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- Foote, Katie, A started transcription
- Bartholomew, Paige, E PhD, LCSW 0:03

 And Doctor Winningham to talk a little bit about global development delay. So there has been kind of an increase of people getting, social workers see people coming with a diagnosis and we just didn't know a lot of information about it. So Grace and Katie are here to give us a little bit of background information if you are needing to. See you for this. Don't forget to look at the chat and you'll get your cloud CME code to text in and do your quiz and everything for credit. So Grace and Katie, if you want to go ahead and get started, you can take us away.
- Tepper, Katy, J PhD 0:38

 Great. Thanks so much for having us. We're excited to be here.
- Winningham, Grace, MD 0:42 Yeah, we're happy. Oh, you go. Yeah.
- Tepper, Katy, J PhD 0:42

I am. Yeah, go ahead. OK. I'm Katie Tepper. I'm a pediatric psychologist in developmental and behavioral pediatrics. I specialize primarily in the diagnosis and treatment of autism in the in the very young population, age 15 months to about four.

But with that comes a lot of diagnoses of global developmental delay. So Doctor Winningham and I will will hopefully be able to strengthen your guys's understanding of this diagnosis and and we're really excited to be giving this presentation to just further strengthen collaboration between our department and. Social work because it's it's an exciting collaboration for sure.

Winningham, Grace, MD 1:26

I'm Grace Winningham. I'm one of the developmental pediatricians and I see a wide

range of patient population and ages, but mostly the little kids. But we'll talk a little bit later about this, but I technically see them into.

That transition phase where they go into adulthood. So we'll touch a little bit about that on how this global developmental delay impacts that. But yeah, I echo Doctor Tepper that I'm excited because I definitely lean on social workers.

In our department, but as well as other departments to close the loop on communication and just support our families.

Tepper, Katy, J PhD 2:16

All right. So a little bit of an outline. We are going to focus our presentation with a we're going to give a brief overview of what global developmental delay is and help understand what that diagnosis means a little bit and then really delve into explore how social workers can provide.

And can can partner with families and and their care team when the child has the diagnosis of global developmental delay. We have a few case examples and then some questions at the end. We also have a little bit of just broad discussion as we're kind of going through this.

To help everybody help ensure that your questions are answered and and that we can kind of discuss the cases as we go through.

OK, so interdisciplinary collaboration is extremely important, right? It takes a village broadly. It takes a village with our own children. It takes a village with our patients, and it can just help kids.

Be you know, it can help kids that are have more developmental differences by having a lot of different people that can can assist. It can really also help us get out of our siloed team model because as as team members we often see kids in this developmental stage.

And for one specific problem. And so being able to talk to social work, being able to talk to the team in general to help say, OK, so this diagnosis right is 1.

But how is it impacting the more broadly? That can be really, really helpful. Uh.

It can create more efficient referrals. If we're all really collaborating and talking more openly about what's happening, we can really support the family from a more 360 degrees idea where we can really support every every aspect of a child's development and a family more broadly.

We can ensure that the the child has comprehensive care, not only addressing

medical concerns, but developmental and psychosocial concerns, understanding that understanding global developmental delay and how we can streamline families in the right path to receive supports and services.

That are appropriate and necessary and really using a unified approach regardless of where they're seen. So if they're seen in developmental and behavioral pedes or if they're seen in the ED or if they're seen in endocrine, wherever they're seen, we can really help streamline and ensure that they're getting the.

The proper services can also really minimize confusion with families. Sometimes we see families that have received a develop, you know, a developmental delay diagnosis from their pediatrician, but they then just kind of there have been no more services that have been sought after that diagnosis was made. And so this. Is where we would really like to ensure that you know the ball doesn't get dropped there in the middle where they are getting connected with services anywhere across the hospital. And then as clinicians in developmental and behavioral Pediatrics, we appreciate and love when we can collaborate with our team members throughout the hospital we.

We see families in in pretty challenging times, but they're often also seeing a lot of different specialists across the hospital and so it can be really helpful to be able to assist in understanding what what else can we be doing here.

And if a child sees a different specialist more frequently, it can be really helpful for them to be checking in on the services to make sure that we're not missing anything more broadly.

Winningham, Grace, MD 5:59

So talking about, you know, what is global developmental delay, I remember being a Peds resident and just seeing this diagnosis listed, you know, very commonly and now being in this specialty, you know, I I've learned the exact definition can be very nuanced.

But you know, I think the most important thing is when you see that diagnosis listed, what do we do to help support these families? But we just wanted to go through like the general definition just for background. So the diagnosis in general is when the child is.

Notably behind peers and at least two developmental domains. So language, motor, social, emotional problem solving. And we usually reserve this diagnosis for children who are under five years old because we cannot yet measure IQ.

Reliably at this time. So although you might see the diagnosis of global developmental delay in kids over 5, technically you know that that child should be reevaluated for whether they then meet intellectual disability, that diagnosis. But lots of barriers in our whole field, you know, with developmental delay, intellectual disability. So one of the barriers is actually getting re-evaluated and going through that formal process. So I think oftentimes that.

Global developmental delay diagnosis, just kind of that diagnostic label gets carried on in their problem list without, you know, that form.

Re-evaluation. But technically, you know, we view this diagnosis of global development play almost like a placeholder to describe these kids current developmental skills. So you know, from technically birth till when they're five years old.

To, you know, really support the need for services and what kind of services they need. And then again, until the child is old enough for reliable IQ and adaptive testing.

So how do we make the diagnosis formally? So obviously we get a general history. So lots of questions to the family, you know, birth history, family history, their ages when they obtain developmental milestones in in general, kind of any kind of development.

Mental concerns. A lot of times. Obviously this is done by their primary care clinician and they use a variety of screening measures. So ASQ peds form the M specifically for autism, but it can.

Capture some general developmental concerns and I think this is that surveillance and screening where you're eliciting concerns based on questioning and then even using a formal screening tool. This is where.

I feel like social workers can reinforce that process, you know, kind of being that if there are concerns listening to caregivers, like what are these developmental concerns and then noting it and maybe bringing it back to the team. We'll talk later, you know, when you do have concerns.

What the next steps you can do are, but I think this surveillance and screening is a good step and a good place where social workers can help start that process. And then so when any concerns do come up, the next step is a referral and we'll again, we'll talk about.

Where this referral can lead to to do these standardized testing and we just included testing names and come across these just for in case you do and you're familiar with

them.

But these are standardized testing that people who are trained in doing then perform the test and determine if the child has developmental delays and then therefore meet that criteria for global developmental delay.

Oftentimes we, I mean every time we also look at adaptive functioning. So when we're doing the standardized testing, you know they're showing us what they show us that day, which as you can imagine, can vary day-to-day depending on a kid's mood.

But in general, I mean it gives us an idea of like where their developmental status is. But the adaptive functioning is just as important and this is usually parent caregiver completes like a form and it describes the kids functioning.

Out in the real world, so in the community and a whole school, you know, what kind of things are they able to do?

Tepper, Katy, J PhD 11:17

And across all of the kind of all of those standardized tests, what we're really doing is trying to compare this kid to other kids their same age just to identify do they have, are they delayed when you really compare them to other kids their same age?

WM Winningham, Grace, MD 11:37

And then again, just kind of briefly going over the common causes. Again, as you can imagine, we don't always know and I think a lot of times it's multifactorial and we can't, you know, oftentimes we don't find a singular ideology.

So multifactorial, we take into account the child's prenatal and postnatal experiences. And I think it's important because we don't, we can't always find, you know, this one reason why this child has these developmental challenges. It's important to validate to families that the uncertainty can be frustrating. But the most important thing we can do is advocate, you know, for support and.

Intervention to help with the current clinical symptoms. You know, what are these challenges that we can help support right now? And you know, once a diagnosis is made, that's when a lot of kind of medical and therapy recommendations can be made. So that can include like hearing, vision, genetic.

Depending on the clinical presentation, sometimes brain MRI and then it's important to know that this diagnosis, global developmental delay, it's very commonly co-occurring.

With other conditions. So like Doctor Tepper says she sees she mostly does diagnostics with autism, but we commonly, I would say majority of the time we also get that global developmental delay diagnosis with that.

But autism is just one example of a really common Co occurring condition, but cerebral palsy, epilepsy, any vision or hearing impairment.

Tepper, Katy, J PhD 13:31

So I think it's really important frequently to step back and say, why do we have to diagnose something? Like why? Why label it? And we're going to talk a lot more about the specific supports, but sometimes in order to access specific supports, you really have to have a specific.

Specific label and that can be frustrating because you're like, well, I mean, we don't know how where this kid really is going to fall in five years, right? We don't know what their development's going to look like, but in order to receive some specific supports, we have to label.

Something in order for those supports to open up, so can really open the door to intervention. Labeling the diagnosis can also support specific medical workups, genetic testing.

Other other medical work that might be necessary, it can really help support the investigative process. So similarly like obtaining the history that genetic testing, it can, it can really just give a baseline developmental testing.

And those rating skills that we talked about earlier to just help us.

Let's understand like what their developmental progress looks like. This is where they fell when they were two years old and had no intervention support. But now they're for and have had really good intervention. What you know, we how we can compare them to themselves rather than comparing them to other kids, right?

Which can be really, really helpful. And then it can also validate the family's concerns because families are often coming saying I'm concerned they're my child is not talking. What's going on? Why is that happening? There can obviously be a variety of reasons for that, but this can assist in helping a family understand, OK.

They are delayed and providing that label can really not only validate their concerns, but it can also help a family understand that like they are very delayed, they're more delayed than just, you know, out. It's outside of the average range of delay and that can be helpful.

Helpful and everybody understanding that there is a concern and the the therapy is

very, very important.

So the potential roles of social work, that's what we're going to go through now of kind of what are, what are the the roles that we think that that social work could be really helpful in. But I'd love to hear what some some of your thoughts of what are the most helpful things that we could be that we could be collaborating on with these kids. You guys can pipe into the chat, you can.

Say it out loud if you want to.

Say it out loud if you want to

- Winningham, Grace, MD 16:07
 - And maybe mention like what department you work into so that can help us.
- Tepper, Katy, J PhD 16:08 Yeah, that would be helpful.
- Weston, Casey, D 16:25

Do do you want? Would you like for me to share my social work roles with your people, with your kiddos?

- Winningham, Grace, MD 16:37 Yeah, and that'll be good.
- Tepper, Katy, J PhD 16:39 Sure. Great.
- Weston, Casey, D 16:39

OK, so I know in D&B I'm Casey, I'm in social worker in D&B and one of the things that we do a lot of to support families when their kiddo has a diagnosis of global developmental delay is just kind of helping them identify what resources. They can access. Would they qualify for our services through KCRO? Do they need speech and OT? And if so, then we help collaborate that. I'm sure there's other things I'm forgetting, but those are the things that are coming right off hand. I'm going to let.

The chat answers me too.

- Tepper, Katy, J PhD 17:20 Yeah.
- Winningham, Grace, MD 17:20 Yeah, looking at that.

Tepper, Katy, J PhD 17:22

It looks like Megan Russell works in child and family mental health and and understanding whether or not a specific therapy modality is appropriate based on cognitive delays. Absolutely. That's spot on care coordination support as well as also. And that's what we were just about to kind of talk on. So we'll keep, we'll keep delving into this about what what these families often need post diagnosis and where we think that social work could really jump into to assist with this. So understanding the impact on families is incredibly important.

The impact of a global developmental diagnosis and any related diagnosis that might come, because as we already said, this is often a diagnosis that is comorbid with something else. So really understanding what that impact is on families can be really, really helpful. Sometimes it can be overlooked, especially when there's more medical.

Acuity, when there's other big things happening, sometimes like global developmental delay diagnosis is kind of brushed on the rug because it doesn't feel like it's the biggest thing, like it's the most concerning thing, right? And if the child has a lot of other medical complexity, obviously keeping them alive is is the most important thing, but.

In the midst of that, I I feel like social work can be extremely helpful and and helping the families say, OK, you know when you're at home, these are the the kind of the things that we can be doing or when you're inpatient, these are the step, these are the places that we can kind of step in to assist with this developmental delay. Um.

Winningham, Grace, MD 18:56

Yeah. So kind of going more specifically on that impact on families, as you can imagine, there's, you know, it's multifaceted. I think the emotional impact on families, so they can react very.

Differently, you know, one family's reaction is not going to be the same as the other and it can cycle. You know, they can be in accepting it and be in an OK place, but then another, you know, life change has happened and they're going through that kind of grieving process.

A lot of we see that, you know, that grief and guilt along with relief and Dr. Tepper kind of talked about that, that's their concerns have been validated. We often hear, you know, concerns and worries that they did something to.

Cause the developmental delay. So kind of hearing that and then reassuring them that, you know, it's not caused by a singular etiology. And then a lot of times we get a lot of expressions of worry about the media and long-term future, you know. We're seeing a kid who's diagnosis, you know, a lot of understandably, a lot of them are asking, you know, are they going to be able to live on their own? But I think regardless of where the family is with their emotions at any given time and any given medical setting, you know, just.

Validating how they're feeling and that many emotions that they're feeling can be true. You know, at the same time, definitely looking at family dynamics, so looking at caregiver burnout and supports for the whole family. So in our.

Clinics we we try to remember to always, you know, see how are the siblings doing? How is the relationship between the caregivers? How are they doing with their mental health and physical health as well? Financially, there's often a double hit, so where?

There's higher medical expenses and needs, and then that takes up time. So there's reduced income because of the demands of the child's needs and navigating, you know, a lot of navigation barriers, so.

Navigating the developmental disability world can be really complex and confusing, even for clinicians. But again, this is where if multiple people can check in at different times in different medical settings, that can be really helpful.

And then keeping, you know, our instructions and priorities with simple steps can be very helpful.

So environmental and access barriers. So although, you know, I think the public has made great strides in helping accessibility for people with any kind of developmental difference, there's still many barriers for both, you know, the physical challenges that. Kids might have and people might have, but social, but also social, emotional and language and also thinking kind of.

The developmental differences that aren't as physically obvious, you know, there's

elopement concerns, there's sensory sensitivities that a lot of our kids have, and then the impact on families regarding like their cultural and faith.

Considerations so.

You know, I think even just exploring the family's beliefs about what global developmental delay is with open-ended questions. So, you know, in your family, how are children's developmental differences viewed?

You know, how do you what? Oftentimes when we give the diagnosis, we often ask like, how do you think dad or grandma or other family members will receive this global developmental delay diagnosis? And I know this is obvious, but you know, always using an interpreter when needed.

You know, during verbal interactions and appointments, but also, you know, when providing written material.

Tepper, Katy, J PhD 23:22

OK. So now we're going to kind of jump into like what are the specific, your specific kind of next steps, so.

Early intervention services would be those Part C services. So that's the birth to three program in Kansas and Missouri. And this is one of those specific, specifically in Missouri, one of the specific interventions that having the label of Global Developmental Delay can open the door to.

Receiving this therapy. So the supports can be occupational therapy, speech and language therapy, behavioral therapy, PT, or just a, you know, specialized instructor. And that's somebody who just kind of comes and provides.

They sometimes say they provide all the therapies, but that's obviously possible. So they come and just kind of support the family in a in a variety of different needs. But it's home-based, it's a home-based parent coaching model. And that's something that's really important to explain to families that they're not coming to do the like, they're not coming to just do one-on-one therapy with your kid and you can piece. Like they're there to coach the parent as to what to do. Tiffany just shared a really important piece of information that they can sometimes provide social work services to assist with resource navigation through.

The birth to three programming. So that's also really helpful information. So with this the family gets an an IFSP, so an Individualized Family Service plan and this is very important because it's it's designed to support the whole family to help them on you know, you know are they having?

Difficulty in what areas as a family because of their child's disability. So it's designed to to assist the whole family. I wouldn't say that it they always strike it out of the park with this, but ideally they're they're able to support the family.

They also are providing progress review and you know they're reviewing their goals every three months to assist to address any concerns to see if the child is making progress towards the goals.

The um.

I kind of touched on this briefly, but every state is a little bit different in how they provide the services and how you refer for the services. So in Missouri you can make a direct referral. Kansas is a little bit more difficult because every area and and I mean in the greater Kansas City area, every county has its own.

Um.

Like way of providing the service, but then it kind of gets more broad into rural Kansas. So that's just something to we could I I have a map and I'd be more than happy to share it with Kansas, but in Missouri you can make the referral directly. And this is important because I will say often families get lost in this process. We can say, you know, get, you know, go, go get early intervention. And if we don't either make the referral or make the phone call with the family in the moment, the likelihood that that happens is really low.

So this can be just important for social work to to check in on this. Hey, have you guys received this services? Is there anybody coming to your house? They never know. Often families don't know what it's called, but is there anybody coming to your house to provide therapy?

Are they coming to help at all? You know, is, is that, is that happening at all? And so that can be just a helpful check in. If it's not happening, let's let's really guide them and make that referral because this isn't probably not the first time they've heard it. So kind of helping with that, that referral process can be extremely important and helpful.

WM

Winningham, Grace, MD 27:10

Yeah, and anyone can refer. So you know, the parent, the social worker, for sure. You know, anyone can make that referral. That's why we also bring this up.

Tepper, Katy, J PhD 27:13 Yeah.

And then you know if your kid, if the kid that you're seeing is above the age of three from, there's the Early Childhood Special Education program. So they could be referred for an Individualized Education Plan. And I know that you are all probably familiar with with what that is and more probably familiar with the IFSP, but the the. Diagnosis of global developmental delay also should qualify them for the IEP, and that would be from three until they go to kindergarten in the state of Missouri. If the child's birthday happens to fall sometime from like April through the summer, they'll receive.

Birth to three services until they turn or until they start school. Kansas is a little bit less consistent on that. I just had a family that was receiving services through the summer because their child's birthday was in May. I will say that's not consistent across the board, so.

Often when a when a kid turns 3 in Kansas, those birth to three services end and they just have to kind of wait until school starts again in the fall. So but when when a child turns 3, then they should be able to qualify for an individualized education plan. Which can really assist in creating the plan for the child to be in school and in special education, and then receive support to address the needs of their global developmental delay.

The parent has to submit the written request for special education evaluation. So this is something else that you know if you're seeing this kid and they're 3 1/2 and you know they've had the diagnosis and they're still not in school.

I would be making a phone call with this family because they are, they're lost, they're lost. The process got lost at some point and so the birth to three services should be assisting in making that transition. It doesn't always happen seamlessly.

And so that's just something if you see them and they're not in school and they're old enough.

Help make that transition for them because and and in my clinic I call the school district with the family and just help make make the transition because again, parents don't. They don't always follow through. They're busy, they're overwhelmed, they're overstimulated. They're raising a kid with a pretty substantial delay and.

That can be a lot and so I would just this is another big place where I think that social work can really help making sure that the kid doesn't fall through the cracks with this. Another just important kind of piece of information with the IEP is if families are having.

Having difficulty with the IEP or doesn't meet the kids needs or they're coming.

They're like the school isn't working with me. This isn't going how I expect. There are specific advocacy groups and those advocacy groups are specific by state and they can they can really assist families in understanding the IEP. They can go to the meeting with them.

A family to just say like, Oh yeah, this is you're right, this isn't really meeting your kids needs. Or yeah, it is meeting your kids needs, it's just not meeting in maybe in the way that you expected. But just advocating for families and with families can be really helpful. So in the state of Missouri, it's called impact.

With like an M pact and in Kansas, it's families together. And I know that there's a few other advocacy groups, but those are the two big ones in in Kansas and Missouri.

WM Winningham, Grace, MD 31:02

So those are kind of the school support, you know, the birth to three and then school support. So there's a lot of other community supports and assistances that are available. But you know, the process, the availability and wait times are often huge barriers.

So the more you know, all of us can check in on it, on these supports and assistances, I feel like the better, you know. And I think with all the support, sometimes it can be very overwhelming and ideally we want to help them get as much as they can. But I think also helping families kind of pinpoint like what support do I need right now? You know, asking families what's the one thing that could help make your life or day-to-day a little smoother and that can also help direct us in providing good support as well.

You know, I think also setting those expectations like it, there are barriers, unfortunately, and that we're here to help them through these barriers and any hiccups and just help them understand the process.

I think the regional office and again this is also local state to state and local for Kansas and Missouri, but that can be kind of the pointing out in the community. So once they're out.

Tepper, Katy, J PhD 32:28 For Missouri. For the state of Missouri, yeah.

WM Winningham, Grace, MD 32:29

For Missouri to really help families with what is available in terms of waivers and

supports and funding. So I think in Missouri that would be a good place to start in referring families.

Tepper, Katy, J PhD 32:42

And another just important piece on the waiver in the state of Kansas, and I'm gonna let Casey and Charlie and Stephanie pop in here if I'm incorrect. But in the state of Kansas, if you receive a global developmental delay diagnosis, there is not a waiver support if that's the only diagnosis that you have.

Winningham, Grace, MD 32:49 Mhm.

Tepper, Katy, J PhD 32:59

There's not a specific waiver for that. If the child turns 5 or 6 and they they receive an intellectual disability diagnosis, then they can get on waiver the waiver wait list, but not. But for global developmental delay in the state of Kansas, there's no state waiver.

Which I'm 98% sure is correct and I see Casey nodding, so I'm gonna say yes. Advocacy. I feel like as, you know, professionals in the world of mental health, we're all pretty, pretty good about advocating, but it can be extremely overwhelming as we're all sitting here talking about this. Grace and I are professionals in this specific field and as we're talking through the support.

It can just be challenging to to navigate. And so really trying to help families understand this is what you have available to you and I want you to use it. I feel like often families are like, oh, we don't need that. That's disability. We don't need that. And you're like, this is your kid qualifies for it. Use it like this was who this was. Developed for really helping them understand like what the IEP is, what the IFSP is and like why they qualify for it, how, what are the services they can really gain from that. That's just going to be really, really important. And then also just empowering families to advocate for their kid. I think that that's.

Can be challenging to be in in those meetings, right? There's many, many, many professionals in there. It's overwhelming. They're telling you what's going on. They're just saying like, this is it and so.

To advocate for their kid in that, if they don't feel like it's what they wanted or what they ever expect, or their kid's not making progress, help them to to feel comfortable

advocating in those moments. Helping families to connect to culturally specific services can be really, really important. So there's faith-based organizations, there's family support groups.

There's a few really good Facebook groups in this in Kansas City that can be helpful just connectors for families because having a kid with a global developmental delay can be having a kid with a disability in general can be very isolating and so having a kid.

With this diagnosis, that's a little bit more broad, like global developmental delay can just be really isolating because I think, you know, you have one kid with a global developmental delay, it does not look like another kid with a global developmental delay out often. So helping them to connect with other families can be really, really helpful.

And then making sure again that they're understand their interpretation needs, their interpretation access that like if they need an interpreter, everyone is required to provide that interpreter, the school, the hospital.

Um

The service providers, everybody is required to provide that and I think that that's that can get really lost in the minutia as well. And so helping families to remember to advocate for that because again, this is another great way for things to fall through the cracks if they didn't ever understand from the 1st place what was supposed to happen so.



Winningham, Grace, MD 36:15

So another way that social work can really help these families, you know, is that this comprehensive care. So that includes this transition to adulthood because our kids get older. And I think the most important thing is just starting that early, starting that discussion and putting that.

The idea that there's a lot that goes on in this transition and you know, kids that have developmental differences, there's a lot more steps and probably barriers to get the comprehensive care that they need when they become adults.

So helping families coordinate that care and I think, you know, this is where I feel like from personal experience, you know, reaching out to the other medical teams and the social workers on like what resources and supports have been provided. So then. The next team can follow up on that, whether it is, you know, talking about this transition to adulthood, but just in general, everything we talked about that

coordination of care. And then you know, again, some of this is just kind of reemphasizing, but you know, providing support group.

Information for parents, but also talking about support for siblings and other family members. So grandparents, family, friends, and just helping them kind of navigate even their own family dynamics and how to share the diagnosis and how other family and friends can help them.

As well and I think part of comprehensive care definitely is you know highlighting the strengths. So we're very used to you know why they see us are the challenges and like how we can help them, but I think really highlight.

What these kids are good at and like what?

What maybe some of us forget to ask, you know, all the time, like what? What's something that's really a strength, a talent of your child can go a long way. Yeah, yes. And another question I just had to ask a family that.

Tepper, Katy, J PhD 38:20

What's their superpower? We love to ask that question.

Winningham, Grace, MD 38:28

You know, what do you wish like other people knew about your child? You know, just kind of asking these families cause they might have not been asked these things understandably. Cause when we see them in the hospital and clinic, we're just kind of focused on like how can we help you with this challenge?

But yeah, I think highlighting the strengths can really provide that care and that communication and trust with the families.

Tepper, Katy, J PhD 38:55

I think something else that we didn't actively say is that sometimes kids receive a global developmental delay diagnosis at 2:00, and then when they're re-evaluated at five or six, they've caught up to their peers. And so that diagnosis falls off and they kind of go on with their life. There are.

Obviously some other kids that when they they receive the diagnosis of two or three, they come back at six or they come back at 10 and they have an intellectual disability at that point and those delays have persisted and so we.

Cannot predict what kids going to to catch up and which ones are not. So it can be helpful to start kind of talking about these transitions from a pretty young age. So

that's this is important to just remember like, Oh yeah, if they're going to talk about if the family's concerned, like let's start.

Talking about what that looks like, because at the baseline, some places, if they wanted to go into some sort of residential care, those those wait lists are insane. And so sometimes they need to get on those wait lists when the kid is like 5. They can't do that with a global developmental delay diagnosis because it wouldn't follow them forever, but it is something to.

Kind of help families wrap their heads around a little bit.

Sorry, Grace, I went a little rogue there.

Winningham, Grace, MD 40:16

No, not important. Yeah, I mean, it is important to kind of go back to what we had talked about before or that again, this global developmental delay is a placeholder, but oftentimes you'll see it just carried, carried through.

Tepper, Katy, J PhD 40:30 Yeah.

WM Winningham, Grace, MD 40:32

And just understanding the nuances behind that.

OK, so now we'll kind of discuss cases. I don't know where everybody's department is and how they will encounter these families, but we just wanted to include just some examples cases on how.

And as real life as possible, how social work can help these families. So in this example is in the NICU. So this baby was premature, very preemie, so 28 weeks and now 39 weeks and ready to go home.

While they were in the NICU, you know, PT and OT came by and worked with the baby and PT noted low tone. OT was working on feeding. It was just very common challenges for these PTS.

So during discharge planning, and this is where we want to hear from you guys, you know, what can social worker do to help with concerns about like what PT and OTFS have seen about the current developmental delays?

And

So how can your role in this discharge planning? Cause I know the medical team is probably talking about, you know, if any medications are needed, follow-up

appointments, any equipment if that's needed also. But how can social worker help as well? Yeah, educate and assist with, yes.

- Bartholomew, Paige, E PhD, LCSW 42:18
- Tepper, Katy, J PhD 42:19
 Brilliant.
- Marks, Angela, V LCSW 42:22

 Do you want us to hop in here as a NICU social worker and tell you everything that we do?
- Winningham, Grace, MD 42:25
 Yes, yeah, for sure. You can, you can, you can educate us.
- Tepper, Katy, J PhD 42:27
 Yeah, see it. What do you do? We love to hear it.
- Marks, Angela, V LCSW 42:30 Yeah.

OK, we absolutely put in the referral for First Steps, either Missouri or Kansas. We don't actually do the referrals any longer. We used to Robin Ryan, our NICU social worker here, did a lovely job of.

- WM Winningham, Grace, MD 42:38
 Thanks.
 - Marks, Angela, V LCSW 42:51
 Indicating that our care managers do that now as part of their discharge. So that's automatically done now, but we actually are the ones that place. We check that box saying that that needs to be done. They put in all the follow-up appointments.

 And we just make sure that all those supports are in place when the patient gets discharged.

- Winningham, Grace, MD 43:22 Yes. Um
- Tepper, Katy, J PhD 43:24
 Amazing. Yeah, fantastic.
 I'd say that's the biggest one, right? Making sure that they're connected with early intervention supports from the time that they leave the hospital.
- Winningham, Grace, MD 43:27 I think, yeah.
- Tepper, Katy, J PhD 43:37 Um.

Marks, Angela, V LCSW 43:37

I think, I think too, it's really important, at least for me. Anyway, I try to explain to the parents because it is voluntary, that the best thing about it is what we do as a hospital is we send to first steps and tiny K we send what our.

OT and what our PT people here have been doing. And so we're not you know the the first steps. People are not reinventing the wheel. They're they're continuing what we've been doing here all along. So if that baby's been here since 28 weeks. Weeks and we've been working with them this whole time. Obviously it's going to be great continuity of care to keep that going, everything that we've been doing and that new person that's coming in from, you know, First Steps or Tiny K is not going to be like, OK.

Here we go, starting day one. No, they're gonna be able to look back, see all those records, everything that we've done and build on what we've already completed.

Winningham, Grace, MD 44:38 Yeah, yeah.

Perfect. And I see in the chat, you know, warm hand off to primary care social worker or outpatient social worker and then provide that care transition to special care clinic social worker for ongoing follow-up needs related specifically psychosocial. So yes. For sure, all of that.

I think.

I see a hand raised.



Fivecoat, Jewel, LMSW 45:15

Hi, my name is Jewel. I'm in the Down syndrome Clinic and I think from the parents that I've met with, specifically the ones that are Spanish speaking, having those family support groups are really important.



Winningham, Grace, MD 45:15

Um.

Mhm.



Fivecoat, Jewel, LMSW 45:35

Just for some of our families that can have a, you know, mistrust in medical professionals, making sure that they at least have the family support and just more of that peer support.



Winningham, Grace, MD 45:42

M.



Fivecoat, Jewel, LMSW 45:50

Can feel a little bit more like approachable for them. And just a plug that Down syndrome Innovations has a quarterly Spanish speaking meeting that's up and running again. So not for global developmental delay kiddos, but specifically if they have a Down syndrome.

diagnosis. Down syndrome renovations had something before and then they didn't and now they kind of have some quarterly meetings that are specific for our Spanishspeaking families. And I know that has been really, really super helpful for that specific group.

Population.



Tepper, Katy, J PhD 46:31 Mhm.



Winningham, Grace, MD 46:32

Yeah, that's great to know. I and you had mentioned something that I remember, you know, I think it sounds like you guys are doing this, that education piece of what earlier intervention is, especially those families that might have some mistrust. I mean, every family has their own.



Fivecoat, Jewel, LMSW 46:32

Yes.



Winningham, Grace, MD 46:51

Experiences with, you know, medical teams, but reassuring them this is not like a social service, like it's not checking in on them because it I I can see that some families are like somebody's coming to our house to check in on our.

Tepper, Katy, J PhD 47:02 Yeah.



Winningham, Grace, MD 47:08

You know, a baby or a child and just reassuring them that this is purely to help with development. It's not, you know, something that is our mistrust in them, if that makes sense.



Fivecoat, Jewel, LMSW 47:20

Yeah, yeah. Having them understand why people are coming to their house is definitely important for the early intervention piece. Absolutely.



Winningham, Grace, MD 47:26

Yeah, right.

Go on to the next case.

Um.

So we did did a general inpatient case example. So let's say Leo is a 5 year old. He's admitted for asthma exacerbation and then you see on the review of his problem list, you see global developmental delay, so.

Again, we'll have a discussion. You know your role with the inpatient team, with the family. You know what?

How do you feel like you could help in this situation?

You can kind of see the next icon, but again, you know, there's a lot of nuances with that diagnosis. But I think if you see that kind of figuring out like behind the scenes, you know what is qualifying Leo for a global developmental delay diagnosis.

Tepper, Katy, J PhD 48:39 Yeah.

WM Winningham, Grace, MD 48:56

Is it motor? Is it language? You know what areas are delayed, you know, and for example, if one of the delays is language, expressive and or receptive, how, you know, how do you feel like that can impact this current hospitalization? And his asthma management at home.

Tepper, Katy, J PhD 49:39

I think it's just important to recognize that if if his, you know, if his area, you know one of the areas of his delays was communication, ensuring that the family has appropriate supports to help Leo understand why he has to do what he has to do for his asthma management, but then also help him understand like what does this hospital stay look like?

You know, what's your day going to look like while you're here? And so creating a little bit of a visual schedule of kind of what his day looks like and then helping the family also create some sort of visual and kind. You know, there's a the asthma for this child at the asthma team has a lot of visuals to show like what you're supposed to do to manage your asthma, but.

For a child who has receptive and expressive communication delays, using a visual support is going to be really, really important in helping them to understand what is going to happen. What is happening? How do I do this?

I think another really important piece of this is checking with the caregiver. What do you guys do at home? How do you, how do you manage this at home? Because they've probably created really creative ways to manage it and you can just kind of maybe tailor those or assisting in.

Whatever way would make sense and then.

The big bell ringer for me too, is checking in on his supports. What's he getting? He's 5. So is he in school? Is he? Does he have an IEP? Does he have a 504 plan? What's he getting? What are his services?

And Megan Russell, amazing. Yes, he's five. Like this diagnosis should be falling off. So maybe sending him back to us to see if he has got up to his peers or if he's, you know, if he's still delayed. It sounds like he's still delayed, so.

- Winningham, Grace, MD 51:13 Yeah.
- Tepper, Katy, J PhD 51:23

 If he's still delayed then then a kind of a check in with D&B could be really helpful.

WM Winningham, Grace, MD 51:29

Yeah. And I we wanted to include this case example because again, you know, especially inpatient, there's more medical acuity things going on. So it's very understandable and easy to kind of bypass that global developmental delay, but I feel like having.

Someone, you know, taking a look at that and being like, how can we actually help optimize his medical care and his hospital stay because of this diagnosis and figuring out, you know, what are those challenges can help the medical team and the patient and family?

Tepper, Katy, J PhD 52:07

I'll go through this one kind of quick.

So Emma is a 24 month old patient. She's here for an outpatient appointment. She received an autism evaluation last week and she was given the diagnosis of Global Developmental Delay and Autism.

M.

So at this point, what do you feel like social work's role is in checking in with the family? They just received this brand new diagnosis.

What are what do you guys feel like the role would be? Of social work.

Bradford, Angela, M LSCSW, LCSW 52:48

I think one of the first steps is just check in on parents on how they're coping and adjusting to this new diagnosis and the likely picture, losing the picture of what they thought their future was going to look like as a family and what the child was going

to grow into.

Offering kind of that mental and emotional support to start and then checking and see if they've been connected to any external resources to the Autism Clinic, things like that for ongoing developmental assistance and things along those lines.

Tepper, Katy, J PhD 53:24

Spot on. Yeah, exactly. Emotional first aid. See how things are going. Again, normalizing their emotions, right? If they're feeling grief, if they're angry, if they're sad, if they're really relieved, normalizing those emotions for the family can be really, really, really helpful. And then service navigation, checking in.

WM Winningham, Grace, MD 53:26 Yeah.

Tepper, Katy, J PhD 53:44

And seeing what they're connected with, has has anybody called you yet? It's only been a week. They might not have received any calls at this point, but just kind of seeing where they're at, what have they kind of figured out? And I also love what Tricia Campbell just said of assessing what their understanding of the diagnosis is. That can be really, really important.

WM Winningham, Grace, MD 53:58 Mhm.

Yes.

Tepper, Katy, J PhD 54:01

Because sometimes families hear autism and that's all they heard and they didn't hear anything else. So they might not know they even have that their kid has a global developmental delay diagnosis at that point too. So I think that that's also really important is just identifying.



Tepper, Katy, J PhD 54:16

Do do they know all of the diagnosis and and what is their understanding of those?

Winningham, Grace, MD 54:26

So in summary, we kind of talked about this throughout the presentation, but global developmental delay is in theory, you know, formally used as a diagnosis in kids less than five years old. And this is when there's a.

Developmental delay in more than one area. So speech, motor, problem solving, social, adaptive, you know, checking in with family, validating emotions and providing supports with referrals can be helpful. And then you know as always working as a team with communication and hand.

And that follow-up will help provide the best comprehensive care for families and just kind of knowing what the local resources are.

OK. So I think the next thing is the questions. I'm not sure 'cause I know you guys have to do it through.

Tepper, Katy, J PhD 55:22
Yeah, I guess maybe Katie can assist with this.

Fivecoat, Jewel, LMSW 55:22
Yes.

WM Winningham, Grace, MD 55:24 Yeah.

Foote, Katie, A 55:25

Those will be in at the post test. So when people go back into Cloud CME, they'll answer those questions. You don't have to go over this unless you want to.

WM Winningham, Grace, MD 55:28
OK, so we don't have to.

Tepper, Katy, J PhD 55:29

OK, great.

OK, great.

WM Winningham, Grace, MD 55:33

I also was just checking 'cause I wanted to make sure we had some time to if there's any questions.

Tepper, Katy, J PhD 55:36 Yeah.

Somebody asked earlier in the chat, are we learning of any direct global delays due to illicit or prescribed meds prenatally?

WM Winningham, Grace, MD 55:56

That's a good question and very complex. I think you know when we get a prenatal history, we ask you know what medications besides prenatal vitamin including you know any medic prescribed medications but also illicit.

Tepper, Katy, J PhD 55:59

Complex question.

Yeah.

WM Winningham, Grace, MD 56:14

Substances as well. And there's a lot that goes into that kind of question, as you can imagine, because, you know, from my standpoint, it's getting a full picture and just seeing, you know, we're not.

Leaving anything unturned. But I often will tell, you know, I can see when families are like, why are they? Why is she asking me this? So just kind of reassuring them that I'm just getting a comprehensive picture. But to answer your question, I think it's hard to. I mean, there are.

Studies that shows, you know, certain medications are more at risk of placing the baby at risk for long-term developmental delays on and also illicit substances as well, but I think.

That's where.

You know, it is multifactorial. So you know there and there's a lot of nuances with that. You know, like how often, what's kind of the dose of these medications and

what happened postnatally, why were they taking it? So there's a lot of, you know, variables that go into that.

- Tepper, Katy, J PhD 57:30

 To your question, sort of and also sort of. Now there's no clear.
- Winningham, Grace, MD 57:36 Yeah.
- Tepper, Katy, J PhD 57:38 Information.
- Foote, Katie, A 57:52

 Are there any additional questions from the group?

 Say otherwise, this was we appreciate it so much. Grace and Katie, this was a fabulous presentation. Very helpful. Just good lot of discussion points and thinking points. So thank you so much.
- B Bartholomew, Paige, E PhD, LCSW 58:15 Thank you.
- Winningham, Grace, MD 58:16 You're welcome.
- Tepper, Katy, J PhD 58:17
 Thank you.
- Foote, Katie, A stopped transcription