



**NEVADA COMMISSION ON
AUTISM SPECTRUM DISORDERS MEETING
EARLY CHILDHOOD SUBCOMMITTEE**

Wednesday, July 30, 2014

1:00 pm

MINUTES

MEETING LOCATIONS

Conference Call From
Grant Sawyer Legislative Building
555 E. Washington Ave., Room 4406
Las Vegas, NV 89101

Agenda items may be taken out of the order listed on the agenda. The items maybe combined for consideration. Items may be delayed or removed at any time.

1. Call to Order, Roll Call, Announcements

Michele Tombari welcomed everyone and called the meeting to order at 1:05 pm.

Voting members Michele Tombari, Toni Richards, Nicole Cavenagh, Shannon Crozier, Debra Vigil and Jon Paul Saunders were present.

A quorum was present.

Announcements:

- The purpose of this subcommittee is to develop recommendations for the 5-Year Strategic Plan for children with autism from birth to 6 years of age. The recommendations will be completed by the end of 2014.
- Our goal is to dream big and bring the best ideas to the table and look forward to the next five years.

2. Public Comment

No comments.

3. Committee Member Introduction

Members introduced themselves, described what they do and stated what they wish to accomplish on this subcommittee. Some of the goals to be accomplished:

- 100% of children diagnosed with autism are well on their way to living independent lives when they leave this age group
- Early diagnosis
- Statewide screening program
- Family support
- Access to therapeutic intervention

- Evidence based early intervention
- Collaboration of agencies and state organizations
- Parent education

4. Discuss Committee Goals and Objectives

The goals of the committee are to achieve early diagnosis and early intervention for children with autism in the birth to 3 year age group. The committee will be fact finding to look at the 2008 plan's recommendations to find out what recommendations have been implemented, what are working, what are obsolete and what are still valid.

5. Review of Nevada's 2008 Strategic Plan and Autism Programs

There are a lot of recommendations to look at. Michele Tombari asked for volunteers to review several recommendations each with the goal of finding out what agencies are implementing the recommendations, if the recommendations are working, not working and are still valid for the new plan.

- Julie Kotchevar with NEIS described NEIS's early intervention process for children with autism from birth to when they transition out at 3 years of age. There was a discussion of the process, procedures, data tracking and the laws around the process.

*See Attachment A for the complete transcript of Julie Kotchevar's interview.

6. Review of Other State's Autism Programs

Michele Tombari asked for volunteers to look at other states' plans and recommendations with the goal of patterning Nevada's recommendations on what is working in other states. Michele Tombari also asked for volunteers to come up with questions for a community development survey.

7. Schedule of Future Meetings

The next scheduled meetings are: August 13, August 27, September 10 and September 24, 2014.

8. Public Comment

No comments.

9. Adjournment

Michele Tombari moved to adjourn the meeting. Jon Paul Saunders motioned to adjourn the meeting, Shannon Crozier seconded the motion. All in favor. The meeting was adjourned at 3:00 pm.

Nevada Commission on Autism Spectrum Disorder
Early Childhood Subcommittee
July 30, 2014, first public meeting
Chairperson Michele Tombari
Interview with Julie Kotchevar

How speakers are identified:

JK - Julie Kotchevar
MT - Michele Tombari
MH - Marissa Hendron
SP - Stephanie Patton
TK - Thomas Kapp
TR - Toni Richards
SC - Shannon Crozier
DV - Deborah Vigil
JS - JonPaul Saunders

Julie Kotchevar was introduced and the interview started at 49:46 into the meeting.

JK: So I was asked to give an overview of how a child enters early intervention. We receive referrals from a number of sources; we serve all children who have a disability or developmental delay. So we receive referrals and we also do a number of Child Find activities where we go out in the community and do screenings, ages and stages screenings, parent screenings, sometimes outreach in order to get families to come in and have an assessment.

Our services are offered at no charge to families, but we do ask if they have insurance that they permit us to bill, but all of our services are provided at no cost. We are governed by the IDEA law, Part C, regular schools are Part B. Actually, Kindergarten and up are Part B. Mr. Thomas Kapp is on the phone and this is heavily regulated.

Usually the children come in, we take a referral, we take family history over the phone and then schedule what we call an MDT, which is a multiple-disciplinary team, they have more than one person in disciplines that will do a developmental assessment. We also have pediatricians on staff, and we have a lot of therapy providers, OT, PT, speech we have on staff. We have a BCBA, a number of BCABA's and behavioral aids, all which can participate in the MDT to assess a child. We can serve children up to age 3, once they turn 3, we aren't permitted to serve them anymore.

We look at all of the needs that a child has and then we provide treatment at the intensity and frequency that is determined by the service plan team, the specific family and any therapy providers who would be part of that child's team. They develop a plan of service and then we provide the services along these lines.

51:50

One of the things we have been focusing on is trying to do better early identification of children with autism.

In the last year we have actually diagnosed 94 children. One of the things that we are trying to do, our average age of diagnosis was about 2 1/2, so we're trying to shorten that so we started using the M-CHAT RS, which provides a follow up option rather than doing multiple M-CHATS, so we didn't have to wait for a child to fail more than one screening.

Hopefully we'll have more data, we actually have to track it manually, and we just started doing this, tracking every single child that's ever failed a screening, do the follow up, and if they fail due to reasons we suspect are autism, then moving them more quickly to the ADOS, rather than having them wait and fail another screening at 24 months. So we have been trying to shorten the age at diagnosis. We have been already able to do that.

52:55

Once a child is diagnosed with autism, we have the diagnosis confirmed by one of our pediatricians, which has been important to families because it provides them with a medical diagnosis instead of an educational determination, which means they can qualify for things like social security disability, it makes it easier for ATAP to put them on the wait list, I'm just teasing Brook, I'm sorry,

We also provide a 100 day kit for every child who receives a diagnosis from us from autism speaks, along with a referral to ATAP, we help them fill out their disability application if they choose to go in that direction, and then we start developing a treatment plan.

One of the struggles we've had in the services system is that if we're diagnosing them at 2 and a half, then in a couple of months we are transitioning to the school district, and we have a very limited window of time with which to offer any comprehensive services, so that has been why we've really been focusing on how we can shorten the length of time for early identification, so that we can then provide more comprehensive services before they leave at age three.

54:01

Does anyone have any questions? I'm not sure how much detail you want, but I'm willing to answer anything.

MH: This is Marissa Hendron, I have a question, is there a wait list currently for those evaluations?

JK: There is not a wait list.

MT: There's no wait list for assessments? Or no wait lists for treatment?

JK: There are no wait lists at all, actually. We had a small wait list in Las Vegas, and as of July we no longer have a wait list for services, and we have not had a wait list for assessments, for actually quite a long time.

MT: Wow, that's good to know, thank you.

JK: We had a short wait list for autism vendors in Las Vegas, but thanks to a collaboration with UNLV and Dr. Croziers we actually finished off all those assessments using the Center for Autism Spectrum Disorders down there, so we were actually really happy to get those done. We actually have close to 20 autism assessment teams in early intervention state wide. We do quite a few autism treatments, we've had a lot of ADOS and ADOS-T trainings over the last year and a half to two years, we have pretty recent trainings and meetings on behavioral therapy and on how to use the ADOS and how we effectively communicate that information to families.

55:33

SP: Stephanie Patton, I have a question regarding when some children are referred out to nonprofit agencies besides NEIS, doing these evaluations and services. How much support does NEIS provide and how much oversight is provided to make sure that these nonprofits are also following the same plan or something similar to what you just described?

JK: I'm assuming you mean the community partners? They also provide early intervention services.

SP: Yes

JK: They're regulated through NEIS because we contract with them, but also through part C because they're also required to follow all the part C regulations. I will say they don't do or not all of the community partners don't do the same number of diagnoses that we do. We have started in the last year a program development process where we have been opening up all of our trainings to any of the community partners who want to participate in them. I've also recently purchased some additional ADOS kits for community partners who could not receive them in the past because they are costly to purchase them.

56:51

So we are continually working, but we do look at them and they are regulated in the same way that NEIS is, but I will say that they don't receive, when we do the referrals, we keep the more complex children at NEIS and we don't necessarily refer

those off to community partners, so if a child has a lot of complexities or the family requests, then the child stays with NEIS, they won't go out to a community partner.

But, as of last year, for example, NEIS completed, I'm trying to look at my data... of the 94 children, 84 of them had an ADOS administered by the state, and 10 of them had an ADOS administered by community partners. So we are doing the bulk of the diagnosis, but like I said we have been working to also include them in all of our trainings.

57:54

And sometimes it just depends on what family requests so that at the meetings they aren't doing as many diagnoses, it could be they are not seeing the prevalence of children because they either opt to stay with NEIS or because if they have other medical complexities they would automatically stay at NEIS. Or they are in the rurals, because Community partners don't provide services in rural Nevada.

SP: Thank you.

TK: This is Thomas Kapp. As far as Part C is concerned, I can assure you that we make sure that all community partners meet the Part C standards, and also I just want to say that we really collaborate with ADSD and Julie to make sure that we're providing the best services for families with autism and children with autism.

MT: Thank you. Other discussion, other questions? Julie I would like to touch on, I know you were saying there are 94 children now who have been diagnosed, and I'm confused as to the dates. Is that so far in 2014 or what are your dates?

JK: July 1, 2013 through May 5, 2014. That's the number of children we diagnosed, not all of those children are currently being served by NEIS because many have turned three and exited. I think we had, the last I looked, approximately a little less than 40 children who are actively being served by NEIS.

59:38

MT: What does that service look like?

JK: Well they receive, I looked at the average number of them receive five different types of services because we also offer PT, OT, speech, nutrition, and behavioral. So, it's hard to look at, the way that our tracking system doesn't actually make it easy for me to say how many hours of what service. I wish that it did and hopefully, we're hoping for a new computer system to provide a lot better information. But basically they have an IFSP which is an Individualized Family Service Plan. Their family and the service coordinator and the therapists, who are identified on the plan, develop a plan that includes whatever services that child would need in order to meet their goals and objectives.

So, if they're getting behavioral therapy then they'll have a behavior therapy plan that is developed by the BCBA, and then the level of hours of treatment are all determined as part of that behavior plan and then implemented with behavioral aides that we employ or that we contract for. So our BCBA has actually been working quite a bit with Brook to try and make the service plans look very similar between what they are getting in early intervention so when they transition hopefully to ATAP that families are getting a similar service model. So that's what we've been working on, but all of our behavior plans right now are being developed and supervised by a BCBA.

1:01:14

MT: Do you have guidelines for that BCBA, do you, as an organization, do you say each child should receive so many hours, or are there any kinds of guidelines that the BCBA works from?

JK: No, we don't provide those guidelines, we used a licensed, board certified behavior analyst, and that's really her responsibility to determine the appropriate treatment for every child that she's responsible for, and we don't tell any therapist regardless of their discipline or any physician that we employ what they're required to provide for that child. We're actually not permitted to do that. They provide whatever they and the family feel is the most appropriate treatment at the level they have determined. That's not something that we dictate as a program.

MT: Just curious if there were any guidelines that were used. So it is just developed based on that individual child's needs?

JK: Yes.

MT: And then what are, do you have guidelines on when service begins?

JK: All services have to begin within 30 days of the plan development, that's an IDEA Part C rule.

1:02:40

TR: This is Toni Richard, can I ask two questions please? So why do you have one BCBA for the entire state of Nevada, I hear you say she.

JK: We have one for northern Nevada and we contract with two others in southern Nevada. We have a total of three, but one is actually a state employee and the others are on contract.

TR: And then, two, so the date of the first phone call that the parent makes to the date of diagnosis, and actually setting up an IFSP is how many days?

1:03:18

JK: Well it depends on, we have 45 days from referral to do an assessment and program development, so it depends on how quickly the family gets in or how quickly they respond. Not every family that gets a referral automatically responds. And then 30 days after plan development they start treatment. Or they have to start within 30 days of plan development. So, that's the general timeline, but again that is really dependent on how quickly the family responds. But we don't, we have not missed a 45 day timeline as far as getting a family in for assessment, in a really long time - over a year. I'd say probably even longer than that. So children are getting in fairly promptly.

TR: Okay, thank you.

1:04:09

MT: Julie, you mentioned community outreach; I would like to ask a little bit more about that. Do you have an ongoing program for community outreach or is just certain events that pop up from time to time? Is there a dedicated plan, like we are going to do this every month? What does that look like for early intervention?

JK: We have a number of initiatives, child find is one of our requirements and we are actually pretty proud. Our child find rate had dipped a little bit down to 1.7 percent but now we are up to almost 2.7 percent, which is the national average, so we are pretty excited about that.

So what we do is, we do a number of different initiatives depending on the region, we can do a variety of health fairs, we have, in the rurals we've been working with the rural counties who have a public health initiative, a mental health initiative to come and do screenings, hearing screenings, to get our foot in the door a little bit because families are willing to have their child's hearing screened and then we can use that as a way to talk to them about developmental delays. We also do training in child care centers so that they can get CEU's and we can do ages and stages questionnaires on the children there because it's often times easier for us to have discussions with the families about a developmental delay than for the day care providers to have that discussion with the families.

1:05:38

So we do all of those, also, we have recently started purchasing ad time on KFPB in Reno. We're going to see how it goes before we do PBS in Las Vegas. To see if we get a good response from that because it is fairly inexpensive.

We actually did it on the Spanish speaking channel that reaches all the way up to Ely, Elko, Winnemucca, and all of northern Nevada. They have a pretty big coverage

map. We're actually interested in seeing what kind of response we get from that. And we do every sort of health fair. We try also to invite ATAP to come and use our tables with us or developmental services because we're all within aging and disabilities services and pass out each other's literature or to use tables we participate in different charity walks. Any avenue really that we can get the word out, we try to do.

1:06:36

MT: Do you have any regular Public Service Announcements that are airing or have you looked into those?

JK: We don't have regular Public Service Announcements, but like I said we have purchased weekly ad time on PBS to see if that will be effective.

MT: I think they have to donate so much of their time for Public Service Announcements, has that been done before at all to help identify those younger kids?

JK: Not that I'm aware of but I don't know the full history of, going back forever, but we have not been approached to do that. We do do some publications with Renown, Saint Mary's, a few of the hospitals down south. We also do in service training for NICU staff about early interventions, so we go everywhere we possibly can, we also try to have standing meetings with large pediatric practices.

MT: Okay. Since you mentioned pediatric practices, I think you said that your staff, the person who does the actual diagnosis, who gives the diagnosis, is a pediatrician, is that correct?

JK: Yes, we have an ADOS team that will do an ADOS, but every determination of the ADOS is confirmed through a pediatrician, one of our pediatricians.

MT: Is a pediatric diagnosis enough for insurance benefits or does it have to be a specialist?

JK: It is as medical diagnosis and our pediatricians are developmental pediatricians.

1:08:20

MT: Can I ask a little bit more detail for screenings? What is, do you have an average age on when you're providing screenings?

JK: We do screenings at 18 months, 24 months, and then when needed.

MT: Okay, do you know if that's in line with... I thought I read somewhere that at 9 months they're recommending screenings?

JK: I am not aware of 9 months and I'm not sure that the MCHAT, I'd have to look at what the appropriateness is, but we don't do them at nine months.

MT: Okay.

JK: There was to start at nine months, and even then, a lot of the diagnosis tools have difficulty under fifteen months. So I'm not sure that we get the full screen at that age?

1:09:14

MT: I think that was something from pediatricians that I read, but I'll look into that more but that, the age for screening everything we're doing is trying to get things earlier, so I was wondering if you had any ideas, it sounds like you haven't seen much as far as screening 9 month olds?

JK: We haven't, but we have seen, a lot of the screenings, from pediatricians tend to be from pediatric practices tend to be kind of inconsistent, and, then, so that is an area that I know when we had the Nevada LEND conference we were actually talking about with how do we get pediatricians out in the community to do a better job of screening and to understand the importance of it. So, we don't typically get a lot of good data from pediatricians, so we always screen at age 18 months.

1:10:11

SC: Shannon Crozier from UNLV. Julie I have a question about what you said about your pediatricians. How many pediatricians does NEIS have and are they, and what specialties are they? Are they licensed developmental behavioral pediatricians? Or are they another sub-specialty are they general practice pediatricians?

JK: They're all licensed pediatricians, I know that one has a developmental, I couldn't speak to all of their qualifications because I don't have all of their resumes on hand, I know that they have been working in pediatrics for quite a long time and have, one I know has specialties in genetics, we do a lot of lot of, obviously autism is not our primary focus, most of the children we serve have other types of disabilities. We also bring in specialists, we have geneticists that comes in and does genetic counseling clinic, we have a cranio-facial clinic, we have metabolic where doctors from the school of medicine come in and do clinics for our kids but we have 3 pediatricians that on staff and they all are licensed pediatricians but I couldn't speak beyond that.

1:11:36

SC: Sure, absolutely, first of all I definitely know you need well rounded pediatricians and I absolutely know they're all licensed pediatricians, I didn't meant to imply that they were just some renegades that you pulled off the corner. I was

curious as to whether or not any of them had the additional license of developmental/behavioral pediatrician because that is an additional license to be one.

JK: I don't believe all four of them do.

DV: This is Deborah Vigill, I have a question. Is there any data about how many pediatricians actually do any kind of autism screening? Is there anything like that, or family practice? You know all the different doctors that these kids would be seeing.

JK: I don't have any of that data, I think that, I don't know Dr. Mario's entire name, but I believe that was an area of interest that he had and that he was looking at that because he actually can offer CEU's to pediatricians in order to talk to them about autism and to screen.

DV: Yes, I have talked to him. I was just wondering if we had any data whatsoever. Because I think one of the things that I've seen is that ATAP is really starting to do a good job of tracking what they're doing, but from a broader perspective it seems like we don't have a lot of data.

JK: I would agree, I know we don't really have any longitudinal data on that and I have spoken to a couple of colleges in Las Vegas, who were wondering why were weren't assembling more information about diagnosis in general but I know that is an area of need. I don't have any information on that though.

DV: OK, Thank you.

1:13:51

SP: This is Stephanie Patton. Quick question. Do you have any information on how many of your kids that failed the screeners or that you guys determined were at risk for autism or diagnosed that end up receiving autism services once they turn three in the school district. How many of those follow through?

JK: We don't have that data because we can't get information from, once we transition to the school district we are not entitled to any information about that child going forward. What we have started doing is tracking internally, every child who failed a screen, the reason why they failed the screen and then whether or not we later determine they have autism, to serve as an internal check on our own quality of service. I don't have any, we just started that in July, so I don't have any data on that to share with you. But as far as once they transition to the School District or if they don't respond back with information about what happens with our kiddos.

SP: Has there been any consideration as kids are exiting, possibly requesting parents to sign consent for release of information, just for that piece, from the school district?

JK: There are certain guidelines that govern educational information, that actually is not even, something called FERPA and so what happens is it really becomes a barrier between what information we are entitled to have and what we are allowed under the education laws and what services say, we're asking the child to maintain that information. The School District would not be likely to give us that information, and then even if we were to track it, we would be obligated to store it for 23 years, so I think from a systems perspective it would probably be someone outside of NEIS that would need to track that data. It sounds like a really good university project and it sounds like it would just because there are certain guidelines, certain laws that make that collaboration a little bit difficult for the state to do it.

1:15:57

JS: This is Jon Paul Saunders for the record. I was just at a commission meeting a little while ago, the one that Michael Harley attended and Jan Crandy actually requested that information. Michael Harley was going to give that information to the commission on how many kids came from NEIS with a diagnosis that were receiving services through CCSD.

LT: I have a question regarding those mandates and those laws. I'm sorry, Lynda Tache, because that's always been a sore spot with me is that, because we were in that whole mix, we got through NEIS and then we went to the School District, so do we have to change the laws? And are those federal mandates, how do we lobby for that to make it more cohesive because we see it all the time with our nonprofit when families will call in. You know they got a medical diagnosis at NEIS but then they won't get the educational autism one and then they're going to another general pediatrician who medically is legal to diagnose, it's just how do we make that Part B - Part C thing more cohesive. And is that a law change we have to make? And is it federal or state?

1:17:00

JK: It's a Federal law, FERPA, is the Federal Education... I'm not sure what the R-P is for, but it is a federal law, and really what the law does is, and take this with my no-lawyer grain of salt, it really places the onus on the family. The family can access the records from NEIS, the family can access the records from the school district, and so they really put the responsibility to give the records and maintain privacy on each individual family. It doesn't work that well for our system to track a child into another system. So I would say I agree that it makes it difficult when we're trying to look at system changes. The other thing I would also say is that early intervention is not a compulsory service, it's voluntary. So not every family is going to come to early intervention, even when they need help, and one of the things that we really

struggle to do is to try to get families to come in and get help, and sometimes kids will show up at the School District and they never came in to EI. They never came in to any service that was voluntary prior to showing up in school because it's required to do so. So I would just say that as a caveat and I agree it makes it difficult when you are looking for system changes, but that would be a federal requirement.

TR: This is Toni Richard for the record. Since this group is to look at 0-5 can we get someone from the School District on this board?

1:18:41

MT: I have contacted the School District, definitely for interviews, I will see if I can get someone to sit on the committee as well, I think that would be helpful.

TR: In the north it could be April Carol. She has been involved a lot with us. And she is in the autism program in Washoe county.

MT: Would you send me her contact information please?

TR: I sure will.

SP: This is Stephanie Patton, I am actually a psychologist with the school district, and I know there are a couple other psychologists that are on other subcommittees of this. I don't know how many are interested in the early childhood, but it's always been hard on our end too, so I think, I personally think one really good idea is for your specialists who are helping these kids transition to the School District that usually takes place before your services end in order to get them into the School District, so maybe if it was more, if your specialists were more encouraged to attend those meetings with the families, since families can bring anyone they want to the meetings. I think a lot of families don't know that, so I think if on NEIS or early intervention side, if the parents were encouraged to invite their specialists or their therapist to those meetings there could be more communication. I don't know of ever being in a meeting where someone from early intervention was present in all these meetings.

1:20:16

JK: I just want to say we do offer to go with families, that is not something that is always welcomed by the School District and we have been asked to leave some meetings with kids transitioning into the school district and that is an area that we do try to work with the Part B side of education on. And I also would say as early intervention we share the frustration with the school district since they do not automatically accept the diagnosis or the determination that we make in transition. That's a frustration that we share as well, especially that's why we have every diagnosis confirmed by a Pediatrician and even then we have parents who tell us that the school district won't accept it and they want to start over and reassess the

child and do their own determination. So, if I think if there was one area for improvement, between service systems, it would be working out some way where they just accept the diagnosis.

1:21:23

SC: This is Shannon Crozier for the record. So one thing that we have to be mindful of when we're thinking of where we are going to spend our time, I think as a committee is also being mindful of what the law is. So the school districts are actually legally required to do their own evaluations, so if we make a suggestion that they don't do that, they are bound by the federal law to do their own evaluations of children to provide services. So we have that situation when we do assessments at our clinic. Parents can't take the reports that we get, and we have a developmental behavioral pediatrician, and a licensed clinical psychologist and speech and language pathologist and the list goes on and they are not allowed, it is just how the law is written, so while it is definitely a frustration, and a problem and hopefully there is a way we can structure some state systems around that. I think that spending committee energy on asking the school districts to do something that the feds require them to do. We do not have very much time as it is as you pointed out, so I think we have to be mindful of where we focus our energy and asking them to do something that they are legally required to do is going to frustrate them. They are going to get angry and it's not going to help us get kids what we want, which is a more seamless transition from early intervention to school based services.

NC: This is Nicole Cavanaugh. I just thought I would piggy back on what Shannon is saying because in our clinic we run into the exact same thing. We have three neuropsychologists, speech pathologists, board certified behavior analysts, occupational therapists. You know we have this comprehensive team similar to UNLV, and I think the thing to always be mindful of is that educational eligibility and medical diagnosis do not always necessarily have to overlap. When the school is doing their evaluation it's to look at what is the most appropriate educational placement and what are the most appropriate supplementary services. It is not atypical that a child may need private occupational therapy and be receiving private occupational therapy, but if those same issues are not directly impacting the child in the classroom, the child is unlikely to get occupational therapy through their IEP.

And so it's not always a perfect overlap between medical diagnostic criteria and educational eligibility. So I agree, I don't think spending committee time on this is super valuable. I think that if we were to do that rather than asking the district to do something that the federal government requires them to do, I think the more valuable focus may be on just improving communication between the community providers on a child's team and the child's educators, that everyone can kind of be on the same page and understand why certain things may be happening in certain environments but not in other environments.

1:24:15

LT: This is Lynda and I know we should probably move on from this, but just again, from a parent's perspective, you know if I were to get that diagnosis for autism at early intervention and then not be told I can have these people in my meetings and then going to the school district and then they say no, he doesn't qualify for that. The parents sometimes aren't in a position to advocate for themselves. I know we have all these systems in place and these providers they understand and make sense but I'm just saying that I just wish they would accept it. These parents get devastated and get lost and it's just our systems have to do better. Because the communication is great in theory, but it doesn't happen all the time. That's not the reality.

SP: This is Stephanie Patton. I think a lot of that has to do with parent education. And it is actually law that you can bring whoever you want, no matter who they are to the meeting. I don't know if parents are being told otherwise, but it's not true, so maybe just making sure that parents are aware of their rights and the actual laws, opposed to just what one person who is frustrated might say to a parent.

MT: Julie to kind of wrap up a little bit, it sounds like we need more communication between the under threes and the over three's. Maybe that is an obvious statement, but I'm curious if the transition work that you guys do to exit them from early intervention into the school district, if more might be done there to help with that crossover. Could you give me some more details what you are doing for the transition, how the parents are involved, how you are involved with the school district. A few more details and maybe we can look at that area to help in that transition.

1:26:25

JK: Well between 90 and 120 days of their third birthday, we refer families to the school district. We will have a joint meeting whenever possible with the school district and the family to help them make that transition and then the school district really takes over as far as doing their evaluation and putting together what services they can expect and what we can do particularly, with the families who are struggling with the school district. I will say we tend to have more trouble with rural school districts than with the urban school districts.

We always refer them to Nevada PEP which can help families learn that self-advocacy, to try and what their rights and responsibilities are as a parent so that they can advocate for the child. So the transition meeting and we develop a transition plan that is mostly prescribed by the IDEA law and what has to be included in that should a family opt not to have that and a family determines at that point whether or not we release the records to the school district. They can refuse. Some families do do that if they are nervous about their child being labeled in regular Part B school, they will ask us not to release the records to the school district and when that happens we still do a transition plan for the family even if they refuse to have the school district participate in it.

MT: Am I understanding that the school district does their eval within that 90 to 120 days before they actually turn three, or did I get that confused?

JK: It's between 90 and 120 days before.

MT: So the school district actually has access to them before they turn three.

JK: Yes they do.

MT: So then if there was an IFSP in place, then during that transition is the goal that they would have an IEP in place day one to start services the day the child turns three. Is that what the goal is?

JK: Yes, that's the goal and we continue to provide the services until they turn three and so yes it is the goal that the day that ours stops, the next day theirs starts.

1:28:54

MT: And when you said it's up to the parents whether they want to release records, if they do agree to release records to the school district, does the school district receive the IFSP, the plan the child was working on before three?

JK: It should be the IFSP and all of their developmental reports.

MT: So any report from the MDT eval at NEIS goes to the school district?

JK: Yes, all their records, the full educational file they get. This would include their medical records, their developmental reports, all their therapy reports, their diagnosis, the pediatric report, everything.

MT: OK. I know we might need to talk to you again, Julie. I think for today though we need to wrap it up. I appreciate all your time and you being so amenable to answer all these questions. I hope we did not put you on the spot too bad and the committee will probably be preparing a list of questions for future interviews or for you to review in upcoming meetings. I do appreciate your time today and thank you. Any other questions for Julie or discussion about early intervention?

TR: This is Toni Richard again for the record. Is there any way we can find the average age of the child when they are finally diagnosed?

JK: For last year, we haven't done it for this year, for last year it was 2 years 7 months, I believe.

DV: But that was for, this is Debra Vigil, that was for those that you did through NEIS and they were referred somehow. But if we are going to get an overall. Is there any way for us to get that information, what the average age is?

JK: Through NEIS and all of our community partners, so for in the Early Intervention system, it was 2 years, 7 months but that was for last year. We haven't gotten the data yet for this year and we're hoping it will have gone down because this is the year that we started doing the MCHAT- RS instead of waiting for two failed screens.

TR: So this is Toni Richard. When you are saying this year, you are talking about the state's fiscal year, of July to July of this year? What is your year?

JK: I'm talking basically this year. Because it's ending in this July.

MT: I think we would like to get more information on ages and delivery of service and those kinds of things, but I think those will be directed by the committee members who are looking at the recommendations from 2008. I did mention one on there about screening. I see under number 46, in 2008 that they recommended that screening would happen at the 9, 18, 24 and 30 month well child office visits. So I know there has been a move to try to get earlier screenings even back then. And then one of the other items on here they are talking about trying about trying to create a state wide neural developmental disorders registry. That's item number 49 on the recommendations. Do you have any input or any knowledge of any registry that is going on statewide?

1:32:58

JK: Are you asking me?

MT: Julie I am going to ask you and then I will open it up, maybe Debbie or if anyone else knows about a registry.

JK: I not aware about a registry, but I will say that there is a provision that school district and NEIS all report annually to ADSD the number of children or the number of people that we have served that have autism, but those are just total numbers, so, we have like 5,400 kids in all of the school districts who have autism. So that is all reported by August 31 of every year. But I am not aware of any registry.

DV: I am not aware of any registry either. I know there has been talk about it, but I'm not aware of any follow-up.

MT: Speaking of follow up, we will be getting back to Julie and I appreciate all your time and if there is no other discussion, I would like to go ahead and close agenda item 5.

1:34:09