

**PRESENTER:** Our session today is called Working with Families when a Child Has an Acquired Brain Injury. And our presenter is the renowned Dr. Roberta DePompei. She is a distinguished professor, director of the School of Speech Language Pathology, an interim dean of the College of Health Professions in the University of Akron. She's also won numerous awards nationally and maybe even internationally in the field of TBI, traumatic brain injury and working with children in schools.

**DR. ROBERTA DEPOMPEI:** Okay, I was telling them, I always have you help me. Years back, I used to present with a colleague, Jean Blausner. And so we were presenting together and we both had these mics on. And I finished talking, so I was standing in the back of the room and she was talking. I thought, I need to go to the ladies' room. So I went right outside the door and of course there's a line, so we're having this conversation about research, because I do -- you know, I'm at the university, so of course I have to do research. Research shows that it takes an average male 30 seconds in a bathroom, it takes women 90 seconds, so there should be three times as many women's bathrooms as there are male bathroom and on and on and on. And I finally get all the way into the bathroom and I go like this and I realize my mic was on. So and I literally was broadcasting back into the room where my friend Jean had said her conversation is much more interesting than mine, let's just listen to her. So it's like, please, everyone, if you see me wandering around with my microphone still on, somebody remind me that I need to turn it off.

We're going to do a couple of things here. Okay, I'm just looking. I had my graduate assistant do these forms and I hope they're going to be readable. I'm going to pass these around. If you wouldn't mind filling this out. Now I'm going to explain it to you in a just a couple minutes. We'll start some over here too. I think if you take it and pass it back there. Keep one for me, okay.

This is called -- when we work with families -- let me just tell you a little bit about me. My doctorate actually is not in speech language pathology and ideology, my doctorate is actually in counseling psychology and my emphasis on my research was on families with a child with a traumatic brain injury, marriage and family therapy. And one of this is an old inventory, it's a good one. And what I found when I went to school, because I literally was drilled into school to get my doctorate degree because it just wasn't working. I was going -- I worked a lot in schools and hospitals too and we were thinking things were okay when they left the hospital, these kids with traumatic brain injuries. And several years later, I would find them in the schools or they would be back and I would see them if something would happen and I'd meet the family. And there was a major crisis all the time. Something was always wrong. And so I began to say, there must be something that we're missing with kids and

their families around traumatic brain injuries and acquired brain injuries. And so one of the -- it literally drove me back to school to study and to do some research about it. And in the meantime, one of the things I learned is, if we're going to work with families, we first of all have to understand some of our traits. So we'll talk a little bit about some of our own traits as we go through today. And this is just a little inventory about how you make decisions.

So you just read the 20 questions and you fill it in. It's a Likert scale. So as you notice, it's one, two, three, five, six, or seven, going from never to always. So just read the question, fill it in quickly. Don't think about it, there's no right or wrong answer. And then there is -- there are directions on how to score it. The scoring is a little complex, but if you sit and just think about it for a few minutes, you probably will be able to get it done. And then on the back, there is a graph where you're going to end up graphing yourself. So you'll end up with a dot somewhere in one of these quadrants. So if you have any difficulty, come and see me. We'll not deal with this until later after lunch so you'll have some time to do it.

So that's a little bit about me. I saw that some of you work in the Pennsylvania Brain STEPS Program, and I'm just wondering what your backgrounds are. So let me see, special ed teachers, okay. Psychologists? Speech Pathologists? OT? PT? Guidance counseling? Regular ed? You're not here if you're regular ed. Okay, who did I miss? Social work. Vision O and A. Okay.

**AUDIENCE MEMBER:** Early intervention consultants.

**DR. ROBERTA DEPOMPEI:** Early intervention? Early intervention.

**AUDIENCE MEMBER:** Special ed supervisor.

**DR. ROBERTA DEPOMPEI:** Okay, very good. All right, well, as you all know, or at least we're going to find out today, if you're working with acquired brain injury, it takes all of us because every child who has sustained some sort of an injury along these lines is a little bit different perhaps than some of the others that we've worked with. Not so different that they're scary and that we have no idea what to do with them. Let me just ask how many of you have worked with kids who have acquired brain injuries. Everybody; this is so good. When I first started and I would ask that question, nobody would put their hand up. And as a matter of fact, my colleague Jean Blausser and I in the very early 90s did a study where we called every department of education state -- special education in the United States. And it took us an average of five calls to find anybody who could talk to us about traumatic brain injury, and this was after the law had been enacted through IDEA, so there should have been somebody in the state, in the

state department that knew something about this population. And my favorite was when we called Wyoming, the gentleman out there just said, don't get wounded in Wyoming. We don't have anybody who works with brain injury. So I was like, don't get wounded in Wyoming.

Okay, so things have definitely changed and people know the terms. I was talking to Brenda earlier. It's always interesting to me when we talk about acquired brain injuries. The population of people who are interested and come to the session is very small, and yet if we said autism, the room would be overflowing. What's interesting to me is a lot of the cognitive and communicative impairments are the same. And so a lot of the interventions and a lot of the concerns that we have are actually the same for both populations and in fact for what we used to call LD as well. So it's always interesting to see who really understands traumatic brain injury.

I do know that we are getting a little bit more interest now because of concussions. And so that is changing, the interest that we do have. Did Pennsylvania pass a concussion law? And so what does that require? What does Pennsylvania require?

**AUDIENCE MEMBER:** Every school district needs to have a Brain STEPS group that kind of oversees anybody with any concussions or brain injuries.

**DR. ROBERTA DEPOMPEI:** Okay.

**AUDIENCE MEMBER:** Requires coaches to be trained and certification of course it requires the parents and the athletes to receive and [inaudible] education information on concussion. There's return to play and removal from play.

**DR. ROBERTA DEPOMPEI:** Guidelines, okay. Okay, so the question was about concussion, and the answers are that in this state, it is similar in almost all the states who have enacted the law that the coaches have to be trained. Do the parents have to be given information? They have to sign off. And the kids themselves have to sign off that they understand what concussion is and that they should report concussion. And then that in this state, there has to be some procedure whereby the kids are followed in school, is that right? That's pretty good. How does that work? It doesn't work.

**AUDIENCE MEMBER:** It's not required.

**DR. ROBERTA DEPOMPEI:** It's not required.

**AUDIENCE MEMBER:** It's like the parents are encouraged to -- schools are encouraged to educate parents with like a training session, but it's not required. It talks about that they should be monitored in school, but it doesn't go in any detail. Nothing's mandated.

**DR. ROBERTA DEPOMPEI:** Okay, and that's even more than most states have, so you're a little bit ahead of some of the other states. One of the interesting things that we did in Ohio, we interviewed parents and most of the parents still feel this is just silliness. You know, they understand there's been enough information about concussion that, you know, we know that some kids get hurt but you know, this little ding in the head is not a big deal. What's interesting then is to meet the parents of the kids who did have the big deal. And we do know that we used to call brain injuries mild, moderate, and severe. And now they're really trying to talk about simple versus complex. A simple injury meaning we got the blow to the head, but in most cases within 30 to 60 to 90 days, that's going to resolve. That is not -- that would be simple, where the complex would be longer term or lifetime learning and living injuries. And we do the same with our more severe injuries. We used to say, well, moderate and severe we can identify. Those are the complex injuries that we're able to identify. It's still the simple types of injuries that we have great difficulty trying to figure out what's really wrong.

So we talked to and got some information from parents of kids who ended up with a concussion, but ended up with a complex injury. And so one of the fathers said, well, if we had only really understood, we would never have pushed her to go back to play. And that's a very common thing that parents will do. They want their child back playing, and of course the child wants to go back to play. So they returned to play sooner than they should. Another parent said she's not the same, this was a college student. In fact, she's not -- she had to drop out of school because she can't attend and light bothers her. She's got visual issues and she just simply cannot be responsible for being at the university anymore. I had a follow-up with that family three years later, she never did return to the university. She was unable and still having a lot of difficulties. So parents have a lot of interest in their children and sometimes with concussion, their interest is more in the athletic part than it is in the academic part.

I was telling Brenda I went to a conference two years ago in January in DC with the NFL was there and the NCAA and heads of Lacrosse and all sorts of sports. And all the speakers were talking about the screenings and helmets and the gear and all that sort of thing except for me. I was the one who got to talk about education and how even college students, even after a concussion sometimes can't not only return to their sport, they can't return to the university. And that was when the NCAA and the NFL representatives were disinterested in what I had to say. So we have a very special responsibility

to our kids and we also have that responsibility to their parents and their families. And it's complex I know because you're in school and you don't get your hands on the parent sometimes as easily, however, I'm going to hope to convince you today that when these kids are involved in learning and language is involved, we really do need to have a plan in place to get family education and family involvement.

So that's the beginning or the introduction to what I wanted to say. Does everybody feel comfortable with TBI and ABI so that we don't really need to talk about what it is? You're all familiar, okay. Okay, very good. Let me then ask you, what has been your experience, what was the family like of a family that you felt you worked with that did very well, that you thought everything went really, really well, what were they like? What did they do? I'll start over here.

**AUDIENCE MEMBER:** The parents were very proactive, and this was quite a number of years ago, so this mother was really ahead of the curve. Really researched her -- research that was out there, going to the doctor's, was really a lead with the school team in providing resources.

**DR. ROBERTA DEPOMPEI:** Okay, so she was allowed to become the lead and she had the information with which to be a good leader, okay.

**AUDIENCE MEMBER:** Education, they educate themselves as much as they can and also they reach out for support, like through support groups.

**DR. ROBERTA DEPOMPEI:** Okay, so two things, they had some information about brain injury when they got to you and they were also willing to work with support groups as they went along, okay. Anything else? All right, how about the family that was not so cooperative and you felt very unsuccessful, what were they like?

**AUDIENCE MEMBER:** Demanding of others and not taking part in facilitating the things, suggestions [inaudible] must follow through.

**DR. ROBERTA DEPOMPEI:** Okay, so they were demanding and were unable to follow through with what was asked of them. Anything else?

**AUDIENCE MEMBER:** I worked in EI, so I think I get to see families start and then grow through their acceptance and I get [inaudible] who are difficult either are overwhelming other life issues a lot of times and so they become very demanding on us because they don't know even know how to cope yet of what's going on [inaudible] we realized the impact or they are realizing the impact.

**DR. ROBERTA DEPOMPEI:** Okay, so they're overwhelmed early on with what's happened with their child.

**AUDIENCE MEMBER:** I've seen a family where the mom becomes the one that's concerned and the father becomes the person that's kind of in denial and then ended up splitting the family eventually

**DR. ROBERTA DEPOMPEI:** Okay, so different parental responses to the injury or illness, okay. All right, anything else? All right, well today we're going to talk about a lot of those particular issues and see what we can learn, what the literature tells us as well as the research as well as I hope common sense tells us about working with these families.

So today some of the things that I'm going to do is I'm going to go back to the literature and talk to you about family systems, then I want to talk about the family responses to the injury, how they cope, and some of their life cycle processes. And then I want to also look at us and look at our own personal coping and communication styles to sort of see how we sort of play into working with those families.

I think probably some of you have already heard or this -- have you heard Welcome to Holland? Everybody has? No, all right, I'm going to read it, it's not very long. And this was written by a mom of a child with disability. It's called Welcome to Holland. When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You get a bunch of guide books and make all your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You get a book of handy phrases and learn how to say a few words in Italian. It's all very exciting. Finally the time comes for your trip. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, welcome to Holland. Holland, you say? Holland? I signed up for Italy. All my life I've dreamed of going to Italy. I'm sorry, she says, there's been a change and we've landed in Holland. But I don't know anything about Holland. I never thought of going to Holland. I had no idea what you do in Holland. What's important is that they have not taken you to a terribly ugly place full of famine, pestilence, and disease. It's just a different place. So have to go out and buy a whole new set of guide books. You have to learn a whole new language, and you'll meet a whole new bunch of people you would never have met otherwise. Holland, it's slower-paced than Italy, less flashy than Italy. But after you've been there a while and you've had a chance to catch your breath, you look around and you begin to discover that Holland has windmills and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a great time they had there. And for the rest of your life, you will say, yes, that is where I was supposed to go. That's what I had planned. And the pain of that will never ever, ever go away. You must accept that pain because the loss of that dream is a very

significant loss. But if you spend your time mourning the fact that you never got to Italy, you may never be able to be available to enjoy the very lovely, very special things about Holland.

Now that was written of course about a child who was born with a disability. Our kids are just a little bit different in the fact that they were normally developing kids. And so somewhere along the line, something happened, an illness or an injury that caused an acquired brain injury and therefore this child's family who may have actually even touched down in Italy for a little while got taken to Holland, got taken on that side trip. I was just travelling this week and I ended up in Chicago with two granddaughters. I was supposed to be in Myrtle beach. So I know kind of those stories a little bit, but certainly I don't know the depth of thinking I was going to Italy with my grandchildren and finding that I was in Holland. So I want to ask, have any of you ever felt like you were headed for Italy but ended up in Holland? Can you tell us a little bit about it?

**AUDIENCE MEMBER:** Well, I have a son who has CP, so I mean, even though he was never normally developing but you always have these aspirations that your child is going to be perfect and --

**DR. ROBERTA DEPOMPEI:** And he is perfect, just in a different way.

**AUDIENCE MEMBER:** Yeah, exactly, exactly. But you, like you said, accept things and expect the best out of them you can and you keep moving on with life. And it's fine.

**DR. ROBERTA DEPOMPEI:** Okay, very good. Anybody else? Doesn't have to be a child with a disability, just a life change that you weren't expecting.

**AUDIENCE MEMBER:** I had a heart attack in December, last December.

**DR. ROBERTA DEPOMPEI:** Wow.

**AUDIENCE MEMBER:** Go to work, think everything's great, next thing you know you're on life [inaudible].

**DR. ROBERTA DEPOMPEI:** Okay, well that would make a little side trip.

**AUDIENCE MEMBER:** Ended up in Holland.

**DR. ROBERTA DEPOMPEI:** Ended up in Holland, okay, very good. Anybody else?

**AUDIENCE MEMBER:** I fell down a flight of stairs, had a concussion.

**DR. ROBERTA DEPOMPEI:** Okay, so and that changed your life. Okay, so we all know and can relate to Holland and the story that's told there. And certainly these parents experience a life change, for many of them that is not going to get back to quote that normal -- that hopeful pattern. It's often -- the question is often asked, why is it so difficult to get these parents to go to support groups and to get them to advocate state-wide and nationally? And I think that we've sort of explained why, because this was not a child born with a disability. They didn't grow with the child. They still believe that somewhere along the line that trick is going to get them back to Italy. And so we do have a different group of parents here, they're not often as active and they don't organize particularly well. And so if we look at that story, perhaps we understand why some of them don't move together to advocate for something that they don't think they need to advocate for for their child.

So the five things that we're going to sort of think about all day today are number one, who's the real expert? And then we're going to talk about coping strategies and communication behaviors that's primary, and the therapist-teacher compared to how the family communicates. What we can learn from families with a member with a disability because really there's a wealth of information, as many of you know, on other populations of children with disabilities. There's not that wealth of information available from kids with traumatic brain injuries or acquired brain injuries. We're starting to gather it, we don't have near as much. So what can we learn from other families and how can we apply it? And then how can we include the family meaningfully in what we do?

So the first question, who's the real expert? The traditional assumption is that we are, that professionals are the experts. And that's absolutely true. We have to value all of our education and be aware that we know all the technical information and the resources. Almost all of you were thinking when we were talking earlier, well that ideal family has knowledge. They have an education. Well, that's what we give them, that's what we share with them. That's why we went to school. And absolutely we are experts in that particular aspect of the disability. But they know about the disorder. Holland tells us that there are two more experts at the table with us. The next one is the person who lives in the disorder. The child who lives in the disorder has information to tell us. And oftentimes, I don't believe we listen to the child. And so we will talk about that a little bit today as well.

And then those who live with a disorder. Parents live with this child 24/7. We see them during the day and sometimes if we're therapists, we see them a little bit during the day. And sometimes even when we're the teachers, we don't see them full time because we have aides and they're going in varying locations throughout the school district. So we have three experts, us, the person who lives in



the disorder, and the people who live with the disorder. So we have to remember that. And I personally believe from many years of experience, if there comes a question about what's really happening, believe the other two because they live together and they have valuable information to share. And it's hard sometimes I think for us to regard the child as an expert or the family as an expert. And yet I will tell you that the most important lessons that I have learned in many, many years of working with the kids and their families and doing research with the families, the most important information is not in the books, it's right there in front of you with a child and their family.

And by the way, if you have anything that you want to ask or say, if you've got some experiences you'd like to comment on or you have a question, we're not really going to have a question and answer period because if you're thinking about it, I need you to ask and we'll talk about it right then and there.

So when I went to school, what we learned was the medical model. And in some instances, the medical model still is pretty helpful, but not always. So what we learned here is the medical model, and by the way, the medical model is exactly the same as the education model, especially the special education model. And it's exactly the same as many of our socially based models. And that is -- and what's the theme or the basis for all of these? These four things, number one, there is somebody with a problem. And in the hospital, we call them a patient and in the school system we call them, whatever, special needs kid or somebody who's struggling in school or whatever we want to call them. In the literature they're called an identified patient, the IP. This is the person who's got the problem.

The second thing that exists is there is an expert, and that expert went to school and they diagnose the issue. So they go through and they give this identified patient a bunch of tests. And then we get a diagnostic level problem where we'll say, this is what's wrong with the child. They're two standard deviations below the normal in these tests and therefore they have to be placed in this type of an environment. We write an IEP or we write a 504 plan or we write -- do an RIT or whatever we do for this identified patient. Then we work with this person and we prescribe the treatment and we change the treatment. This isn't working, this is working. This worked really well, we don't have to do this anymore, let's do something else. And so we move them through the procedures of our treatment.

And then expert decides when the treatment has -- or if the treatment has been successful and when to discharge. That's pretty much the medical model or the educational model. What it does not include is a couple things. Number one, the identified patients or family is not on here. So we really didn't even need the family, did we? Because we had the person with a disability, we tested them, we prescribed for them, and we decided if they needed to stay in special ed or if they could move to regular

classroom or hopefully the ultimate goal is they get a diploma and they graduate and they're finished. Thank you very much, we're done with that. So nowhere in this model do we look at diversity. We didn't look at culture. We didn't look at family. So there are some places for the medical model. Certainly if I have appendicitis, I would like my doctor to use the medical model. I don't want him to call in a team and I don't want him to call in the family and have a consultation to say, okay, should we take out the appendix or not? I want him to make -- he's the expert. I want him to diagnose the problem. I want him to treat the problem. And I want him to say I'm okay.

So the medical model has a place and certainly the educational model has a place. But what I am submitting to you today is that when we are dealing with traumatic brain injury or acquired brain injuries, it really may not be the model that applies well because this child is just a little bit different. And in fact, I'm not sure it applies to many of our special ed kids. I think that there might be a different way to take a look and see what might make a little bit more sense other than the medical model, or the education model.

In fact, some of the research that's coming out now, Wade, Gary Taylor, and Keith Yates all in Ohio. And then I've also just put a chapter out last -- in fact it's coming out now on family resilience. So in the past, if you look at any information, you read an awful lot about the burden for the family. Family burden is a huge, huge aspect of what's in all of the literature that this has caused major issues for the family. They're unable to cope. There is major issues that come along. Other children start to have difficulty. The whole family falls apart, et cetera, et cetera. And yet if you look at Yates's and Wade's studies, what you see is that that is true in about 22% of the families. And the rest of the families actually are coping in one way or another with acquired brain injuries. And so the term family resilience has started to come into the literature. And families who are resilient are starting to be looked at a little bit differently. So we know that there is a burden. I'm not suggesting that there isn't. I'm not suggesting that there isn't loss or grief or lack or -- loss of dreams for your child. We know that that's all true. Yet we know in a good three quarters of the families, somehow they come together one way or another and are resilient and work through their adversities.

So I guess, I want to stop for a minute and ask, is that shocking to you? What do you think about that percentage of families that actually are going to cope with this situation? And across disabilities, I think it's fairly true, but let's stick with ABI for now if we could. If you think that your families are mostly resilient or mostly falling apart from burden. And I do have a degree in counseling, so I do know what silence is all about and [inaudible]. Yes.

**AUDIENCE MEMBER:** I think that the families that I've worked with have been resilient. They've -- it's been difficult for some of them, they've really have had to really push ahead, especially when they have other children and, you know, just day-to-day life. But I think that they've, you know, they've coped pretty well.

**DR. ROBERTA DEPOMPEI:** Do you think that there would be one thing that you would say about those families, a characteristic?

**AUDIENCE MEMBER:** I think they remain positive. I think in two of the students that I am thinking about, they remember the good things that happened and the good parts of -- they were both boys, of their sons. And they really remain positive --

**DR. ROBERTA DEPOMPEI:** Okay, so it's a positive attitude. Okay, so they got a positive attitude.

**AUDIENCE MEMBER:** Just to piggyback on what she said. I've had a family with us now for an entire year and when we first got them, they were very negative. So everything at school that we would say, he did this today, it's a baby step, that's what they said. Oh, just wait, the issue is going to drop and -- so they were very, very negative. And the falling apart and now they've gotten to a point where I think they're being more resilient. They're starting to celebrate the small successes. They're starting to accept a little more support and so we're starting to see they're bouncing back as a family.

**DR. ROBERTA DEPOMPEI:** Okay, good. And I imagine your support around them is helping them do that.

**AUDIENCE MEMBER:** There's a [inaudible] a lot of other people.

**DR. ROBERTA DEPOMPEI:** Yes.

**AUDIENCE MEMBER:** Definitely [inaudible].

**DR. ROBERTA DEPOMPEI:** Okay.

**AUDIENCE MEMBER:** Well see, even the family they have had a burden or maybe the couples have separated, the family that the remains -- the part that remains intact have been very resilient.

**DR. ROBERTA DEPOMPEI:** Okay, so whatever remained -- the circle of support that stayed was solid enough to be supportive, okay.

**AUDIENCE MEMBER:** What I've seen is that the parents who turn to each other instead of, you know, blaming each other, because a lot of times there's sometimes guilt involved, if it was a car accident or you know, whatever it may be. But the parents that cling to each other can -- you know, you see them

thriving more. And also, those that have some type of religion in their life and so that they try -- you can see them trying to not blame anybody, trying to, you know, cling to that seems to help.

**DR. ROBERTA DEPOMPEI:** Okay, okay, anybody? Yes.

**AUDIENCE MEMBER:** I've seen two things. The parents are heard when they come into the meetings. Like we listen. And then hooking them up with somebody who's been there so that, you know, they're not alone. Because if we don't have a child with TBI, we really don't know what they're going through. So by having that mentor and then just being open to what they're talking about.

**DR. ROBERTA DEPOMPEI:** Okay, so those are all characteristics that I think we'll find as we go through the day are on the types of activities and supports that we would like to give to our families because those are the characteristics of the families who are resilient. I personally was very surprised by the data because you pick up any textbook on traumatic brain injury, and of course if there's ever anything about the family in the textbook, it's the very last chapter. You know, it always amazes me that even when you go to a conference, I'm really excited that I'm here for a whole day. You rarely get to talk about families for a whole day. You usually get it thrown in the last 45 minutes when you're going, oh, you know, well, I think I know about families anyway, got to go. And everybody's out the door, especially if it's a family panel. Because I don't know why. So whenever I do conferences, my family panel starts the day. They get to tell all the professionals first what it's like, and then we go from there. But I mean, your textbook is like the medical problem is first, and you go sort through the continuum of care and then you throw the families in at the end if it's in there at all.

So anyway, but you know me, I've been looking at the family literature for a really long time. And really and truly almost everything that's written about families is the burden. Very rarely until recently have we started to see about the family resilience. So I personally was very shocked with those statistics of about 75% of families that were in the study. Of course, the problem is any time you do a study, who volunteers for the studies? The homogeneous group of people who were doing fairly well and want to share their information. It's not the ones that you would go wow, that is a major family with a major lot of issues. They're not going, me, me, you know, let me take the survey. So there's always the chance that the ones who really are the ones who are the ones who are falling apart the most were never really in the survey to begin with.

But anyway, I think the point here is that family resilience is enough that we need to know that there are families there who have strengths that we can pull upon and help them to develop. So I'm

going to just take you through family systems a little bit. And many of you already know this information. I want to apply it as we go, however, to acquired brain injuries.

And so the first question I have is, is that -- I mean, this is the family, right. Is the family you work with? No, why not? What's your family system look like? Mother, father, grandparents and kids, two point --

**AUDIENCE MEMBER:** Traditional.

**DR. ROBERTA DEPOMPEI:** The only thing that's missing there I think is the dog. So anyway, is that we've got, the traditional family? Ozzy and Harriet and the Brady Bunch. No, so what is your family system that you typically work with look like? You do have some that look like this, but what else do you have? What's the family system?

**AUDIENCE MEMBER:** Single parent.

**DR. ROBERTA DEPOMPEI:** Single parent. So we have single parents.

**AUDIENCE MEMBER:** The grandparents raising --

**DR. ROBERTA DEPOMPEI:** Grandparents raising the children.

**AUDIENCE MEMBER:** Kids living in group homes.

**DR. ROBERTA DEPOMPEI:** Kids from group homes. And so who is their family?

**AUDIENCE MEMBER:** Usually the caregivers.

**DR. ROBERTA DEPOMPEI:** The caregivers, that's correct.

**AUDIENCE MEMBER:** The people who own the group home.

**AUDIENCE MEMBER:** Foster parents.

**DR. ROBERTA DEPOMPEI:** Fosters, foster families. Blended. Yours, mine, and ours. And we also have, don't forget, we have homosexual couples who are raising children. They also may children with disabilities. All right, so we have a lot types of family systems. The definition for a family system, the traditional definition is those are related by blood, adoption, or marriage. So a family system is those are related by blood, adoption, or marriage who see to each other's daily needs. That's the general definition of what a family system is like. It would be nice if the Hallmark card was right and this was our family, and we do have families like this. But I think now, was it the latest statistic that a true, intact

family is under 50% of the general population in the United States now. So we have many other types of family systems that we're going to find ourselves involved with.

Some terminology from family systems literature. We have what's called homeostasis. Every family system at your house has homeostasis. And so you kind of go through every day allowing a certain amount of balance, crisis, and happiness within your family. It's kind of like the thermostat, which we wish they would turn up in here today right now for a little while. But what happens with a thermostat is that you'll tolerate a certain amount of cold, but if it gets too cold, you'll expect the heat to come on so that you'll be warm. You'll tolerate a certain amount of heat. But if it gets too hot, you expect the thermostat to turn the air conditioning on. So we sort of have this balance that we will tolerate, and we sort of go from day to day. Well that's a lot like our family operations. We go from day to day and every one of our groups is kind of -- well, they'd all be different if we all came and watched each of us perform. It wouldn't take you long to figure out that my family system is not exactly like yours, but it doesn't make it right or wrong. It does mean that our homeostasis is just that balance which we want to have tolerate.

However, along comes a crisis and for our purposes, our crisis is that illness or that injury, which is the traumatic or the inquired brain injury. And what happens there is our family balance is thrown out of homeostasis. The balance no longer exists. And so what happens with this family at the time of the illness when you first meet them is that they are trying very hard to get the thermostat back on to get back to their homeostatic basis of being comfortable. And so you get things like, we're going to work as hard as we can, listen to me, he was a football player. He needs to get back so he can play football again. And you're sitting there going, this kid doesn't see, this kid is not going to walk. We've got major problems here. And so what happens sometimes is as professionals who have background and information, we try to force the family at that point into our homeostasis. No, you're wrong. Just listen to me for a minute. This was a serious injury. Your child is never going to whatever, go back to gifted classes, be an athlete, play the piano. Whatever the family is trying to tell you, we are trying to say, but listen, our testing. But wait, this is not who this child is now.

We have the give the family an opportunity as was mentioned over here to accommodate too what has just happened. Their homeostasis, they're just trying to get back to what they know. And so it's a problem sometimes for us because we think they're in denial. We think they're doing something else that's unrealistic. No, they're really just at the beginning trying to get their family back to how it was, and that's very, very normal. It's not denial. Van Heck would say, denial is what we

put ourselves into long enough to deal with the hand we just got dealt. And so it's not bad to be in denial. Three, four years later, yes. But right now, not such a bad thing. So please understand that this is what happens. Now there is such a thing as unhealthy homeostasis. And I will just give you an example that of an alcoholic family. There is a balance in an alcoholic family, that is their homeostasis. Alcoholism is the balance. In some homes, unhealthy homes, abuse is the homeostasis. That is what everybody's used to, that's how everybody lives. So one of the reasons that residential alcoholism facilities are not always successful is why? They're taken out of the homeostasis, you're put somewhere where there's another balance going for you, and then you get to the point where you're taken out of the residential facility and you're put back into the home's homeostasis. And what happens? You go back because the whole family is used to it. So the family still -- I had families who have said, alcoholic or not, he'll have to deal with it because we always have a cocktail before dinner. Well, if you have an alcoholic member, you probably need to change that balance in your family. But the homeostasis for that family didn't change unless the family had counseling around changing that balance. And so when you return to a system where the balance whatever you're used to and you don't change that balance for the good of the person who is returning to the system, that person doesn't have a big success rate.

And so homeostasis has a lot to do with that. Homeostasis can be healthy. Most of us, it is. Different for some of us. But healthy versus unhealthy for some of our families where behaviors exists that everybody seems to think is normal that the rest of us would consider unhealthy. That's what homeostasis is. It's not always -- it's not ideal, it just how that family is used to operating. Questions or comments about that?

Okay, we also have in our family, family roles. Now we don't sit down and have a meeting and say, you know, let's just get together and figure out what role everybody gets to have. They just sort of evolve over time. So what we have in most families is the breadwinner, and that's the person who goes out and makes the primary amount of money. We have the decision maker, that's the person who decides how to spend that money. We have the troublemaker, that's the person that you can always point to in your family as the person who did it wrong. In my family, that's my son. I used to hate those candies that are in cellophane wrappers because, you know, you have them sitting out so nicely in the living room, and the wrappers never seem to get thrown away. They're always on the floor, behind the sofa, like you know, somewhere but not where they're supposed to be. And in my family it always my son. Guaranteed, if there was a mess somewhere, my son did it. And I walked in to the living room and here was my daughter throwing one of the cellophane wrappers behind the chair. And in my head I said

to myself, look what my son has taught my daughter to do. Now that's a pretty good indication that you've got a troublemaker in the family. That's the person who ate the last cookie and left the box and didn't throw it away, et cetera, et cetera, et cetera.

`We also have a hero. Well, let's go back for one minute. We have an achiever first. The achiever is probably many of you because you're here at a session, you like to learn. The achiever is the person in the family who gets counted on to get it right. You're the one who went to school, you're the one who got decent grades. You're the one who leads the family in -- if there's an emergency, you gather people together. You make the phone calls. You make sure other people have information. You know what's going on. And from achievers there is a certain group who are called heroes. And the hero is depicted as Charles Atlas. The hero is the person who holds the family up high, and this is the person who always gets called. This is the person who takes the lead no matter what the crisis is. This is the person who is always in charge of the family no matter what, except that even Charles Atlas got tired of holding the world up. And so our heroes in many families resent their position and get very tired sometimes of having that position.

So and then we have a clown, and that's the person in the family who can always be counted to get things off cycle, to not make such a crisis anymore, to make us laugh, to find the silver lining, to find another way to look at a set of circumstances. We also have the eldest child, which is a role. That particular role is often one of two kinds. One is this is a person who always is independent and way out in front of everybody else or the eldest is tied the most strongly to the parents. So that role can be one of two. And then we have the baby, everybody knows who the baby is in the family, and that's the one who usually gets their way. That's what at least everybody else in the family says. Sometimes the baby doesn't think that. But those are usually the roles that we come across. In a brain injury, what you oftentimes hear is one of two things from the family, either that this is the achiever. And so this is the family who comes to you and says, we have to get this back on track. We're all coming together. We're going to work with this kid if it takes all day, every day. We're going to get them back the way they were because they were the leader in the family. They got all As, they played football. They played in the band. They were chess champions. And we are going to make sure this ideal, lovely, personable child is who they were versus the family who says, well, you know what, here we go again. He's been in trouble with the law. He's always been belligerent. He's had all kinds of traffic violations. So now he has a brain injury. He's always been the troublemaker. What the heck, it's just one more thing. And usually you'll hear both of those.



Now the family loves both of them. I never said I didn't love my son, I just said he was the troublemaker. I mean, we love our roles no matter what they are in our family system, but we respond differently. And if we're listening as the expert on the outside, I would suspect that you might think differently of those two families. The family who says, this is our kid, and he's a wonderful person and we're just going to do whatever. Your impression is what?

**AUDIENCE MEMBER:** Supportive.

**DR. ROBERTA DEPOMPEI:** Supportive, this is what we need 100%. This is great. And when the family says, oh, whatever. He's got -- he's just causing another problem here. It's just unbelievable that, you know, what he's done. We're exhausted, we can't deal with this anymore. Your response is?

**AUDIENCE MEMBER:** Non-supportive.

**DR. ROBERTA DEPOMPEI:** Non-supportive. Now did you ever think to yourself, I wonder what role this kid had in the family? Because it might make a difference. Now I just took you through, it didn't take very long, you can go home tonight. In fact, I can do it with you right now. Who are the clowns? Any clowns in here? Okay, who's the achievers? There you all are. Okay, any heroes? There's a hero, a couple heroes. Okay, what about troublemaker? Did I ask that one already? I did. How about the breadwinner? Okay, and the decision maker? All right, so it doesn't take very much time. I do this with families, not the first day I meet them. But I'll just say, you know, I'm just curious, and I'll just give a little descriptor of some of these roles. And I'll say, what roles would you all put yourselves in? And what role would you put your child in? And once you get that information, it does help you to understand maybe some attitudes that you're dealing with from the family. And so just a pretty simple little experience to get some additional information about your family.

We also have family rules, kind of exactly the same deal. We don't sit down and go, okay, here's the family rules that we're going to operate under. But we kind of sort of have them. So there are tons, but I'm only going to go over a couple with you. One is power. Power families, power usually resides with the parental couple or the whatever dyad is running the family. And so power always resides with them no matter -- now you do know that teenagers grow up and that's about the point in time when you start to see the desire for them to take some power for themselves. And so the wise family system allows adolescents some ability to have some power over themselves, over decision making and what have you. However, in real power families, that never happens. And so sometimes that's where we see some juvenile delinquency and a lot of rebellion because they can't get any independence for

themselves. This is the family that no matter how old you are when you go home, you're in a power family, your parents would say to you, you bought a Ford? This family doesn't buy Fords. I cannot believe that you're sitting there with that car. Whatever made you decide to do that? This is a family who will say, don't give him anymore mashed potatoes, he's full, but never ask you if you were full. So power families -- power families can become destructive types of families.

I had a French teacher, and at the time I thought she was ancient, but you know, looking back she was probably in her late 20s when I had her. But she always -- she went to my church. And she always talked about the fact that she lived with her parents and that her parents had told her, she was an only child, that if she ever married, they would die. And so I went to church and she'd have a boyfriend, they'd be in church. And then it wouldn't be too much longer that it would be announced that one of her parents was in the hospital. And the boyfriend would be gone. And while that seems a little strange, it actually is documented in the literature that family systems can -- you can make yourself ill in a power situation in order to control the rest of your family. So this went on literally until both of her parents died, she never married until both parents were dead and then she married. And she had, I think, I don't know because I didn't live with her, but it seemed like she had a nice life. But she lived in a situation where the parents were absolutely power over her life to the point where she would break up with a boyfriend rather than have one of her parents ill. So that's a real power situation for that family.

All right, so let me go ahead and talk about some more family rules. So that's power. The other - - another type of family that you will run into is the family who keeps secrets, and this is the family who does not care to share -- if you're taking a family history and don't seem to be able to get it because they just don't seem to be able to give you the answer, you know, like we all know Aunt Martha drinks, but we don't talk about it outside the family. We just don't do -- not let anybody outside the family know. So if I'm going to ask you, is there a history of alcoholism in your family, you're going to dance around the question, right. So families who keep secrets are very difficult to get information from. And so again, if you're working with a family where there's an acquired brain injury or traumatic brain injury, one of the questions that you probably ought to be asking is about abuse because we know that certain number of our children have been abused. And so some families, you can actually -- I always ask the question, that should be in your family history. Now some families are not going to admit it, but actually where this is a history, a father who perhaps was abusive and now is out of the picture, moms will tell you or dads will tell you that the mother was abusive. So but of course if they keep secrets, they're not going to share. But where these types of families are involved, you always need to ask the questions.

Again, if they're a family that keeps secrets, it's going to be almost impossible to gather a cohesive -- and you begin to think there's something wrong with you. Like I'm asking these questions, I don't seem to get the answer. It may be because they're wanting to give you the answer. It's not necessarily that you're not asking the right questions or that you're not understanding. But families who keep secrets are the ones who are probably going to give you the most difficulty around those issues.

And then we have one that is a rule and a role, and that's called switchboarding. And in this family, there is one person who has the communication role. And so all information flows through this person. So we have the switchboard and so Judy comes home and she says, mom, I got invited to go the prom. And mom says, oh, that's really wonderful. Mom goes to dad and she says, Judy got asked to the prom and dad says, that's good. She can take the credit card and spend \$150. Mom goes back to Judy and says, dad says we can go shopping. We'll get -- we can spend \$150. All right, so everything goes through the switchboard, and the switchboard oftentimes is a person who actually not only deals with the family that's in the home, but deals with the siblings and relatives as well. So in a switchboard family, there's one person who calls and alerts everybody else. And if you want any information, you call back to that person. You know, Harry's in the hospital. So nobody calls Harry or Harry's family, they still call the switchboard to find out what's going on. When are the visiting hours? When is he having surgery? Et cetera, et cetera. Well, guess what happens to the family if something happens to the switchboard? The rules are broken and the family literally is unable to communicate even though that seems really strange. If it is the switchboard who is no longer functioning in that role, the family has major communication issues. And yet we don't recognize that and we just think this is a disorganized family that doesn't communicate well. They've lost their primary communicator. So that's what happens there.

I see some heads nodding. I'm just curious about recognition of any kind of rules in any of your families. We did roles, so now anybody recognize any of those rules going on?

**AUDIENCE MEMBER:** Well, can you have a blend?

**DR. ROBERTA DEPOMPEI:** Sure.

**AUDIENCE MEMBER:** Okay.

**DR. ROBERTA DEPOMPEI:** What you got?

**AUDIENCE MEMBER:** Oh absolutely power and secrets.

**DR. ROBERTA DEPOMPEI:** Power and secrets. We're working towards a dysfunctional family here.

**AUDIENCE MEMBER:** You know, I'm just looking at, you know, my family growing up. Of course, you know, I don't about anybody else, but that's the first place I go when start thinking about --

**DR. ROBERTA DEPOMPEI:** Well yeah, that's exactly what we're hoping for.

**AUDIENCE MEMBER:** Yeah, okay, you know. But oh yeah, don't talk about anything. Sweep it under the rug, absolutely.

**DR. ROBERTA DEPOMPEI:** Okay, so and we do have a lot of families that just don't want the disharmony so they will just keep it all to themselves so they don't have to have any problems.

**AUDIENCE MEMBER:** And if you ask, like if you ask three different people in the family about a specific issue, you get three different answers that all come from their perspective.

**DR. ROBERTA DEPOMPEI:** From their perspective.

**AUDIENCE MEMBER:** Hoping that they're, you know, not going to divulge anything.

**DR. ROBERTA DEPOMPEI:** Okay, okay, anybody else? I saw bunches of heads nodding, yes.

**AUDIENCE MEMBER:** I just want to -- I feel like all of a sudden, my marriage is a little bit -- going to [inaudible]. My husband's family are, among other things, switchboarding where I can't -- like Thanksgiving, we know Thanksgiving, we know when it is. You know, the date might change, but it's always that Thursday and yet everything is last minute. And it's his sister, and there's a lot of extended family, you know, the cousins, the aunts, the whole thing. There's a huge -- and when his grandparents both died, everything really went to his sister, but his sister is the switchboard. And that's how I get all the information about birthday parties, family holidays, anyone is ill or something, I call his sister. And I never understood why and I would say, what is wrong with your family that nobody talks to each other and there's never good communication? But it is through her.

**DR. ROBERTA DEPOMPEI:** And it's her role.

**AUDIENCE MEMBER:** And now I feel like it all makes sense and I can relax a little bit.

**DR. ROBERTA DEPOMPEI:** Good, so you can give it up now.

**AUDIENCE MEMBER:** I'm trying to make everyone talk to each other and it's like pounding my head --

**DR. ROBERTA DEPOMPEI:** Probably not going to happen.

**AUDIENCE MEMBER:** No, it doesn't.

**DR. ROBERTA DEPOMPEI:** Okay, well now you know why. Okay, good. If nothing else happens, what motivates [inaudible].

**AUDIENCE MEMBER:** They might need a private session, but.

**DR. ROBERTA DEPOMPEI:** Very good, okay, anybody else?

**AUDIENCE MEMBER:** I think it's interesting in terms of I do a lot of communicating with my siblings through my mother. You know, I think just as we got older and moved, she's the common switchboard. You know, we all talk to mom so we get information about each other, but I think it's also, I mean, we're at that generation where we're starting to take care of our parents. So when someone has that role of switchboard in it, it's just the age where they're not remembering things as well.

**DR. ROBERTA DEPOMPEI:** Not going to be able to do it anymore. So who's going to be the new switchboard?

**AUDIENCE MEMBER:** Oh, I mean, there's a sister-in-law.

**DR. ROBERTA DEPOMPEI:** I guess, see, there's always somebody, there's always someone waiting in the wings, right? Okay, very good. All right, let me just see what's next here. I'll just do this and then we'll stop and take our break.

**AUDIENCE MEMBER:** Can I ask?

**DR. ROBERTA DEPOMPEI:** Sure.

**AUDIENCE MEMBER:** Where does that information come from about your family rules, the power -- you said that there were more. Where do you get this from?

**DR. ROBERTA DEPOMPEI:** There are tons of family systems books, textbooks. In fact, if you just look up family systems, marriage and family therapy, there's a book called, something about the barracudas. Can't remember. Or email me and I'll get you -- I'll send you some of my references, but it's just if you look up family systems and power, you'll find it. Family systems and not power. What we were just looking at? Roles and rules. Family systems roles and rules.

Okay, all right, so another one in family systems is dyads and triads. So what we have is in your family system, dyads of course are two-person relationships. Every two people have a different relationship. Your relationship with your mother is different than your relationship with your father. It's

different than a relationship with one sister than the other sister, or one brother or what have you. Every two people have a different interaction. I don't know if any of you remember the Smothers Brothers, but Dicky and Tommy Smothers, they used to always say, mom always loved you best. Well, it wasn't that she loved the one more than the other, but the relationship between one was different than the relationship with the other. So we have dyads in families.

We also then have triads, and that's when we introduce a third person. And oftentimes when we introduce the third person, we change the dyad. So the two gets changed because a third one enters. So whether it's three siblings or it's mom and dad and you, however that comes out or however that happens, and certainly with your kids, it's the same story. Every dyad is different and when you introduce a triad, it changes. I will never forget at our university we have a speech and hearing center. And there was a little girl with cochlear implants and she was a sweet little thing. And she would come with her mom and it was fine. You know, just everything was going really, really well. But everybody would say, you know, I don't know what happens, but when grandma's around, you know, everything's weird. Well, one day I was in the elevator with them and this grandmother was relentless on the mother and the daughter. So we're in the elevator and she is like, why did you dress her like that? She looks like a bum. And then she said, well, she picked out her -- I don't -- you never let her pick out her own clothes. What is wrong with you? And this woman never stopped. And I'm in the elevator going, oh, my gosh. So I'm watching it. I mean, she is like this and this little girl is just -- you could watch her. You could just watch her just be so upset and sort of in rage. Well, it isn't five minutes later, she's screaming down the hallway as they're, you know, going to go down and do whatever they're going to do in therapy. And the mother is screaming at the grandmother now, see what you did there? And I mean, this whole thing erupts. And so I went in to the supervisor and said, you got some interactions here. Well, I don't know why she behaves like that. She behaves like that because her grandma's here. And so what you need to start to look at is what happens behavior-wise in dyads and triads. So sometimes dyads work out really well or sometimes it's a bad dyad. You know, maybe you don't get along with one of your siblings. But introduce a third person, your mom or somebody else, it calms it down a little bit. So it can go either way. But dyads and triads are always very unique and very different.

And something that's very interesting for us to pay attention to, again, you don't -- sometimes we inadvertently create triadic problems. We have the child that we're working with and we know there's a brother or sister in the building and we send the information home with that sibling. Well, you've just triangulated that child. You've just made that child a parent. So if you have a message about

Johnny that's got to go home, the message has to go home about Johnny either you send it home or you call or you email, but you don't send it home with a sibling. And lots of times I see it happen whereby you say to that sibling, he was really bad today, let your mom know. Now what? What have we just created? We've created the triad between you -- well, two triads. You and the two kids and then you've asked the sibling to make a triad reporter of the bad news to mom or dad. So we have to be careful that we keep dyads as dyads and if we're going to send triad information, it needs to be good so that everybody can be happy about that information. We don't send bad news home through a third party, especially if it's another child.