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Transitioning to Adult Care

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>> DR. SHAH: So, hi. It's a pleasure to be here today. And thank you all for having me. My name is Parag Shah. I'm a general pediatrician at Lurie Children's Hospital, where many of you might be. And recently there's been a focus over there on transitioning care.

So I think I'm just going to talk to try to help those of you who are parents of possibly children who are 15, 16, 17, 18, or younger, who will eventually have to go to this transition. And I notice that many of you have gone through your own transitions, most likely, and have made some -- you had some things to say and faced some challenges and not such good things to say about the transition into the adult world both in healthcare and all the other aspects of adult life.

So I hope this talk -- it's directed -- I'm a general physician. Like I said, it's dealing with general pediatrics and transitioning in general with a chronic illness.

Hopefully there's some information you can take away here. The resources and the websites that point on here are in the handouts in your folder. Just so you might find them useful, you will have them so you don't have to write them down or anything like that.

So I work here, so disclosures.

Transitions, some of the facts and challenges and barriers and then what you can do to help yourself and your children transition for this exciting, but scary, process that's going on.

Hopefully there are some resources at the end that you can use and take with you as you help yourselves or your children.

So transition is exciting, right? Many of you in the room have gone through it. You're more independent….less mom and dad. I did spend an hour out there speaking to some of your kids up there in the room that they're in. So people talk directly to you as opposed to talking to your mom and dad in clinic. And you have more responsibility.

So the funny thing is: It's scary because you have more independence. There's less mom and dad. People talk directly to you and people give you more responsibility.

And that's kind of what's up there. We're talking about the exciting and scary things about transition; people had the same things to say about both.

So I put this slide up there right off the bat. I think many of you in this room, you're here. And you've been through this. And you already know this better than anybody else is that the best thing that you can do for yourself and to help prepare your children is to become a strong self-advocate. And that's probably why you're all here, anyway, in the first place.

But I put this slide here, and it will come up again in the end, because to make a long story short about this whole presentation, this is really what it comes down to, and this is where we want to help your children become independent, become the best self-advocates they can. Many of you have been advocating for yourselves and your children for a very, very long time and know how it works and know how important it is. And it's something that I'm sure that you all want in your own children. And so that's what a lot of this is, one thing to take away, this is what you want to instill in your children. And anything that can help you get that self-advocacy is really what we need to focus on.

So there is a transition definition that exists out there from the American Academy of Pediatrics. The purposeful plan movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems.

When you transition from 10 to 20 years ago, the purposeful and planned part, that's really 20 years ago, the transition. And for many of you, it might have been this way -- okay. This is your pediatric place. You're done here. I'm your general doctor. You got to go find an adult doctor. May have been the way it went.

Nowadays, the trend is towards this planned movement with pediatric institutions are taking the time to help prepare. We're making that actual transfer of care process to the adult world a little built better and a little bit more organized and a little bit of preparation and things like that. So that's the nice part about this phrase is we include that purposeful planned movement.

Just some general facts about transition…. In general, 90% of people with chronic illness are surviving their illness. That is a hot topic. That wasn't the case 20, 30 years ago. It's become a high priority for that reason for a lot of large organizations like the Institute of Medicine. And with that comes with money and thought for transition.

The thought for pediatric will lead to better outcomes. This is the study of various other chronic conditions, diabetes, epilepsy and others.

The key is: What is that systematic preparation? What is it that we're talking about? How are we to best prepare to improve the transition outcomes? That's where the research around transitioning really lies.

Most of the people make this transition with preparation from the pediatric side. And the interesting part of this is that children, parents and pediatricians are all saying the same thing. Children say we're not getting any transition. The pediatricians are saying we're not doing it.

So sounds a bad thing, but it's a good thing that everybody is on the same page and we know what we need to do.

So what are some of the issues around transitioning? Why is this so hard? As I'm talking to many of you here in this conference here, I know that for every condition, it's a little bit different. Finding adult providers that know about NF seems to be a common theme around here. But in general the pediatric side, PP, pediatric providers, have the knowledge for pediatric conditions, and that's true in general.

In order to provide a time and all the services that you need for transitioning, the preparation and things like that, we talk about lack of time. Adult providers also admit their own lack of training. They don't know a lot about these pediatric conditions in general. We know that's the case with NF in the adult world in general.

Difficulty meeting a lot of the psychosocial needs of our families from the adult side. They're not as well endowed with the resources that some of the pediatric institutions naturally have.

Lack of time and reimbursement is always going to be the case.

And then lack of coordinated transfer from the pediatric practices. That's something in the pediatric world you can do a little bit about and you guys can help advocate for. Transfer of care so that the adult physician that will eventually be taking care of you and your children know about the condition and how it affects you specifically.

Families and patients have reported that I've been at this pediatric institution for 18, 19 years, why I want to move on? I'm nervous about somebody that doesn't know anything about me and my condition, I'm nervous about going somewhere where they have a whole different culture of care in the adult model, in the adult world.

So what are some of those differences between pediatrics and adult life in general?

In the pediatric world, we tend to have a focus on development. On the adult world, it focuses on job skills. So how is your condition and how is anything, how does it affect you in terms of your function, in terms of job or college, for that matter?

In the pediatric world, we tend to ask a lot of -- we tend to probe a lot. We do those kind of checkups.

In the adult world, more people ask you. So what brings you in here? What can I do for you? How can I help you? And you have to be the initiator.

Going back to the self-advocacy theme that we really want to talk about for you and your children, and self-checking is important. I added that on here for NF specifically. I think learning how to do self-exams, knowing your body and knowing any changes that occur are really important here.

So the difference between pediatric and adult health care, some of it is stereotyped, some of it's true and stereotyped.

In the pediatric world, we tend to be more provider and parent-controlled, whereas in the adult world, the patient, you and your children tend to be responsible for bringing up issues, what you need.

We tend to have pediatric world more comprehensive, multidisciplinary clinics where you can see subspecialists involved in your care at the same place, at the same time; whereas, in the adult world, you're sent off to see an ophthalmologist, go here, surgeon, here's a referral. That's just the way they're organized.

Less social work and case management assistance in the adult world. And, again, going back to that self-advocacy theme, the adults, you need to be more proactive to get all the services that you want.

How many people in here have experienced some of this as an adult? Just a show of hands?

So when we start thinking about transition, we tend to recommend teenagers 11 to 13. That's more introducing the topic. That's parents and youth. Partly because it's more receptive to the future and thinking about it. There's less of a gap in peers between 16 and 17-year-olds. More because we want to introduce it and not have it become as a shock when somebody turns you into 17 and all of a sudden say, what do you mean I'm not going to be seen here anymore?

What to ask pediatric providers if there is a thought about moving on to the adult world and changing providers? Well, we talk about transition policies and clinics having a policy on transition. And most people think that revolves around, well, the training team is going to be like this.

It doesn't have to be like that. It's more about the process. How will you help me? How will you assess my child and make sure they know and have all the skills they need? When will we talk about insurance? When will we talk about who will I see as adult provider? Can they come back to you if they're not a good fit? These are the kind of processing that we want to outline in policy. These are the kind of questions we want to ask.

We know that transition doesn't revolve around a specific age. Everybody is very different. And hope their cognitive and development abilities and lifestyle -- some people are staying at home for college, some people are moving away. And all these things affect the age of transition in general.

So, how do you prepare? And what is the systematic preparation? This is just a list of things to think about as you, your children sort of transition to the adult world. And there's a lot. And it can seem very daunting.

This list is actually in that handout. And we're going to talk a little bit about some of these. I know finding adult doctors is a big one. But a lot of these other things are all very unique and different in the adult world than they are in the pediatric world. So we'll briefly kind of go through these. It's meant to be an introduction to some of the things that you might want to think about as your children are transitioning to the adult world and maybe you might think about as you transition to the adult world.

There are a lot of checklists that exist. I did not find one for NF. This is one of the things that certainly a lot of other groups, foundations or societies have kind of put together. And it's very tailored to what they need. So, for example, spinal bifida foundation has one that includes a lot of things about self-cathing, knowing how to cath yourself, knowing when you're having change in your symptoms and things like that.

Self-examinations could be something that you would put on there and knowing how to do that.

And so a lot of health care institutions have used this checklist. We, for example, are going to have a checklist such as the one on the left incorporated into our electronic medical record to track people to make sure they're learning all the skills they need.

But there are general things on the checklist that everybody needs to know. Know the name of your condition, how to describe it, the medicines you take, know how your condition affects you specifically. And that's what we're going to talk about here. So some of the things that you -- so a lot of the general things that you want your youth to know.

Any associated medical problems. So we all know NF leads to other associated medical problems.

The names of your medicines, how it affects you. How to contact your providers. Making sure your children know the difference between routine, urgent and emergent symptoms and how to address each of those.

And important red flags that kind of come up. Change in skin, neurological symptoms that are change, knowing what they are and talking it over with your provider so that your children know when they become independent, go off to college and then you fear a lot of times.

Reproductive counseling is a big one that affects NF and you can make sure that your youth know about what this means for them.

So, some things that you can do to kind of enhance the knowledge, try and describe each of those medical issues in three sentences. If somebody came up with three sentences, it works kind of well. It's not a dissertation, it's not one word. I have something growing on my skin. It's a little more indepth and shows you know a little more but you can be clear and concise on it.

Making sure how your illness affects you, because we all know it's different for everybody.

Learning about your history from this is for your youth to learn about your history from you all, because there are a lot of things that probably happened when they were young that they don't remember.

Creating the medical record. Need a little example of a couple of these on the next slide.

These portable medical summaries show up for patients that show up in the medical room. They have some of their medicines, allergies, conditions, just important things about them. There are hundreds of these models that exist out there. We use a three pager at Lurie. We use something like this. Starts off showing what you want to know about me. And it's patient-maintained. So it's something you would take home, maintain possibly electronically.

The one on the right there looks a little bit more like a résumé. Looks very professional and passes a lot of information into a one pager.

The problem with maintaining large summaries, big binders, because I happen to work in a emergency room, and we have various conditions that we don't know everything about. We have a lot of binders. The more you have, unfortunately, the reality is the less likely somebody is going to read it. So having a nice concise summary is a very valuable thing to have.

Not to say you shouldn't keep the records or anything else that goes on, but having the summary and have it neat and concise is a valuable thing.

What kind of skills do you or your children sort of want to have as they grow into adulthood? Well, surprising some of the things we take for granted is quite challenging and difficult for some of our kids. So being able to make an appointment with the doctor. Call your doctor and talk to your doctor.

We meet a lot of youth that they're great, very vocal and verbal at home. But when they walk into the clinic, they sit on the side. We all know they have a lot of things and can say everything. It's intimidating initially. We definitely want our youth to kind of get over that.

How to fill the prescription, ordering medical supplies and how to do that self-examination. Knowing the changes in your body that may occur.

Knowing the things in the clinic or in the office, making sure the provider is speaking to your child. If you find them speaking to you, it's very easy, as parents, to jump in because you know it's faster. And as NF providers, too, when parents start speaking, we have a certain amount of time -- it's very easy to jump into these conversations with the parent and forget about the youth. I'm sure a lot of you guys have experienced this or yourself that that happens.

So just making sure that you're aware of that. Making sure the child answers the questions. Gives them a chance. Give them extra time. It's a valuable skill to learn and it goes a long way in promoting that self-advocacy when they become adults.

Make your appointments. When you leave the office, go to the front desk and make it yourself. Again, another good skill. And preparing some questions to get away from that intimidation that comes from talking to your doctors. Make up some questions if you don't have it. In your children, talk to them upstairs. So I know there's a lot of things they are thinking about in terms of asking their doctor something that they wanted to run past them.

In general, when you turn into an adult, we as parents and providers sort of go on from the people that deliver the care to becoming consultants and young adults, the youth kind of go -- when they're in early childhood, they go on to be the recipient of care all the way to being supervisor of the care. Kind of a nice model that I found that kind of describes that pretty well. The provider and the family. Become consultants. What do you think? Do you think that's okay? Okay. Then yes.

Adherence, compliance. Always a kind of big issue with medications and things like that. Always want to keep in mind what exactly the barrier is. There's lots of different barriers we forget. Side effects that you don't want to do it. Could be a schedule issue. Somebody taking medicine twice a day but 8 a.m. and 8 p.m. and you wake up every day at noon. Thought he missed his 8 a.m. dose and never took it. About six months into the course somebody realized do you know what? It says twice a day. You can take it at noon and 12 midnight if you want. Started becoming more compliant.

Social stigma of medicines is also a big factor sometimes. So using resources to help improve the compliance. There's text message reminder systems. There's pill boxes. Each of those are sort of directed towards one of the barriers. If you're forgetting a text message will help you. But if your problem is you're having -- getting a text message is probably not going to happen if you have side effects.

Finding adult doctors.

I don't have the magic answer for this. I don't have answers that you would probably like. There are a lot of ways you could help find adult doctors. We've met with some of the larger managed care organizations. We'll talk about insurance in a second. That's a big transition when you move on to adulthood.

Asking your current doctor if they know of any. Many do. Many will hold on to you and become your primary care doctor. Again, this is all directed towards finding the primary care doctor who knows a little bit, something about it and can help you out.

Consider your parents' doctors. Call the insurance company.

This is where I wanted to get into the fact that we did meet with some of these managed care companies, and they are nowadays taking on more of the care and more sort of all of the care of their clients and their constituents.

They are trying to know who's in their network and who specializes in what conditions and what kind of chronic illnesses and may be able to help you out.

Check in with your local support groups, if they know.

Calling large medical hospitals and university centers, tertiary care centers that many of you and your children are going to or have gone to to get all their comprehensive care in pediatrics.

Ask any kind of case managers, care coordinators or friends.

Basically use all the resources you have at your disposal to try and find somebody that might be recommended who knows something about NF. As I was talking to you guys, it's kind of fun to know something about NF.

So obviously the first question: Do you know anything about NF? Ask them. But you want to know what are their office hours? Do they take your insurance? How do they communicate with you? Do they have the physical facilities that meet your needs? Not all offices are as accessible as you would think.

Are they willing to talk with your pediatric provider in terms of the transfer of care and get the records? How are they going to do it? What kind of things are they willing to do? What hospital might they be affiliated with? Where do they refer you for some of your sub-specialty care you might -- ophthalmology, things like that.

Now, we move on to college/work. Some of your kids may be going on to college. So preparing college, all general things you want to think about. Creating a plan for your medical supplies, anything you might need while you're away from home. Checking with the school health clinic.

And I know a lot of us think that health care, anything about good, bad, the most people with chronic illness, they don't have good experience with the school health clinic. That doesn't mean they will be entirely useless. Good to check in with them. We've had doctors send letters to the school health clinic so they know about the condition and appreciate it and at least triage appropriately for your children. So you can be a little more confident that they have a plan in mind for when your child shows up at the school health center.

Discuss risk taking behaviors and how that really affects your condition with the medical team.

And then obviously checking with insurance provider about state coverage, knowing about accommodations in college is a tricky subject.

In high school you have a certain level of protection that's provided to you with IEPs and 504 plans. It's not that it goes away in college. In college, we have, for example, somebody from DePaul who comes and talks about foundations for our kids. You must ask for the accommodations. You have to register. They have various names for it. The office of disability, the center for accommodation, whatever it is at your particular college that you're interested in. And there's a lot of personalization to this. So a lot of people don't want to register. And a lot of people don't feel like it's good and necessary. All the complications that can come with that. But the only way you get accommodations.

Some examples of the accommodations people can get, obviously this applies for the learning disabilities with this population. Substituting courses, notetakers, priority registration, front seats, things like that.

The one thing that they're not required is the substantive content of the testing. So they can't make easier or make it different. They can provide any kind of accommodation that you might need to give you a fair chance, give your children a fair chance as compared to other children. So you do have those rights and you do have to ask for them and be a little bit more proactive in college than high school.

And many of you are probably aware throughout in high school, too, within your school systems is not perfect, but it's a little bit more so in college.

There are some resources there that are on your pamphlet there.

Here are some of the things that we ask parents. The one thing think I wish that I knew and they would do.

Talk about various things. Networking with other parents. Knowing that they could have gone somewhere to get the accommodations they needed, specific accommodations they wanted, that they wish they would have known about. Knowing your rights. And just things that they said.

Work. So working with a disability, just a brief overview of some of the protections that are provided for you and your children when they go into the workforce. And many of you are probably very aware of this. But the Americans with Disabilities Act covers a lot of this. Reasonable accommodations to qualified employees.

The stipulation that's on there that's a little vague -- and why this goes both ways in a lot of current circumstances -- are unless such accommodation would propose an undue hardship. That could be interpreted a million different ways. That's where the wording of the Disabilities Act and where a lot of confusion come in and interpretation, let's say, comes into.

But your responsibility is to actually ask for accommodation that might be necessary. It doesn't have to be in writing. It can be a formal letter. This is an example of a letter you can give to your employer to help you out with those accommodations.

So you're entitled obviously to be treated with respect, to have confidentiality and to disclose. When you go to college and with your friends, the kids upstairs, choosing to disclose at any time during the employment process, before the interview, after the interview, anything like that.

To receive accommodations for an interview. The Americans with Disabilities Act clause applies to interviewing for a job, too. Something to think about for the kids when they are applying. And you do have the responsibility to disclose any means that you might have for the accommodation that you might need? You don't have to disclose fully about your condition. It's who you need to disclose to, what you need to disclose on a need-to-know basis, and that's perfectly fair.

This is personal, and knowing the law and what exists out there for you is very helpful.

Health insurance obviously a big topic for a lot of people.

There's a lot of changes that happened. And the social worker can cover this better than I do. So I'll try to give you the best I can.

Insurance has traditionally been a very significant barrier to any kind of transition for youth 19 through 26. That's changed a little bit. There are a variety of insurance options for children and adults, might be very different.

Learn how to read benefit plans. This is something we do in our life skills program. It's challenging. Many of us as adults haven't done it until we had kids or until you have a chronic condition and you really feel it's important.

We do it for kids at various levels all the way from 11 to 17. We do like an "Insurance Jeopardy." And they do really well on it once you give them the basis on how to read it and do it in a nice way. It's intimidating at first. Go through with your children. Might take them a long way.

The health insurance options, I won't go through this in detail because this is quite a large topic, but as kids we're used to insurance getting care; but private assistance, adult, the big change from the Affordable Care Act. Previously, to get adult Medicaid, you had to have a disability and have a certain level of income. Now disability criteria went away. For the first time, adults without disabilities are able to be on Medicaid.

Disability as adult, the definition of disability as an adult is different than as a child. If you receive SSI as a child, you need to have a certain income level. You need to have requirements above and beyond that the children need.

As an adult with disability, again, focuses a lot more on work, and your ability to maintain gainful employment. So just keeping that in mind, that that might change or your classification might change and it may affect your government benefits that you might be eligible for.

One of the big things that's going on, not part of the Affordable Care Act but also this move towards managed care, I don't know how many of you guys have experienced this for you or your children. It's happening more in the adult world. But pediatric world also where a lot of groups are, for public insurances are taking on -- trying to enroll in the managed care program. We have thoughts about what the programs are. You get letters in the mail. They're trying to enroll everybody. Illinois and Cook County by 2015, all pediatrics are managed care.

Private insurance plans, many of us -- everybody knows, group health plans, exchanges for everybody who want to enroll themselves in private insurance, obviously not parents until 26. Your kids until 26 on your insurance. That's the new change now.

But college and university insurance is a tricky one. It's still sort of in limbo what's happening to these plans with the new changes with the public insurance and the exchanges that exist out there now as options for young adults.

So college and university insurances are not always as comprehensive as you think. Learning how to read the benefit plan when you enroll the kid in college and you enroll in their insurance, it doesn't always cover everything that they should. They tend to be a little bit more limited.

There's a lot of resources out there to sort of support. Healthcare.gov we know about. Needy Meds is a program that has come together. And you would be surprised what's on there, if you find you're having a hard time getting a medicine or anything to that effect. You have the website. Maybe they have some options for you in terms of sort of pro bono services for medications and things like that.

Guardianship may be an issue for some people with NF or some parents with NF, rather, for their children. We will tell you a little bit about the process.

We typically start considering the 17th birthday. For Illinois, we have state guardianship that I put on your sheet, too. You don't need an attorney to establish guardianship. You can do it yourself.

Generally in Illinois the forms are filed through the county courts. And then they need to be filed on the 18th birthday, and they are found on that birthday. You'll need to see a physician generally within three months and they'll have to fit it out, three months of the child's 18th birthday to have it filled out. Multiple physicians, and they can use information from the school evaluations and generally have a good information from the family about this and about what this means.

Guardianship overall is when one person maintains the legal power over another to make all decisions. But just knowing that there's a lot of spectrum in there. So there's a lot of alternatives to guardianship that aren't -- they're not all taking control of your child's everything, finances, medical decisions and things like that.

Power of attorney becomes a big one. The child saying I don't feel prepared. I'm giving my power of attorney to you so you can make decisions. It's easier to get medical records. Easier for you to maintain decisions. And then they could take it back whenever your family decides it's more appropriate.

Guardianship, once you get it, is difficult to give up. It's not thought of as a temporary measure. It's thought of as a permanent measure. You have to prove to the court what's changed that you don't need the guardianship anymore.

And so power of attorney, joint bank accounts, healthcare power of attorney, these are all alternatives, and it's worth to talk to somebody about it.

So I just want to end with some transition resources that exist out there in case you wanted to learn about some of these topics in more indepth.

This is going back to to the summary thing. Health vault is free. Outlook account. Great way to maintain medical summaries online. Google used to do One Google Health, but they did away with theirs. Also very good. You put in it is very expensive, you upload scans, you can put any medications as it changes, you can keep track of things, it's accessible to anybody online. Password protected by your Outlook account. It's one of the more sophisticated online free health summary things that I found. And there are certain things that link up with this. Not as expensive as you think, but there are some that exist.

I will help you out with something if I can help you find anything. This is the only sort of transition brochure I found out there. And it covers lot of the same topics that I kind of covered. Maybe has some more specifics on there. About 5 or 6 pages, I think.

And the NF Network has a great descriptions about NF and some of the issues that will affect you and your children and some of the resources that exist on there. So to learn about the condition itself and help your children learn about the condition is a good thing there.

My Med Schedule is a free online app for various things like medications, anything else that would be kind of going on. It's a little bit more robust and helps you kind of learn a little bit. You got to have a text messaging plan with it. If you don't, you will get charged for each one. But we have a lot of our youth use that.

It happens to be one of the transplant literature, it helped bring up some of their markers. So that's why I focus on this a little bit.

There's a few sites that maintain some of these handouts on various different topics that we just talked about. You can go into it a little more indepth when you talk about transitioning your adult in world.

The American Academy of Pediatrics. And they got a large grant that we were all a part of city-wide or statewide in Illinois to come up with these brochures. They are actually kind of nicely done. Colorful, easy to read with bullet points and things like that. About three pages.

There's some transition videos that exist on various topics. And all of these resources are in your handout.

And Lurie Children, we maintain a couple of PDF sheets and things like that.

So just some final thoughts on what a foundation or an organization can do to help their members transition, we worked with a few other groups to think about things like this. A formal checklist of knowledge and skills. What are important for you to go off into the adult world? Something a foundation can do.

Comprehensive resource site. One page fact sheet for adult providers. A group in Indiana at the Indiana University developed a whole stack of one page FAQ sheets that they send to transition their kids out there. They got great feedback and presented some of the research at some of the transition conferences. There is a proprietary. They don't give them out. But they're updated, and there's session from the adult provider. One page on various issues that might come up. And so that could be something that the foundation can kind of work on.

Understanding some of the common issues and knowing the resources is a big deal.

So just some things to remember about transitioning. It involves learning about yourself, your medical condition. It's a process not an event. That's really a change from a couple of years ago and a good change and can help the process be smoother. Starting early is always helpful.

And, again, things you want to keep in mind self-advocacy. That's as important as anything else.

So, again, thanks. This is our kind of contact information.

If anybody wants anymore information, I hope this was somewhat helpful. Questions? Comments? Thoughts?

Or anybody want to share their experience about transition that might help somebody else in the room?

>> Dr. Tonsgard: Maybe you want to comment on the importance of a lot of people with NF, especially children, are covered under Public Aid. And then the transition to finding an adult doctor is more difficult.

So maybe you just want to comment about that and warn people about early transition.

>> DR. SHAH: Right. One of the groups I was referring to, one of the groups in the City of Chicago, we happen to have a few of these groups who may be well equipped to take care of youth with chronic illnesses and NF is MedPeds groups. They take care of pediatrics and adult doctors, pediatrics and adults. So they are trained in both and can take care of both. And they're used to some chronic illnesses and as youngsters and regular adult problems that everybody has, which would scare off a lot of pediatricians, myself included.

But because of the transition in insurance, insurance is a big barrier here. Public insurance specifically becomes a big barrier. It's hard as an adult if you have Public Aid to make an appointment. You're 19 years old, you're trying to make an appointment with a clinic, you can't get one because you have public insurance and somebody is not taking it. It's much easier to get in these groups when you are less than 18 or less than 19. A lot of these groups that we've talked to do take children with public insurance.

And then if you're in their clinic and you're seeing them, they will continue to see you. They're not going to take you off.

So something to talk to your providers about, something to think about as you get to be 17, when you think of 17, 18, 19, transition to 21, think about the early transition because insurance becomes a barrier to get into an adult clinic when you have Public Aid and have NF and some of the special clinics is something to think about. I think that's what Dr. Tonsgard is referring to, it's a good point, because we experience it a bit.

>> No other questions?

>> I have a question. You're an ER doctor. Do the medical bracelets help where they have the number? Do they actually use those when they go online and see everything?

>> DR. SHAH: They do. We use a free site. I think it's called

Lauren's Hope that makes medical bracelets for people. We recommend it for a lot of our kids. It's very personal again if you want to wear a bracelet. This site simply makes them look cool. However cool I guess they could be. And however you think they're cool. Some do and some don't.

The issue is, first of all, whether you want to have it. We don't use it as much in the emergency room. But they do use it -- EMS services has been trained. We've known about EMS services, your 911 calls. Various townships and cities are trained starting to look for one. And they're thinking a lot about allergy population and they're thinking lot about seizure disorders and things like that. So if they find somebody on the ground, at least go a lot further now.

>> They have a number.

>> DR. SHAH: Chips and you can read them.

>> And read all the medications.

>> DR. SHAH: Absolutely.

>> I don't know if they used them.

>> DR. SHAH: I personally have not. We have had people come in with medical summaries. And again, we're not dealing so much because it's a pediatric place, we're not dealing so much with a person who is found who cannot talk. We have parents bringing in their kid. So obviously the parent can tell us a lot about the history.

But they are more sophisticated now, and if you're worried about your child or something like that somehow being found, possibly it is probably worth it because there is EMS service in various counties and townships are trained on reading them.

>> And recognizing the pretty necklace.

>> DR. SHAH: Recognizing them. They have a long way to go. I'm not going to say that everybody out there knows everything about every type of bracelet. There's a long way to go. But they're starting to be trained to recognize these things and get them plugged in when needed.

>> If there are no questions. Thank you.

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