>> All right. If I could get everyone's attention.

I see 1:45 on my watch so we'll go ahead and get started. I wanted to let everyone know that this is family advocacy in the IFSP. I'm Chris Payne Soros. We were also supposed to have Sarah Honig Feld co-present with me. Sarah, unfortunately, had an unavoidable conflict today so today you have the Chris show for the next hour!

I do teach law at a Law School. I also was a classroom teacher, so I'm used to seeing students in a horseshoe shape and seeing people on the periphery and in the back of the classroom and I'm trying to get students to move front and center so this is different to see you there already. So thank you for being here.

I'm the educational policy council for the National Association of the Deaf, NAD. I work with Sarah hon ig Feld who is the educational policy specialist for NAD.

Before we get going, I wanted to share that everyone has access. Can everyone see me, where I'm standing, or can hear the interpreter who's using the interpreters?

Sometimes I get so excited that I move and then you're not able to see me, so I'll stick to where you can see me.

So this is our plan for today. We are going to start with some introductions. I'll review our learning objectives. And then get into our content. Content of the presentation, parts of the IFSP, specific concerns for Deaf/hard of hearing and Deaf-Blind children, and also resources for families to avail themselves of.

This is the first presentation after lunch on the second day, so I expect everyone is ready to go into a food coma. So we are going to interact a bit. I know it's difficult on the second day. Everyone might want to nap but we are going to have a little interaction to make sure that doesn't happen. Again, I'm used to teaching law students and undergrad students so I can find ways to wake people up and make sure that you're participating.

As I mentioned, I'm the education policy counsel for the NAD. I provide legal advice to NAD on issues surrounding Deaf education. I also work one-on-one with some families, Deaf families, hearing families, who have d/Deaf/Hard-of-Hearing children to address any number of barriers that they may be experiencing educationally upon identification or with a Deaf child who, in a post-secondary institution, has some rights that aren't being addressed. There are some specific legal issues and advice I'm able to provide to connect those families to resources that exist and I work together with families in that way.

I also work in collaboration with a number of other partnering organizations and agencies, be they schools or kind of the gamut.

Last fall, I joined NAD. Prior to that I was a teacher. I still teach part-time and I also worked in private practice with a law firm. That was a number of years ago. I taught elementary school prior to that at a public school.

I'm also a parent of two children, one of whom is 9, who's Deaf. And next week my youngest is hearing and will turn 8. So technically, is still 8 now but will soon be 9.

I happened to meet my son's teacher's father yesterday. What Dune?

-- what do you know?

He was staring at me and said I know you from somewhere. After a few exchanges we found out that he was in fact my son's teacher's father. If you're wondering if I am that mom, yes, I am, because my teacher's dad knew my name. So okay!

Start from there.

If at any point I have been acquiring sign language since my son did and I have been keeping up with him ever since. If my sign isn't clear, by all means, raise your hands and I'm happy to clarify. I would like to get a sense of who is with us today. Parents, family members, d/Deaf/Hard-of-Hearing -- who have d/Deaf/Hard-of-Hearing children?

Okay.

How about professionals?

Anyone here in a professional role or capacity?

Could be both. Right?

A parent and a professional. And who am I missing then?

Okay. I think that covers everyone.

These are our learning objectives for today. We are going to talk about parts of the IFSP. There's a lot that you'll get to know before we're done.

Some of which may be new, depending where you're coming from. We'll outline special considerations for d/Deaf/Hard-of-Hearing and Deaf-Blind children within the IFSP. And we'll also seek to identify and name resources to consider during IFSP development for d/Deaf/Hard-of-Hearing and Deaf-Blind children.

Early intervention for parents and families is foundational to the success of d/Deaf/Hard-of-Hearing children.

And we really, as parents and family members, want to become successful advocates. And to do so we must be empowered to not only understand the early intervention system but also how to be active participants in that system.

So this workshop will hopefully provide families and professionals with an introduction to the IFSP. We'll have some interaction and maybe some shared knowledge to achieve that objective.

I'm going to hurt myself if I keep my lanyard on while I'm signing. I might end up choking myself.

I am equally clumsy whether I'm speaking in English or whether I'm signing, if you happen to be curious.

First off, we'll talk about the IFSP and some Deaf -- get a big picture view of that, how to understand the IFSP in its entirety, globally, which I think is a great thing to do.

My husband used to refer to the IFSP as my infant son's report card. And I would say, wait a minute, no, that is not the case. A report card is reflective of the past nine weeks, let's say, or the past quarter. IFSP is much machine more than that. He would look at me like okay, I guess IFSP jokes are not on the table.

So that's how my house goes.

So what is the IFSP?

It's an individual family service plan. It contains a lot of information that can be helpful in terms of putting yourself or your family in a position as a family member or also make sure that the IFSP is not missing critical components. IFSP is a legal document and it's important for families to understand. Sometimes families feel like it's just a document to be passed around and signed, but it is, in fact, a legal document.

And it's important that it's about your child, their specific services and goals, because it is a legal document.

So it's important that the information contained in the IFSP is accurate and suited to what the family needs. There's some things that the IFSP is not. It's not a report card.

It's for planning purposes and it describes the services and how they will be provided, the attending goals and how those goals will be measured and achieved, and then it tracks the child's progress towards those objectives. It's important to remember that families are at the center of the IFSP and the IFSP needs to be strengths-based. If you're not excited already by what I've shared, the next part is going to be a little more technical so here it goes. We'll see.

Let me get into some specifics about the IFSP.

It includes a great deal of information including the child's present levels of physical, cognitive, communication, social or emotional, and adaptive development based on objective, per se, objective criteria.

It includes the family's resources, their priorities and concerns as they relate to supporting the development of their child. It includes measurable results or outcomes expected to be achieved by the child and the family. It includes developmentally appropriate pre-literacy and language skills and how -- I cannot emphasize -- how those time lines will be achieved and the skill development necessary as well as the early intervention services necessary to meet the unique needs of the infant or the family.

This will take -- outlines how it will take place in a natural environment where early intervention services will take place. We'll talk about the duration and who specifically will be coordinating those services and responsible for ensuring that those services occur.

When a child turns two, the plan turns toward transitioning for preschool. So the IFSP is reviewed on a six-month basis. So much can happen with infants within that six-month time frame. The Department of Education does have a model IFSP that contains federal requirements. States also then can add additional requirements. So some states' IFSPs look different than other states' IFSPs.

Let's get into some of the details around IFSPs for d/Deaf/Hard-of-Hearing children.

For many families with d/Deaf/Hard-of-Hearing children, there's a great number of new experiences. They're navigating early intervention and that alone is a new experience. They're navigating a number of new things, new experiences that are layered on top of each other.

When families are thinking about what they want to include in the IFSP, sometimes it can be difficult to know where to start.

So here are some suggestions for families to think about.

And again, there's going to be a great number. The legal terminology is not important. What's important is that it's an accessible document that families can take advantage of. First of all, ask yourself what is your child doing now?

How does your child communicate their wants and their needs?

What is the child doing physically?

How are they learning?

And what else downstairs about do you notice about your child?

Of course, family members know their child better than anyone. So the information that you can provide, if the family can provide, and the insights are critical to the IFSP.

And provide a real-life perspective. From the family, because it's difficult to develop an IFSP without family members' involvement because they're a critical component. They're central to the IFSP being effective.

>> In working with families, we need to make sure that we're including extended families in this conversation as well to make sure that we can support the child. It depends on the family dynamic and it depends on the child individually. There are other family members who can be experts as well as the parents. And we need to know what they know and the family needs to be open to learning things that they don't know. The IFSP hopes that your child will grow and learn and we all have hopes and dreams for our children, right?

So children with IFSPs can also have it formally written in a legal document, which is really helpful for parents, and questions and concerns that you have can also help the child and you can include those in the IFSP as well.

There have been other presenters who have addressed this point in depth and whether or not people or children have cochlear implants. That doesn't mean we wait until the technology is a fit or if it's the best fit for that family. So we need to make sure that we have access to language from the start. And if they want to use technology, they can do that. If they want to choose to use spoken language services, they can continue to do that as well.

So they don't need to pick one. It's important that families know what the options are and that they're exposed to all of their choices.

Within IFSP it's important to think about history and it's important to think about the language environment.

So language is really important. d/Deaf/Hard-of-Hearing children are at risk for language delays, so we need to make sure that we're talking with early intervention providers to be sure that the child's linguistic development is appropriate.

So this could include having your child receive services specifically from trained professionals as well.

And it can be sign language. It can be spoken language. It can be both. It's whatever the family decides to use. And Deaf Mentors can also help in this process. They also play a vital role and we want to make sure that they can navigate the EHDI process even if it's short-term.

A short anecdote. I'm a former elementary school teacher, reading books all of that stuff. I wanted my children to develop love of books and literacy, anything printed, I wanted them to be all about it. Then I had my own child and they were identified as Deaf at seven months old. So not the newborn but 17 months. And then I noticed that when they were a newborn he would be a little wobbly but he could sit. And with a Deaf baby I felt I was a little bit confused. So if I sat behind him, and I would hold the book and talk with him in the way that hearing people do in a very natural way with a hearing baby, I wouldn't be able to do that at seven months old. He was not hearing. He was a Deaf baby. And I thought, okay, I was trying to figure out, all right, I have the baby here, I can have the book near me. How can I get the baby to look at me and the book at the same time?

I need three hands. I need two to sign. I need one to hold the book. How am I going to figure this out?

So it was so nice to have a Deaf person involved. They showed me very different ways of logistics and it's a very simple example and there are many, many more of how, if you involve Deaf people, they will help you read to your children, they will show you all of these strategies that they've learned over the years. And I mentioned I'm already a little bit clumsy. I've said that, right?

So I'm trying to figure out all this stuff while I read the books to my kiddo. So anyway, anecdotes are great, but the point of this is you need to be specific about auditory access and the services that you need, so ask for Deaf mentoring, ASL services taught by Deaf people. Request resources within the IFSP so that they're legally bound. And you can see up here on the slide the last information of auditory access is really important, too. You want to be very specific about that. We want to make sure we know what a child hears during testing and make sure it's not -- it is the same as the real world.

It's very different when you have a test and what real-life context looks like sometimes, so we want to make sure we're identifying things properly.

And again, the audiogram will show specific numbers, but we need to make sure that that's really what's happening in real life as well.

So now we are going to talk about assessments.

Are you ready to focus on this?

>> Let's go ahead and pair up and I think we are going to move into an activity.

Just to have a share with your partner or a small group. Will either is fine. You can utilize the space as necessary to talk about what approaches are helpful in making sure that families are two things, both fully involved and fully informed in the IFSP process.

I think we'll give this about 10 minutes before we come back together to talk in a larger group.

Attention.

I'm sorry, I have kids, so -- if we could come back as a group, that would be great.

So we have these questions here. And would anyone like to share what they discussed as a group?

Anybody?

Anybody?

We have a volunteer!

I'm so happy to meet you in person as well.

>> Great to put a face to the name. I'm Julia -- from California School for the Deaf. Through my work as an early language and education program consultant, I always offer ASL assessments for free with the sense that I can sit with families with the SB2, that's our LEAD-K law, and go through with them is your child meeting these milestones, go through the checklist, and also talk with the child's teacher about what they see in the classroom or at home visits. Then I can do some observations as well and what the child is achieving in terms of language milestones we can put a strike on some they haven't yet achieved, we can put those as appropriate milestones as goals for the IFSP. That makes parents empowered. I would like to see these, I need a Deaf coach, I need XYZ in order to achieve those milestones.

>> Yes, thank you. Do we have any other brave soul who wants to share?

Anybody?

I see some people perking up and some conversation in the back.

What do you think?

>> Hang on one second. If we could just wait for the interpreter to come with you, that would be great. You just have to wait for the interpreter and a microphone would be awesome.

>> As I was saying, we're parents. Our daughters are under three so we'll be transferring from the IFSP next year into hopefully an IEP. We were discussing if we could look for anything to be changed, it would probably be explaining it more. The people in charge of our IFSPs, they're always in a hurry. Everyone's overwhelmed right now, overworked, has so many kids that we're just basically told to sign and move on.

I'm not sure what the other questions were. I had a hard time reading it. But I -- .

>> I apologize for that.

>> It's okay. Anything else?

What were the other questions?

I just want to answer it correctly.

>> Really the questions are, what approaches are helpful to make sure that families are fully involved, fully informed in the IFSP process.

>> Yeah, I would say just definitely explaining them better and reading them over instead of just emailing them over to parents and saying sign and send it back. Just more personal involvement with that would be great.

>> And one other thing that came up from a more structural perspective is it seemed like there wasn't enough staffing in the programs. So if there was more investment in the staffing, then the case loads can be smaller and people can take time to do that explanation.

>> Thank you. That's a really good point. I'm going to get back to that a little bit later, but you're absolutely right. It's not okay to just sign things and move on. This is a legal document.

Do we have another participant who wants to talk?

>> Hi there. I'm the moderator, but I'm also a parent. We were having a nice discussion here about -- I'm sorry, what area are you from?

>> Micronesia.

>> Micronesia. We were just talking about how important culturally to understand where the families are, because not every family needs a certain box. So really understanding the needs of the family culturally, the dynamics of the family and how they work, I think that that's the most important part and that was what was integral to my sense -- development and my -- .

>> Yes, thank you. Would you mind passing the microphone to the next person?

>> Yes, I am also a parent and we were discussing something similar and I want to add that once you get the diagnosis, especially if you're a hearing parent, you're -- what my service coordinator did in the beginning was she was being the lead. And kind of like I don't even remember the time we did the IFSP, because she was just driving me into it. But then one time when I finally accept that I was ready to take the leap, I got it and we did it together. But at the beginning sometimes we need more help.

>> Uh-huh. Thank you.

Any other comments?

If you could pass the microphone, that would be great.

>> Hi, just joining the session, but -- .

>> Give a second to make sure the interpreter's in place.

>> I think one thing I see as early intervention providers between our service coordinators and families is sometimes a miscommunication with a family friendly -- trying to describe the IFSP in its entirety and effectively but using language that is in layman's terms and asking kind of opening the space for clarifying questions from the parents. I think sometimes we get in such a rush to get our paperwork done, like you said, sign it and move on, that we forget to leave space for those questions and we might not be giving permission for questions and clarification.

>> Yes. Thank you.

We have one more comment. I see a hand in the back.

>> Thank you for running the mic. I appreciate you.

>> I just wanted to add there are some models that can be -- in early intervention that -- the evidence-based practices that can be more family-centered. And in particular, we've adopted the routines-based model. And part of that is driving the goals and the plan based on a detailed, in-depth interview with families. So that interview with the family can last anywhere between one to two hours. And all of the goals that we develop on our plans come from that family. So you can't develop the IFSP if you haven't really spent time getting to know that family, getting to know their context, knowing what's important to them, and prioritizing what they need and want in their life. So there are models out there. That's not the only one, but there are other models out there that really are less medical, less clinical, and really focus on goals coming from families.

>> Yes. Thank you.

Any other questions or comments?

You can go ahead and put the microphone down. I'm not even sure where it is. Okay, perfect!

Several themes came up during that discussion and I will discuss them even more.

And discuss additional ones as well. The thing is, every state is a little bit different or very different, and how families, how many families they have, how many families are not supported is very different. How much information is provided timely really depends on the state. How much time there is to review. If families have any gray areas, remember, I'm that mom who's like I have my hand up because I don't understand something and I'm a lawyer, by the way. I'm white, middle class woman and if I get upset, I have to manage myself in the same way that the system is established.

And people view me in different ways. If I'm asking all kinds of questions or anything like that, you know?

And we don't want families to be in a situation where they feel that they can't ask those questions. And even if they're viewed in a different way, depending on the environment.

I have another story about showing up to my son's school but we will hold that for now. One of the things that we discuss when we have time to pull everything together, when we take a look at testing and assessments and evaluations in the IFSP, does the tool assess what it needs to and is the child using more than one language, for example?

Sometimes it does assess what we want to, sometimes it doesn't. So if the child is using ASL and English, it's really important that they have both languages tested separately. One test in English. One test in ASL.

And we want to make sure -- how many of you know who the tests are normed against?

That's something that's really important. And assessments and evaluation in the IFSP would be a whole other workshop because most of them are normed against hearing children. So we need to make sure that it's accurate that we have assessment and evaluation in the IFSP.

And we make sure that we the evaluations and assessments are fitted to our children, and that could begin, like I said, be a whole other workshop that could be a day's lecture. So all of the work that we have, it's not a perfect system. We are working in a very imperfect system. And the system doesn't consider or does not consider well multilingual children with multi-cultural backgrounds.

So we need to make sure that we're thinking about everyone's background.

When we talk about IFSP goals for d/Deaf/Hard-of-Hearing children, yes, language communication, important!

Important!

Right?

But it's not everything.

It's not everything.

Language is important for the IFSP, but remember, this is the goal for your child and they have to be broader than language and communication. We need to think about social emotional development. We need to think about family resources. And think of the whole child and have all of that reflected in the IFSP.

It also should include information about goals that relate to the child and family's cultural identity and have accurate information about hearing levels. It's not only during the audiology appointment and during that test. Family supports and resources, the goals need to be specific and measurable.

So when we talk about the service grid in the IFSP, this is the part of the IFSP that lists appropriate services that will happen for the future months when the ISP is in effect. It might be an assessment or a certain number of visits. It's really important that the child specifically when they approach the age of three or it's like two or three months before they turn three, they are going to age out of early intervention. So it's important that families keep a record of services that they've gotten, also what they've requested, to make sure that they have all of this in the process.

So you have to establish it early and track it well. And that will make a difference for the IEP development as well. And I see some families in the back. You need to make sure that you're tracking services until the age of three, and then you have that transition for once they age out of early intervention.

Because we also discussed Deaf adult involvement already, so that's really important as well. We see many families that want service in both ASL and spoken language and that request is important. So we need to make sure that we have all of that in our meetings and we see families -- we see many families that want services in both, so we need to make sure that we request that. And ASL needs to be provided to the same extent as spoken language.

We'll discuss that more later.

Often there will be specialists for spoken English, but SLPs spoken language and teachers and ASL will be offered in support but it's not the same. We know that. But a lot of the families don't. So we need to make sure that the services provided are sign supported and we want families to know that if they want services, they need to have service providers who are equal in quality in spoken English and ASL.

Natural environment is defined as both home and community-based, including language-based programs for d/Deaf/Hard-of-Hearing children.

Now we are going to transition to something very exciting, for me at least.

So when a two-year-old is close to being three, two and a halfish, they will start the transition planning in depth. And we make sure that families think about different opportunities for their child. I encourage you to think about using the word opportunity, not options.

I like the word opportunity.

Because it's what's possible. What at this point we can provide for my child, rather than options. They are typically ranked and some families will have the impression that they have to pick the first one, so it's better to talk about opportunities.

And think about all of the different opportunities available at placements and request to know all the possible placements and opportunities, not just what the team thinks is appropriate. Ask to visit placement sites, for example.

You can visit all of these placements.

And families can ask the team what are the opportunities for my child, ask each team, and also language development; which language are you going to use?

Will they have access to d/Deaf/Hard-of-Hearing peers?

Will they have access to Deaf adults?

What support can we provide at home?

You need to ask all of these questions early.

And you have to think about the support that they can provide at school, the things that you can provide at home. If I'm a hearing parent, in the past I taught elementary school, I know if reading skills are on par with your grade level or not because of my background. But I don't have -- you can see my signing. I'm not my child's language Bono by any means, so I need to make sure I'm providing at home what he needs and at the same time make sure I get support from my community for what he needs as well that I'm not able to provide. I need to make sure that what's helpful for hearing families to connect with Deaf families. Not because they will make the same decisions. Maybe they will. Maybe they won't. It really depends on the family. It depends on the child. But it information sharing on how the families make their decisions is really helpful. And then saying why you don't make the different decision, that's helpful too. Because a lot of hearing families don't have that. They just talk to each other. It's the norm!

But that doesn't help me at all to know another hearing family. I want to know what the Deaf families are doing and see if that will work for me.

So a lot of that goes back to how hearing families connect with Deaf families and how they're involved with Deaf adults throughout the child's life, especially in the early intervention process.

We're getting close on time. I just realized.

These are obviously not all of the resources but some that could be helpful for parents to figure out the IFSP and the whole goal, talk to people, meet with people. Families have had different experiences going through the IFSP process. Not every situation will directly apply to your own, right?

But it helps to learn to understand what other families go through. And also, when we are talking about d/Deaf/Hard-of-Hearing children, all d/Deaf/Hard-of-Hearing children become adults. And in the past, there were d/Deaf/Hard-of-Hearing children, they make connections with Deaf adults and that's really important. All of the adults have told us this. So it's important that you make sure that you consider that when navigating this process and connecting with other families, ASL classes, organizations that are here today, some of them had the tables in the exhibit haul, the Clerc Center, ASD, National Center on Deaf-Blindness. There are so many resources. Don't sign any documentation if you don't feel comfortable, including the IFSP. It's awkward. It's hard. You feel pressure. And it becomes worse in the IEP for the child.

You want to make sure that you're reviewing the IFSP before you sign it. If you're not sure what something means, what it represents, it's inevitable. Somebody will be good cop/bad cop, right?

I'm always the bad cop in my relationship and that's fine. My husband is like hey, yeah, how ya doing, everything is fine. I'm like no, don't say that!

Anyway, yes, people are busy. It's impossible to read the IFSP during the meeting when you have a table full of people all around you. It's impossible. So request it ahead of time. Take some time to review it. If you want to ask other people what they think, there's nothing wrong with that. You're supposed to do that. You absolutely can, even if you feel awkward. Take the time to review it.

Remember it will follow your child. So if you want to make sure that the child is qualified for different services, it needs to be included in this document.

And before we finish, this conversation can continue at the 3:45 workshop. We are going to discuss IDEA and 504 and the ADA. My jokes don't get better, sorry about that. But we will be talking more for sure.

I have the time at 2:43 right now. Thank you for your time. That concludes this workshop and I will stay for questions, absolutely.