes of care — something that affects the individual that went to that place for care.

So to start with in quality improvement, you most often start with the process. So what we've been doing over the last few years is looking at how adults with CP when they come for their visit to their provider, how that provider asks them if they have pain, and specifically, if that pain is affecting any of their activities.

What we know, and I think everybody experiences this, is when you go see your provider, it's very varied. There's a lot of variation in what different providers are doing at a visit — what they ask you, what type of visitors is, what type of provider it is, and all that variation in care. So if you went to see one provider in Ohio, they might do one thing at a clinic visit. If you went to another provider in New York, they might do another thing.

And we know that a lot of variation in care is part of the reason there's poor outcomes or varied outcomes. So one of the principles of quality improvement is to standardize how things are done. And that doesn't mean we don't customize to individuals, but we do standardize certain things so that we can decrease the variation. So in improving the quality of care, a big step is to improve or standardize ways we do things so part of the network and the group, what we've accomplished so far is we have standardized across four centers in the network how they're asking adults that come for visits if they have pain, and if they do, is it limiting function?

And we've used things from the literature to do that. We didn't create a scale or anything like that. We've used something that's in the literature called the Huey three pain domain. So we've gotten that far with the network, as far as asking clients, or adults, when they come for a typical visit, if they have pain and if it limits function. The next part of that is to improve the quality of care, because ideally, we want to get the adult to the right provider to get treatment and to improve their quality of lives and decrease their pain. But along the way, there's a lot of steps. So the next step in that is to be able to classify what type of pain they have, because different types of pain might require different treatment, and that's where this next step is headed with CPARF funding — that we will start classifying the pain using the same quality improvement methods we've used to screen for pain, and then start to identify types of pain in the large group of adults, because we're across four centers.

**Dr. Mary Gannotti** 17:20

And I think that Amy did a really great job describing the process in terms of improving the quality of care. And just to reiterate what she said before, what we found in our community-based registry and what other people have reported in the literature is that adults with CP are not receiving appropriate pain relief, that adults with CP are having opioid misuse. And this is because they're not probably receiving the right types of treatments. And that's why it is so important to classify pain to make sure that people get the right diagnostic tests, referrals and treatments to alleviate the pain so that it doesn't interfere with function, because the consequences are significant — economically, socially and physically, of decreased physical activity.

**Dr. Marie McNeely** 18:13

Absolutely, and I think you've done a great job really emphasizing the importance of being able to classify pain and the importance of having it as part of that evaluation in a clinic visit. But can we go into some detail, maybe next, on how pain is evaluated and classified?

**Dr. Mary Gannotti** 18:27

Now, what we're talking about is a provider who is not a pain specialist. We're talking the frontline provider, usually the physical medicine doctor or the developmental pediatrician/ internist who is seeing someone in a clinic visit, and the hope would be to even translate this in a perfect world to primary care providers.

So we're talking about a screening and a classification that's very gross in terms of broad and not the minutiae that you would see with a pain specialist. A pain specialist would use probably different electrical testing or pressure testing, questionnaires and looking at responses to treatment.

What we're thinking about is just one or two questions. Similarly with our screening, we ask people very simple questions, do you have pain? Yes or no? Does it interfere with function? And then, how much does it affect function? So then for classification, we need to identify two or three key questions that the provider can ask so that then they can action actionable steps for referrals or further testing or for treatment pathways that would be effective. So right now, Amy and I are in the process of trying to get consensus agreement among adults with CP, providers, pain experts, neurologists, and people that are going to actually be asking these questions, PM&R, physiatrists, and developmental pediatricians. What questions should we ask? And we're not there yet, but we are pretty sure that they'll only be one or two questions.

**Dr. Marie McNeely** 20:27

Wonderful. And I think you made a really important point there, and just this emphasizing that it needs to be easy. It needs to be practical. I think while it's great to have all the detailed data that you might get from a pain specialist making sort of a list of questions or a process that can be followed and easily inserted into the average clinic visit is critical. So can you comment on kind of the logic that went into deciding what this would look like?

**Dr. Amy Bailes** 20:50

Yeah, like Mary said, you know, it's important that we get some information to get them to the right place, to get the right care, and in doing so, we know that there's a few different types of pain. Some pain is because of damage to the musculoskeletal system, and that makes sense. We're all most familiar with that. There's also damage to nerve tissue, and sometimes there's no damage to any tissue, but you still perceive pain.

All those types of pain have different words for them that we won't mention here because they're technical terms. A lot of people have a combination of things as well.

So what went into deciding this is knowing that, from our community of practice providers in the quality improvement group, we know that at the point of care, we need to make things feasible, and we need to start small and build on those successes. So in doing so, Mary has a lot of experience with building consensus. It seemed appropriate to go through all the different things about pain or domains of pain, and get people's opinion on what they think is most important in order to move us forward to doing the right thing at that clinic visit.

**Dr. Marie McNeely** 21:59

Absolutely. And I think there's information that you can get that can help just sort of understand the pain better. And then there's sort of the practical knowledge that will really impact the trajectory of treatment, which it sounds like you're really trying to get at the latter.

**Dr. Amy Bailes** 22:14

Yeah.

**Dr. Marie McNeely** 22:16

Well, I think this is a fascinating project, and I'd love to talk more about it. So can you tell us more about the goals of your current CPARF-funded study that involves this screening and classifying pain in adults with CP.

**Dr. Amy Bailes** 22:24

Sure. So this is a three-year project that we're really excited to get started on, and the first part of it, like we've talked about so far, is to really establish consensus among researchers, clinicians and consumers, people with cerebral palsy about what we should be using at these clinic visits to classify pain in adults with CP.

So we have to go through a process that we anticipate will take several months to reach consensus, and then the next step of that project is to actually use quality improvement methods to increase using those tools that we decide upon from our consensus group and make sure that we're doing it across four centers, so we'll learn from that as we go about that. And that's our second aim of this project. And last in our third year, we hope once we have reached at least 80% of all the visits both screening and classifying in the way that we tested and found successful, that we will be able to collect information from a large sample of visits of adults to these centers to describe the different pain types in this large group of adults that have been treated across these centers. So in doing so, we will hopefully be able to describe the distribution of the different pain types in a large sample that would be otherwise very difficult to do if we only did it at one center. So having the network and doing it in this way really allows us the affordability of learning from each other, spreading good practice and accumulating a larger sample in a quicker period of time.

**Dr. Marie McNeely** 23:59

That makes sense. And Mary, are there additional details about the study that you would like to share?

**Dr. Mary Gannotti** 24:04

One of the things that's really exciting about this is the community of practice and this period of time that we have to build consensus which it's really about learning from each other and then making group decisions on how we should proceed, and that is the biggest challenge. But once we get people on board with what we agree to do, then that becomes very exciting, and it is a very unique opportunity, because in the United States, we do not have socialized medicine. We do not have a national registry for adults with CP, so it's wonderful to have this learning health network where in such a short period of time, we can get hundreds of adults with CP and get information about them.

**Dr. Marie McNeely** 24:54

Absolutely and I think this consensus process is remarkable. I think for me, getting four people to agree on where to go for lunch is difficult. So can you talk a little bit more, Mary, about this consensus process? Who's involved, and how do you really get everybody to agree and get on the same page?

**Dr. Mary Gannotti** 25:10

Well, people don't always agree, and that's the first thing is we identify a certain level of agreement where it doesn't have to be 100% but it has to meet a certain threshold. People need to be committed to meetings where we have open discussions, and we do have people with different perspectives.

A very important perspective is the perspective of the consumer or the adult with CP. We've been very fortunate to have several informative people involved with the beginning with these projects directing us onto what are the right questions to ask. Because a lot of times adults with CP have pain, but they just don't mention it ‘til it's too late. So we've had some really good insights from them.

We have neurologists, as I said, pain specialists, a broad range of people. And we do have to keep coming back and having discussions and voting. And you start really big where we decide on the big idea — this is what we're doing. What is the most important aspect? And then we narrow it down to the question, so it's an iterative process.

**Dr. Marie McNeely** 26:25

Yeah, that makes sense. And I'd love to talk about a particular comment that you made there, that sometimes people, specifically adults with CP, might be reporting pain too late. Can you maybe dig into that a little bit and explain why this is happening?

**Dr. Mary Gannotti** 26:39

Well, I think that we've heard several times anecdotally, and it is in the literature, that people with cerebral palsy may start experiencing pain, you know, as early as they can remember, two years old. So then they just assume that there's a certain amount of pain that's just baseline, there's just a certain amount of pain that they're going to have to function.

And then oftentimes, they ignore it as it gets worse and worse, until it really begins to interfere with the function. And at that time, the musculoskeletal changes that might have happened, or the changes that might have happened for the central sensitization of pain — because if you have the same chronic pain over and over and over and over and over again, your body starts to — can adjust to it and then just make it always feel like you're in pain. You have a physiological reaction.

So it might be that it becomes very complicated to treat because you might have mixed pain. You might have also had bone changes, and maybe now a nerve is pinched, so you might have three types of pain. So I really feel like physical therapists need to change their practice for children and look at that child and say, what are going to be some of the things that we can talk about for prevention now that will help them later in life?

We need kids to exercise and build bone and build muscle and build heart, cardiac status, but we also need to think about energy conservation, joint protection, and ways to move efficiently and safely for a lifetime, which is something that I don't think we've explored fully for this population.

**Dr. Marie McNeely** 28:42

Absolutely, and I think just sort of the education that people should realize that pain is something that they shouldn't just have to live with, they should try to be seeking treatment and not just ignore it until it sort of gets to that point.

Well, let's talk a little bit more about the study then. Can you give us some details on how it's being conducted, and perhaps what you have learned so far.

**Dr. Amy Bailes** 29:00

Well how it's being conducted, as we're approaching it, you know, in the way that I described our goals — the first thing we're doing is trying to reach consensus on tools or what questions we should be asking at the visit. So that's the first thing we're doing, and we're in the process of doing that right now.

We have regular meetings, participants that are in the consensus group answer questions on a survey, and it's iterative, like Mary said. If we don't reach consensus, we revisit and ask questions again. Sometimes we revise them.

What's been really neat is that we have had several meetings with the group where people share their opinions, and people are coming from all different backgrounds, and there's definitely compromise that has to be made when you're reaching consensus because, you know, researchers want to get all the information, and clinicians are like, I don't have time for that in my visit. And the consumers are like, just help me. So we are going through the process and learning from the process. We're really at the early stages of it, and then as we move to the other goals, we will use different methods to achieve those.

I do think there's something important that I have learned from this, being that I am surely not a pain expert some of the others on the call. But one thing I have noticed is that there's a lot of different terminology people use to describe a similar thing. So I think the one important, important thing, and this is just so important in life, right? Is that whatever terminology we're using, we need to make sure each person understands what you mean by that, and that, if you call it *this*, and I call it *that*, can we decide what we're going to call it, what makes most sense? So that's a big learning that's been evident in this first beginning process of this project.

**Dr. Marie McNeely** 30:38

Certainly. And I think this is really common in interdisciplinary research, where you're bringing people with different backgrounds who might have these different terms as you described, for the same sort of phenomenon.

**Dr. Amy Bailes** 30:47

Right, right.

**Dr. Marie McNeely** 30:48

And this is a great example of a challenge, Amy, that sort of comes along with the process. Are there other challenges that you've encountered so far, maybe that you anticipate may arise as you try to more broadly implement these pain screenings in the classification?

**Dr. Amy Bailes** 31:01

I think a first challenge is getting funding to do such projects. So that's always the biggest challenge. So thank you, CPARF, for supporting us in that way.

As far as challenges along the way, what's really nice about quality improvement is that as we develop these things and tools, let's say you start with four particular questions in a clinic visit. I'm just saying that as an example in quality improvement, we don't have to stick with that. We can learn from that and then adapt. We can adapt our situations and then try something different at a clinic visit, or adapt how we maybe do it, if there's different ways to do things in the electronic record.

So those are the challenges that I anticipate having. We know not everything we try is going to work, so we have to have an open mind. And then, you know, if things don't work, we'd have to feel comfortable abandoning an idea. So that's a term used in quality improvement. If you try something to improve what you're trying to improve, let's say classifying pain and it doesn't work, abandon that idea. Go get another one.

So these are all challenges that I think are challenging because as researchers and people that want to do the right thing, it's hard for us to admit something doesn't work and move on, but it's also part of the methods and the process, so we have to embrace that. And then, of course, the big challenge is, after we accomplish this, how do we sustain it at these four centers? And that's in the literature that it is hard to sustain things, but we do have a committed network, so we feel good about that, and then we hope that when we figure this out in the four centers, we can spread it to other centers within the network.

**Dr. Marie McNeely** 32:34

Absolutely, I think those are really important challenges that you identified, Mary, are there others that you're seeing that you'd like to add to the list?

**Dr. Mary Gannotti** 32:40

Well, one of the beauties of trying to build consensus among people from different perspectives is that they have different perspectives, and at the same time, that is the challenge. And people might have very different desires or wants or methods or things that they have done and would want us to copy it, or people might have very strong opinions.

So I think that that is a really exciting part, is for everyone to learn from each other and really have the group define the goal specifically, like we are in trying to get people referrals and the best treatment, and that oftentimes, is part of the beginning of a quality improvement process where you make a smart aim, and you go from there. And that's part of what we're doing now is trying to get to that point. And I think that's a formative process that can be a challenge,

**Dr. Marie McNeely** 33:41

Absolutely. And you mentioned smart aim. Can you just explain what that means?

**Dr. Mary Gannotti** 33:46

Why don't you explain it, Amy?

**Dr. Amy Bailes** 33:47

Yeah, a smart aim is it's an acronym that stands for specific, measurable, actionable, realistic, and time-based in helping you determine what the aim of your project is. They use the term smart aim, so it's the aim, like what you're trying to achieve in the project.

So I can explain it in terms of our global aim for our work is to improve the quality of life for adults that have cerebral palsy. One of our smart aims has been to increase the screening for pain that limits activities in adults that go for visits from, let's say, 20% to 80% by December 2024 so that's a smart aim. It's very actionable, and you can measure it, and it's a range from 20% to what percent. So that was our first aim for part of the work we've already accomplished. And then our next aim is going to be improve the classification of pain at visits from whatever we decide our baseline was to our goal and give a time period. So a smart aim just really helps you hone in and focus on what you're trying to achieve in this part of your overall work.

You can have several, you know, as a group of adults, working on this for CPRN, we have a portfolio of projects we could say, and the smart aim for this one is to improve classification in at least 80% of all adult visits at four centers by a certain date.

**Dr. Marie McNeely** 35:10

Well, Amy. Thank you so much for giving us the details there. And I'd love to talk about just sort of the big picture idea of conducting research specifically on or with adults with CP. I think this is an important topic because there are a lot of adults out there with CP. So for each of you, can you explain, maybe, starting with you first Mary, why it is so important for you to research in this area.

**Dr. Mary Gannotti** 35:33

Well, for me, it's an extremely compelling subpopulation of individuals who have been largely ignored by the federal government, and in terms of the lack of infrastructure support that we have in our medical system because we're isolated hospitals, the orthopedic surgeons, even within the Shriners Hospitals, it's been very difficult to do high-quality outcome studies on interventions, so some adults with CP feel like they're guinea pigs.

When you look at the overall health and well-being of adults with CP compared to the general population in the United States, the outcomes are horrifying in terms of the odds ratios and the risks for secondary conditions, everything from mental illnesses to physical illnesses. And I feel that there is such a gap in what we do with our children, where we don't look towards adulthood, and it's really a biased, stigmatized view.

Everyone acts like adults with CP just started living this generation. That's not true at all. You know, one of the Pharaohs of Egypt was a spastic hemiplegic. So let's get real. It's all about stigma and that we just pretended like adults with CP didn't exist.

We know that adults with CP, even if they didn't have an intellectual disability, were put in institutions up until in my lifetime, anyways. So this is my soapbox, right?

And I think it's low hanging fruit. There's things that we can do for prevention and there's things that we can do for treatment. So for me, it's sort of an advocacy issue. And I think if we look at trying to reduce the overall health care costs for adults with CP, it's going to be good for society and the individual.

**Dr. Marie McNeely** 37:28

I couldn't agree with you more, Mary. Amy, is there anything that you'd like to add for your personal reasons for why it's important to be conducting research on adults with CP?

**Dr. Amy Bailes** 37:35

Well, I think Mary mentioned a lot of really important things. I think that there's more awareness in the fact that there are so many adults living with cerebral palsy, even more than children. But nobody knows that.

We all got into this work because of our passion for movement and our passion for helping people with movement disabilities. So it's a natural progression and a natural thing to see that is important. So I think that there's so many people living with disabilities. Cerebral palsy is one of them, and historically, we have not paid enough attention to people that have disabilities to not only decrease healthcare costs, but improve quality of life and the ability of people to participate in their society and communities, and for that reason, I think this is a really, really important area of study and area of work.

**Dr. Marie McNeely** 38:28

Then what are the next steps for this particular area of research related to the CPARF study that we talked about today? Perhaps we'll start with you first, Mary,

**Dr. Mary Gannotti** 38:36

One of the things that I'm excited about for this area of research, with the centers that are participating, we are now going to be instituting a standardized way to screen and classify for pain for adults with CP in their center. And that will allow the research scientists and the therapists and clinicians to work together with this consortium that we have in our learning health network to design treatment studies or to track outcomes for treatments or design other types of studies that are important to evaluate the responsivity of adults with CP to pain or different interventions. This community of practice has already started with other spin off projects looking at pain treatments. So I think that this is just a really rich way to improve on the ground practice and then provide structure for additional future research.

**Dr. Marie McNeely** 39:38

That's really exciting. And Amy, would you like to comment on the quality improvement side of this next steps?

**Dr. Amy Bailes** 39:43

Well, like Mary said, with regard to the quality improvement parts of this project, the next steps would be to spread whatever we learn and find successful to other centers within the network so we can do more work. Ideally, we want to know which treatments work for who, and we want to make sure they get those treatments.

So for example, one thing we could think about, you know, let's say, five years from now, in our portfolio would be a project that would be looking at — improve the number of adults that have like such and such type of pain that get treatment within three months of them identifying the pain, or something like that. We want to then use methods to get the treatment to the right people, just like when you go to the doctor and you have asthma, let's say, they want to make sure you get the right medicine for your asthma in a timely way. And that would be something similar that we could do using quality improvement methods along with the other more traditional research methods in studying these issues.

**Dr. Marie McNeely** 40:41

Absolutely, and I love that these quality improvement methods and approaches are really applied, and they really have the potential to have big impacts.

So maybe, Amy, could you elaborate a little bit more on the process of really translating this research that you're doing to bring those findings from your research into the real world to help people with CP and other disabilities.

**Dr. Amy Bailes** 40:59

I think everybody that's listening, I would guess, and people that they know, and their loved ones know how long it takes for information, like, for example, there's this treatment out there. Well, how come nobody offered it to me?

It really takes, you know, there's a quote in the literature that it takes 17 years for something to get into practice. So let's say we find out that, I don't know, swimming helps people with pain, but it could take 17 years for that to be implemented. So the nice thing about quality improvement is it does allow us methods to hopefully translate or bring things that we know work directly into real world care faster, so that we can help people with CP.

And the process of doing that is bringing together experts in various areas, stakeholders, and research consumers, like we've discussed this whole call, so that we can talk about how to get these things into real world care.

**Dr. Marie McNeely** 41:53

Absolutely and Mary, is there anything that you'd like to add on this translation process?

**Dr. Mary Gannotti** 41:58

Well, I'm really excited that CPARF, CPRN, and CP Foundation are really taking an interest in the care of adults with CP, and I'm hopeful that maybe that we can collaborate together, as we can work together to improve care for adults with CP, with maybe some clinical practice guidelines. And I would imagine the work that we do from this quality improvement will the smart phrases that are being put in Epic and what we develop for the classification of pain would become part of, you know, guidelines for how to care for adults with CP. So I'm hopeful that this could have a very big impact.

**Dr. Marie McNeely** 42:42

And could you explain just briefly what Epic is?

**Dr. Amy Bailes** 42:44

So Epic is the medical record system, like the electronic medical record that a lot of hospitals use so near how we've talked about some of the things we do or interventions, things we try to increase clinicians, screening of pain at the clinic, visit and that type of thing. Some of the things we try are changing the electronic record and how providers are documenting, and what it looks like when they go into the medical records document.

And that helps to facilitate asking at the visit the right questions, or what we're trying to do, like — do you have pain? Is it limiting function? How is it limiting function? So that's what Epic is.

Some of the things we're learning from our quality improvement practices we are implementing in electronic records so that it's part of the workflow for the provider. While a lot of the hospitals in the network use Epic, not all of them do. So that is another challenge to spreading our work and things like that that I didn't mention previously. So that's what Epic is.

And if you are a consumer and you're going to see your provider, I think nothing speaks louder than you asking — are you doing this sort of work? What is your medical record system? Are you part of a network? This is what I've learned about. So I think that speaks louder to hospitals and institutions for implementing things than it does having a noisy provider or clinician.

**Dr. Marie McNeely** 44:07

Yeah. I think that the patients drive that. I think encouraging listeners to be their own health advocates is absolutely critical/ And so Amy Mary, you've shared a lot of insights with us today. If listeners want to learn more, what is the best way for them to do so?

**Dr. Amy Bailes** 44:22

Well, I'd start with going to the Cerebral Palsy Research Network website, which is www.cprn.org and you can find out lots of information about the network and the different things they're involved in. And then you know as well, if you have specific questions for me, you're welcome to email me at amy.bailes@cchmc.org and Mary?

**Dr. Mary Gannotti** 44:43

Yeah, so in terms of the CPRN Cerebral Palsy Research Network, there's also a YouTube video channel where we have webinars about topics that might be of interest to you as an adult with CP you can join MyCP at cprn.org backslash/myCP, and when you join there, you can put in some information about yourself, and they'll give you surveys that you could take and you could participate in our community registry.

There's also a forum that you could participate in, and you can ask questions to other adults with CP or providers, and then you'll be put on an email list to get information. We'll have a forthcoming toolkit that is also being sponsored by CPARF, so I would go and sign up at my CP and become part of our network to get more information. Or you can email me at G, A, N, N, O T, T, I@hartford.edu

**Dr. Marie McNeely** 45:47

Wonderful. We appreciate you sharing those resources, and thank you both so much for joining us on the show today.

**Dr. Amy Bailes** 45:52

Well, thank you so much for having us. It's been great to share this information. I hope that you found it helpful and look forward to working together in the future.

**Dr. Mary Gannotti** 46:01

Thank you so much. I'm really honored to have been part of this podcast. I hope the information was helpful, and please feel free to reach out to me for more information. Thank you very much.

**Dr. Marie McNeely** 46:12

Well, we truly appreciate both of you joining us on the show today. And listeners, it's been great to have you here with us as well. When you have a moment, please subscribe and leave a rating or review on your favorite podcast platform to let us know what you think of the show. We look forward to connecting with you again in our next episode of Changing What's Possible.