

# 86| Intellectual Disability – With Dr. Jennifer Huffman

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**Speakers:** Jennifer Huffman, Ryan Van Patten, John Bellone



**Intro Music** 00:00



**Ryan Van Patten** 00:17

Welcome, everyone, to Navigating Neuropsychology: A voyage into the depths of the brain and behavior, brought to you by INS. I'm Ryan Van Patten...



**John Bellone** 00:25

...and I'm John Bellone. We'd like to wish everyone a Happy New Year. One quick note before we introduce today's guest, we have accumulated quite a bit of content

over the last three plus years. We recently grouped our episodes by theme on our website so that it's easier to find a topic of interest and then to locate multiple episodes that are relevant to that topic. Themes include cultural and global neuropsychology, pediatrics, geriatrics, cognitive interventions, and many more. You can find episodes grouped by theme at [navneuro.com/category](http://navneuro.com/category).

**Ryan Van Patten** 01:01



Today's episode is a conversation with Dr. Jennifer Huffman. Jennifer is board certified in clinical neuropsychology and pediatric neuropsychology. She's a lifespan provider and has extensive experience with children with neurodevelopmental disorders, including intellectual disability, which is the topic of our conversation today. She also authored the chapter on ID in the Clinical Neuropsychology Study Guide and Board Review book edited by Kirk Stucky and colleagues. So, with that, we give you our conversation with Jennifer Huffman.



**Transition Music** 01:35



**Ryan Van Patten** 01:45

All right, Jennifer, thanks for making the time.



**Jennifer Huffman** 01:47

Thank you. It's nice to see the faces of the voices I listen to quite a bit.



**John Bellone** 01:54

[laughs]



**Ryan Van Patten** 01:54

[laughs] We have faces for radio.



**John Bellone** 01:56

[laughs]



**Jennifer Huffman** 01:56

[laughs]



**Ryan Van Patten** 01:59

Today, we're talking about intellectual disability, or ID, which is a neurodevelopmental condition, which means that the symptoms begin while a child's brain is still developing. It occurs in roughly 1% of the general population, maybe a little less. The two core types of symptoms that we think about are intellectual impairment and adaptive functioning deficits. For ID to be considered that would be a standard score of 70 to 75 or less, accounting for measurement error. So tell us your thoughts on this intellectual impairment criterion, and then talk about some of the test batteries that you prefer for children of various ages.

**Jennifer Huffman** 02:51

Sure. Well, I mean, I think this criterion makes sense. We need to use clinical judgment when making diagnoses at the border. So that would include any careful assessment of relevant factors like cultural considerations, cooperation, performance validity. Obviously, careful assessment of adaptive functioning is always critical in these cases. I think people would like to have a cut-off that's black and white - you know, anything below 70, for example - but rarely is that the case in our field. We can't really rely and stick to those kinds of cut-offs. So really what we're left with is some judgment and being flexible in our understanding of this.



As far as battery, my preferred battery really depends on the age of the child and the severity of the ID. I started out in my training using the Bayley Scales of Infant Development with young children and infants. But I found the organization of the Bayley to be difficult with the populations I was working with, which included some hearing impaired kids or children with autism spectrum disorder. So I switched to the Mullen Scales of Early [Learning] for infants and toddlers, or the Differential Ability Scales that I can use with young children or even older children and adolescents with severe impairment. I find these scales to be a little less sensitive to or affected by language barriers. You can use some of the subtests designed for younger children with older children who are low functioning and get an estimate of those skills. If language were a significant barrier, or you were working with a child with hearing impairment, I might consider the Leiter as well because I think that's a good measure of some of the nonverbal skills. If possible, I like to use the Wechsler scales, but mostly with older children or adults, or individuals with mild impairment who are pretty communicative, verbally. I find the language processing demands, even for some of those nonverbal subtests, to be pretty high for some of these children.

On the adaptive behavior side, I started out using the Vineland, the interview format, and I really prefer it as a solid interview. But over time, I've really gravitated

toward the Adaptive Behavior Assessment System, or the ABAS, with my battery just given time constraints with the interview. I find that, at least for my population, the ABAS does a pretty good job as long as I pair it with some pretty specific instructions about how parents should be responding. I like to expand upon the written instructions in that measure.

Now, as far as other aspects, obviously including performance validity tests, or PVTs, is important, depending on the severity, the adaptive deficits, and academic skills. Sometimes you need to think about alternate administration methods or interpretation. Depending on referral questions, you might add any other range of measures you would include with neuropsych assessment like language measures, the PPVT or EVT, attention skills, basic academic skills, memory. I really like the Beery-Buktenica Visual-Motor Integration test. As another example, I might choose the Purdue Pegboard over the Grooved Pegboard because those smooth pegs are a little easier to manipulate for kids with ID. Then [for] rating scales, you can use a broad measure. I tend to prefer the Achenbach Child Behavior Checklist and the Conners rating scales, but others may use measures like the BASC. Again, depending on the referral question, you might be including something like the Autism Diagnostic Observation Schedule, or ADOS, or some of those accompanying interview measures as well.

**John Bellone** 07:37



Really a wide range of tests and rating forms. I'm assuming you not only lean on parents, but also potentially teachers, other guardians, or family members for some of those rating scales as well.

**Jennifer Huffman** 07:49



Absolutely. Of course the more information you can get, the better. Especially if you're looking at some of these developmental concerns for the first time. For parents where this might be their first child and they don't have nieces or nephews or younger children whose development behavior they've observed, they may not understand how these developmental differences are anything other than what would be typically expected. So sometimes you do need some of those collateral reports to give you another point of view.

**John Bellone** 08:28



Can you also talk about normative data here and how you choose norms? In particular, how norms might - you know, IQ has improved over time in many places

around the world if we look at the Flynn effect. I'm curious how you think through using different normative data.

**Jennifer Huffman** 08:46

Yeah, that's a great question. Well, first of all, with the Flynn effect, I think the research here is equivocal. One of these questions, I think, some research and facts suggests it's declining over time or may have never existed in the first place. So [it's] a little bit controversial here. But some proponents have argued that there may have been, at least in the past, about 3 points [increase] per decade. We find, though, that that's been decreasing, for whatever reason, in past decades and not consistent even across domains. So, for example, fluid intelligence may increase more and we don't exactly understand why this is. Some try to make adjustments for this, but this effect, if anything, seems to be nonlinear.



I think IQ test selection and norms, really like all of our tests, need to be based on current research. If you're using a test that you're really familiar with, and there's a solid research base for that test, then, in some cases, it makes sense to continue using those tests for consistency in interpretation over time. So, for example, if you're thinking about certain high stakes tests, like, I use the an IQ test for cases of capital punishment or in determining maybe a prediction for future services or the need for future services in medical malpractice cases, for example, it is important that you select a measure that you have a lot of familiarity with. So just because the WAIS-5 or the WAIS-10 came out last week, maybe that's not the best reason for choosing that new test. Even though the norms may look better, I would argue we really have to wait for some of the research to back that up. Because I've seen through my career quite a few big shifts in the way that IQ has been conceptualized in some of those indices. It takes a little bit of time, even for seasoned clinicians, to get a real feel for what some of those new indices or tests or subtests are measuring and how those particular measures may be impacted by some of the limitations that kids with ID bring to the table. If you look at a measure like the DAS, the second edition has been around for a while. The norms may seem to some to be outdated, but at the same time maybe it's the best tool for a certain group of patients given some of the advantages to using that particular test.

I like some of what's happening with the new normative studies. I think including a wider range of culturally-diverse individuals and really paying attention to the fact that we're including a representative sample. Making sure that we're including enough children at the tail ends of these distributions is really important before making the shift. But it's pretty complicated, I think. For me, one of the most important things is that shift to adaptive functioning so that we can focus on that

more instead of relying on a very specific or narrow IQ score. I think that alone helps us to minimize some of the errors that we might see in interpretation.

**Ryan Van Patten** 12:44



Certainly having more recent norms is an advantage given that there are sociocultural and economic changes over time. But I wanted to clarify, it sounded like you mentioned that the Flynn effect - this idea that IQ scores in the general population, at least in some Western nations, have increased over time - that idea has become controversial. Is that right?

**Jennifer Huffman** 13:06



Right. So I think that there are certainly some proponents of that, and some that argue that this has been decreasing over time. So, for the interested individual [it] requires a little bit [of a] deeper dive, I think, to fully understand what that means.

**Ryan Van Patten** 13:25



I see. Well, staying on the topic of cognitive functioning broadly, delayed episodic memory is not typically tested by an IQ battery. You mentioned that seeing these cases where the referral question is ID, you might test more abilities than just an IQ battery. What do we know about memory performance in many children with ID?

**Jennifer Huffman** 13:49



Yeah, this is a great question. I think it's one that we're really learning a lot about as we do more and more studies that look at specific groups of individuals with ID. We know that there tends to be some similarities in that most kids with ID have memory problems. We know that. Some of the research today has not identified any particular patterns of memory strengths and weaknesses. We're thinking now that that's probably because previous research with ID sort of lumped everyone together. As we've gotten more sophisticated in our understanding of some of the various causes of ID, we're starting to separate out some of these groups and study them individually and see some patterns. We're developing a newer understanding of ID that leads us to understand there could be some peaks and valleys in their strengths and weaknesses. This could help us to understand why some of the previous studies have been inconsistent.

Without going into all of the specifics, we can look at a couple key groups like Down syndrome and Williams syndrome, because that's one where the research has highlighted some difference in implicit versus explicit memory. They're relating those differences to some of the neural pathways that they're seeing, that are

affected by this disorder, which, of course, is very exciting to neuropsychologists. There's some indication of some temporal lobe and hippocampal findings that could explain the long-term memory encoding and retrieval problem in Down syndrome in particular. Certain studies are showing [that] Down syndrome individuals score lower on explicit memory tasks, like remembering stories or lists or the Rey complex figure, yet have relatively preserved implicit memory, like repetition priming, or procedural learning. Whereas with Williams syndrome, we're seeing relatively strong verbal and visual long-term memory, but deficits in spatial long-term memory and implicit procedural learning. So to the extent that spatial temporal organization is necessary for representing the events of episodic memory, it makes sense that individuals with Williams syndrome would have particular difficulty with this given general problems with visual spatial functioning.

It's really causing us to think differently about memory in some of these conditions. [It] helps to remind us that, when we're evaluating individuals with ID, we may need to expand the types of tasks we're doing and not just give one list memory task, for example, but to look at different aspects of memory and be talking to people because, like you said, we're not typically testing episodic memory. Some of the questionnaires that have been developed for individuals with Down syndrome, for example, ask specifically about some of the orientation and other aspects of an individual's functioning - do they remember what they had for dinner yesterday? Or do they remember a big event that happened yesterday? Getting caregivers to think more about that type of thing may help us to understand some of these difficulties a little more specifically.

**Ryan Van Patten** 17:48



The memory difficulties and a hippocampal, medial temporal dysfunction in Down syndrome makes sense in the context of the fact that people with Down syndrome are more likely to develop Alzheimer's disease earlier in life.

**Jennifer Huffman** 18:01



Right. It also helps us to understand why their language is particularly impaired. So, even relative to their developmental level, we see language, especially in later adolescence, is noticeably more difficult for these kids, especially expressive language. So knowing more about those pathways does help us to make some of those connections.



**John Bellone** 18:27

My understanding is that, historically, ID is thought to affect cognition in a global way. Whereas, [now] we're talking about some of the more specific cognitive profiles.



**Jennifer Huffman** 18:37

Absolutely. Our understanding of intellectual disability as much more than global impairment, and, again, more of these peaks and valleys is really relevant to working with these kids and families today.



**John Bellone** 18:54

Yeah. You talked a little bit about adaptive functioning and some of the scales that you use. I wanted to talk a little bit more about it because it's so important in this diagnosis. [The] DSM discusses deficits in conceptual, social, and practical domains. Can you quickly talk through what those terms mean?

**Jennifer Huffman** 19:14

Right, this is a great question because this is the area that DSM and current researchers are really pushing us to go in. To really delve into adaptive functioning in a way that we probably wouldn't have done earlier on. One of the things that I rely on is Table 1 in the DSM-5. It's got really nice, specific examples of each one of these domains by severity level. So when I'm working with a child and thinking about the classification, it's usually a couple of pages that I will reference in the book.



When we're thinking about conceptual skills, this is generally referring to cognitive and academic skills. So reading, writing, time, understanding of money, abstract thinking, executive skills like planning and prioritizing, cognitive flexibility. This is where we consider short-term memory, use of objects, sorting objects, any of these cognitive or academic skills fall within that conceptual domain.

As far as social, this is also really important to think about. It's the ability to perceive social cues, use of communication, whether it's verbal or nonverbal or using assistive communication devices, a conversation, how easily does a child carry on back and forth conversation, their general use of language, understanding risk in social situations, that maturity versus immaturity continuum, social judgment, whether or not these children are at risk for being manipulated by others, their capacity for friendships and romantic relationships, and, of course, any response to

their social interaction. These are features that we think about when we think about that conceptual domain.

From a practical standpoint, we're thinking here about those activities of daily living like personal care, how well are they brushing teeth and dressing [and] toileting? How about grocery shopping? Are they able to use transportation like public transportation or drive? Can they prepare nutritious foods? Are they able to bank or use money? How do they manage their money? How do they engage in recreational activities, activities for play, and whether or not they're capable of working?

**Ryan Van Patten** 22:13



The social domain, to me, explains a good part of the overlap between ID and ASD. You see a lot of these ASD features coming out in the social domain of adaptive functioning within ID.

**Jennifer Huffman** 22:25



Absolutely. That's really one of the key things that we need to look at when we're making that differential diagnosis. And that's spelled out explicitly in the DSM-5 as the area really to be focused on. We can talk more about that later.

**Ryan Van Patten** 22:44



Yep, we will. [laughs] Another important point about adaptive functioning, is that although IQ score is very important in making the initial diagnosis of ID, determining severity - mild, moderate, severe, profound - is based more on adaptive functioning than on scores on tests of intelligence. In my mind, this is due to the fact that IQ tests are less reliable at the tails of the distributions. But, also, it's because of the centrality of adaptive functioning with respect to level of care, the need for assistance in daily life. That's where we're differentiating mild, moderate, severe and profound ID. Is that right?

**Jennifer Huffman** 23:28



Yep, I think you really explained it well in terms of understanding that those IQ measures that we have are really less valid in those tails. We're already talking about a small portion of the population, and with some of those more extreme cases, it's an even smaller portion. One of the biggest challenges in using IQ tests at that tail end of the distribution is that for more involved kids, we expect to see more motor delays or sensory impairment, like visual impairment or hearing impairment. So a child at that severe or profound level may even not be able to

verbalize or gesture to provide a response. Then you have behaviors that might interfere. So if you've got a child, for example, who is autistic and has social communication deficits, [it] may be very hard to get joint attention long enough to administer some of our tests and get an accurate assessment. That's why it becomes so important for those cases to think very carefully about the adaptive functioning of that individual.

**John Bellone** 24:50



Yeah, and in terms of percentages I've seen, and going off of your book chapter in the Stucky et al Board Review book, it sounds like roughly 85% of people with ID are in the mild range, about 10% moderate, and then smaller percentages in the severe and profound ranges. Can you talk a little bit about the differences in cognition, behavior, and adaptive functioning in the different categories along that spectrum?

**Jennifer Huffman** 25:16



Yeah, absolutely. So mild, of course, makes up that largest portion. We expect to see delays in language. These children are usually fluent speakers by adolescence, so we see them catching up with their language skills in some ways over time. We can see them function academically, usually up to about a 6th grade level. What we notice is some immature and rather concrete language or problem solving skills. They can do pretty okay with their personal care, but they may need support for more complex activities of daily living. We can see that they can have competitive employment with jobs that do not require conceptual skills. Oftentimes, they will require support for some of those more complex decisions. So, for example, making a decision about whether or not to have a surgical procedure, and legal decisions about where to live or how to manage large sums of money, or raising a family and some of the complexities that might be involved there.

With moderate ID, we often will see functional language by adolescence. So able to communicate about those basic wants and needs. The academic skills [are] typically up to a grade 2 or 2nd grade level. They often need moderate supervision. We do see that capacity for meaningful relationships with family and friends, but they may have difficulty with social judgment or more refined social skills. They can often care for basic personal needs and household tasks, but may need reminders. We do see some employment here that requires more limited conceptual and communication skills with some support. So they may have a job coach or support person to help them at work, but are capable of doing some repetitive tasks. Here

we start to see that some maladaptive behavior can cause social problems with moderate ID.

With severe, we expect to see more limited language, like use of single words or phrases or gestures for communication. We see poor academic skills. They may have some familiarity with the alphabet and counting, but we typically don't see more complicated reading [or] writing types of skills here. They often depend on their family members quite heavily for pleasure and help. They're not able to make responsible decisions for themselves or others. They can sometimes work, but work and recreation often require pretty constant supervision and support in something we might call a "supported employment situation". Maladaptive behaviors for some of these individuals can include self-injury.

In the profound range, these individuals may learn single words. We often see no academic skills. They require pervasive supervision support for all activities. They might understand simple instructions or gestures, but it's mainly nonverbal, non-symbolic communication. They sometimes will enjoy relationships with really well-known family members - mom, dad, brother, sister. They might be able to participate in some activities of daily living, like helping to get themselves dressed. Usually we see simple actions with objects form the basis of their work. We often see a lot of comorbid physical and sensory impairments that can prevent them from using objects or participating in activities. Here's where we might see the motor limitations that literally limit their ability to point or engage with objects, or severe hearing a visual impairment that may prevent them from seeing or responding. We, again, see some maladaptive behavior with this group as well.

**John Bellone** 30:00



My understanding is that many children with mild ID are diagnosed around the time they start school. Difficulties may become more apparent, but more severe variants can be diagnosed sooner. I'm wondering about early signs and symptoms, even pre-kindergarten types of symptoms. Also whether or not formal testing is ever useful for toddlers and young children.

**Jennifer Huffman** 30:24



Okay. So with early signs and symptoms you're really looking for - you know, I often see in the medical records of these kids, their difficulties are referred to as "global developmental delay". So they're coming to the attention of their pediatricians or other early on specialists who may be administering tasks or tests looking at some of the skills and finding general delay. This involves failure to meet milestones at

age-expected time. So if we have a child, we're expecting them to walk around 12 months of age, plus or minus a few months. So maybe a child is a late walker, but still within normal limits at 15 months. But if they're still not walking by 16 months, 17 months, 18 months, then that usually is going to be something that comes to the attention of a provider. Similarly, with speech, we're expecting to see those first words come online around 12 months of age and then we see pretty steady progress forward. If we're not seeing any speech by two years of age, then we really start to become concerned. And especially here if we see a regression in development, or we start to see some stereotyped movements, maybe there's head banging that becomes a problem or other self-injurious behavior, then it starts to raise our suspicions as well. [In] kids with ID, we're not seeing just language impairment, but we're seeing that late walker, who also has language impairment. For some of the more severe variants, the ID will become apparent really early on if, for example, they're showing facial features of Down syndrome or facial features associated with fetal alcohol syndrome and you're seeing some of these delayed developmental characteristics. That's what we see in the earliest stages. But sometimes these just go unnoticed and it isn't until school age that the pieces start to fall in place because that gap becomes more noticeably wide. You see parents [of] kids with these kinds of delays giving you a lot of explanations for why they see this development. "Well, he was the youngest of three and so all of the other kids talked for him." They'll come up with explanations for the delayed development. "Well, we just carried him all around, so we really didn't expect him to walk and that's why he was delayed." But it becomes important for us, in these evaluations, again, to start putting these pieces together.

**Ryan Van Patten** 33:34



How common is it for you to see children who are a bit older where mild ID has not yet been diagnosed, even beyond kindergarten, you know, 8, 9, 10 or early adolescence?

**Jennifer Huffman** 33:47



I can remember distinctly evaluating an 18-year-old who had a clear mild ID and had never been diagnosed. She had been serviced through her local school district with maybe an Other Health Impairment, or - actually no, it was learning disability. She had been given a learning disability [diagnosis]. One of the red flags is when you see a learning disability and it lists off all six or eight or however many learning disabilities you can possibly have... [laughs]



**John Bellone** 34:24

[laughs]

**Jennifer Huffman** 34:24

In basic reading, in reading comprehension, in reading fluency, and math problem solving, and math computation, and written expression. You see these learning disabilities in all domains and suddenly you start to get suspicious because that sounds more like a global developmental delay. But this was a girl who was a sweetheart and had very highly educated parents who had provided her with a lot of key support and really minimized her adaptive functioning difficulties. They just described her as a "spoiled child" who they did everything for and that was the reason she was showing these delays. But the testing showed clear difficulties otherwise. So it's not uncommon to see some of these kids slipping through the cracks. I think they tend to be pretty well-behaved girls, at least from my own experiences.



**John Bellone** 34:42

But there are supports that people can get when the ID diagnosis is made - federal and state supports in the US. You mentioned they fall through the cracks, so it's often not a good thing if it's not diagnosed. We can get them more help, which we'll talk about more in a few minutes.



**Jennifer Huffman** 35:47

Yeah, so in this case, the child was seeing me as part of a transition program with a question about what kinds of supports our local vocational rehabilitation services agency could provide for her transition from high school to beyond. The student came in and when I asked her, "What do you want to do in this next step? What do you see yourself doing?" she said, "Well, I want to go to college because everybody's doing it." And [her] parents really had that expectation as well. This was one of those examples where the ABAS really let me down with the adaptive functioning because the parents rated her as doing exceptionally well in all areas, yet she scored in the mid 60s on all of the testing I gave her. So I had to sit down with the parents and review the ABAS with them and talk about how I thought they hadn't really responded to the measure in the way that the instructions and measure had intended. We talked about clarifying what it means to give full credit. That these are tasks that a child is capable of doing independently and on their own, without help, without assistance, without prompting, and suggested that they revisit these items. When they came back and we went through it together, we arrived at a score that was much more consistent with expectation in that mid 60s



range. They were really overestimating that. You'll see this written whenever folks are discussing adaptive functioning, there can be a lot of bias. Unfortunately, we don't have good validity indicators on these tests so it's hard to know when a parent is overestimating their skills other than just using good common sense. You can look at an item and think this child is no way capable of doing this. But the parent just didn't really understand what this meant or what this was asking or what the rating was intended to convey. What I explained to the parents is "You're running out of time. You've got to have a developmental disability diagnosis before age 22 or your child will not qualify for future services." That was a really important conversation to have because at age 18 there wasn't going to be an opportunity for future assessment most likely. So it was important that we get this one right. It turns out, she really did need and benefit from some of the supports that the diagnosis offered her. So it was a good thing she had come in for the eval [and had] been referred by a pretty savvy case manager who had suspected something like this was going on.



**John Bellone** 38:55

Unfortunate [that] it was missed, but fortunate that she got to you, at least before it was too late.



**Jennifer Huffman** 38:59

Right.



**John Bellone** 38:59

You highlighted the potential problem with self-report or even collateral sources of information where they might be biased or they might not be fully aware of the difficulties. Ryan and I encounter this with older adults when we try to assess functional decline. If the person [is] saying that they're managing their medications and their finances okay and their adult child doesn't really know or they think it's okay, it's hard to get an accurate gauge on functional ability sometimes.



**Jennifer Huffman** 39:28

Absolutely.



**John Bellone** 39:30

I wanted to go back, you had mentioned the importance of having diversity in our normative samples when test developers are developing different measures and normative data. I wanted to talk about the importance of considering cultural

background when assessing for ID. [A] typical western IQ battery might not be appropriate for certain patients and conceptualizations of intact adaptive functioning might differ across the world, or even state to state or in different areas in the US. I'm curious how you approach conducting culturally-informed evaluations in culturally different clients?

**Jennifer Huffman** 40:10

Right, this is a great question. I think it's more important than ever now to be in tune to these concepts and ideas. I really think that, as we go, this is something that I wasn't necessarily trained in specifically, but I think we need to be asking our clients direct questions about their racial and ethnic identities, as well as religious background, and help them tell us how they think these things might affect their child's development.



For certain cultures, it is expected that the parent does everything for the child. The child is to be spoiled. [laughs] I have found it interesting that certain cultures will push back on an ID diagnosis because they, one, may not recognize mental disorders in their culture or, two, again, may just think that whatever behaviors we're seeing, or a child's lack of engagement on an assessment measure, for example, just may be explained by the fact that this child doesn't have any expectations at home. For example, they're not ever expected to clear their plate from the table, so why would that question be included? So we really have to understand more about where the parents are coming from so that we can help them understand what our tests might mean and put those into context. It's important to address that directly in the report, including with recommendations. Here, I think it's important not to make assumptions. This is why we have to ask them. So just because an individual comes to us with brown skin and with a background that suggests a Latino or Latinx heritage, doesn't mean that that individual identifies with that culture. So I think the best thing we can do is ask the questions. Maybe we're the only ones asking those kinds of questions because in a different setting, in primary care, maybe there isn't time to get into that. But I think we should be asking it directly and giving them an opportunity to tell us what's going on.

I know you guys just put out a podcast with Dr. Stringer. You started the podcast - I was listening to it in the car - but you started with a couple of websites that I thought "I got to check those out." Because it sounds like a great resource for us to learn more about the culture. If we know that there's a particular racial identity or ethnic identity that we're working with, we can explore what some of that means.



**Ryan Van Patten** 43:08

Yeah, those are EthnoMed and everyculture.com. They're both great for doing our pre-work before seeing patients.



**Jennifer Huffman** 43:16

Right. You know, it's just like anything we do. One of the advantages I have in sending out history forms ahead of time is that I can get some prep work in beforehand. Just recently, I was evaluating a child with a rare genetic disorder. It's great to know that in advance so that you can do your research and studying and start to understand what is it about this child or this diagnosis or condition that I should be thinking about and looking for? What's been reported in other cases?



**Ryan Van Patten** 44:05

You mentioned rare genetic disorders, that's a good segue. Let's start to wade into etiology for a few minutes. So let's assume a normal distribution of IQ scores, we would expect that about two and a half percent of people would have an IQ of lower than 70. But IQ score, as we've mentioned, is only part of the picture. There are specific brain insults that can lead to ID. We can talk about some of them - genetic disorders, TBI, prematurity, hydrocephalus, you had mentioned alcohol exposure in utero. Let's talk about genetic causes for a few minutes. You had mentioned Down [syndrome] and Williams syndrome, tell us a little bit about Fragile X.



**Jennifer Huffman** 44:48

Fragile X is the most common familial or inherited form of ID with a known genetic cause. Most males, around 80%, have moderate to severe ID, with a mean IQ somewhere in the mid 40s. For females, the IQs range from mild ID, around 30%, to average [IQ], and along with a risk for math disability, they tend to show better strengths in reading. With Fragile X, we may see what they call "cluttered speech". Memory may be better for stories than abstract information. So this is, again, where we see some of those differences with memory. We also see deficits in working memory and cognitive flexibility. We expect executive functioning deficits, sensory problems, ADHD symptoms, hypotonia, or low tone, and we see poor eye contact. An ASD diagnosis somewhere between 25 to 47% is what's reported with males and this reflects the poor social and communication deficits we see with this group. We expect more developmental problems or behavior problems when we see those comorbid symptoms as well.



**Ryan Van Patten** 46:25

Fragile X being more severe in boys is because males don't have a second X chromosome to balance out the problems with the X chromosome. Is that right?



**Jennifer Huffman** 46:37

That's right. We tend to see more males than females in general with a range of neurodevelopmental outcome problems and that tends to be one of the explanations. Females get a second chance [laughs] with the second X copy to make things a little bit more right.



**Ryan Van Patten** 46:58

Right.



**John Bellone** 47:01

Like Ryan said, there are a number of other genetic conditions. Eventually we'll have to do other NavNeuro episodes on these specific conditions, but is there anything you wanted to say about some of the other ones or just in general about the genetic conditions?



**Jennifer Huffman** 47:16

Well, as you know, the number of genetic conditions we're discovering just expands by leaps and bounds. Up on my computer right now is some research I was doing before we talked today on the 15q13.3 microdeletion syndrome. That's just an example of one of the thousands of genetic conditions that we may run across as neuropsychologists, so we can't prepare for them all. But one of the more common, of course, is Down syndrome, the most prevalent form of ID with a known genetic cause. We see here those common physical symptoms like facial features that often lead to early diagnosis. That's one of the advantages there, that even infants and babies without having had any of the early screening tests or amniocentesis that alerts you that this is coming, the diagnosis is often given quite quickly. We see here, again, the delayed development and attainment of those milestones. Those delays become more pronounced as they reach school age. We may see and hear parents telling stories of these kids who seem to be developing normally and picking up on things quite readily in preschool, but by school [age] we see that gap starting to widen.

ID for Down syndrome is usually mild to moderate, it's only rarely severe. These kids have a short attention span, poor judgment, and impulsive behavior. Here we see nonverbal learning and memory tend to be strengths relative to verbal skills. So

that verbal delay that I talked about, and receptive [language], or their understanding of language, tends to be better than expressive. Here we see executive deficits that become more pronounced with age.

They can often have these personality assets - they're cheerful and social as a general rule. Sometimes we see more externalizing behavior problems when they're younger, more acting out, and then this can change to more internalizing behaviors with maturity. I've seen that in one of the cases that I've been following. The mother is really sensitive to the possibility of Alzheimer disease. In fact, I learned about some of the actual tools out there for assessing this in individuals with Down syndrome. She shared with me some of these tools that she had found and researched and was convinced her daughter was showing these early problems when, in fact, my assessment suggested that she was just struggling more with depression and anxiety. For her, I had the fortune of looking at records over time and then also she's been back to see me a few times, so I've got my results for comparison.

Individuals with Down's are at risk for a range of other health problems like with hormones and glands, hearing [or] vision problems, and heart abnormalities. Some of the lifespan problems that we were seeing early on with Down syndrome kids were often because they just weren't being treated appropriately medically. So they really do need comprehensive medical care. But we also know they are prone to developing Alzheimer's disease and die pretty shortly within diagnosis, like 8 years. So for both Down syndrome and Fragile X, we actually see declining IQ scores into adulthood. We think this is more about a lack of progression in skills as opposed to a regression or actual loss of skills. That's really important to know as well if you're looking at scores over time, just because you see some declining numbers we may expect that. So be careful.



**Ryan Van Patten** 51:51

They're declining relative to same aged peers, but not relative to themselves.



**Jennifer Huffman** 51:57

Exactly.



**John Bellone** 51:58

Listeners might wonder about the connection between Down's and Alzheimer's disease, but my understanding is it's due to the extra chromosome 21 where the amyloid precursor protein gene is located and that they typically develop the

pathology of Alzheimer's disease in their 40s and 50s. That's my understanding, at least.



**Jennifer Huffman** 52:21

Right.



**Ryan Van Patten** 52:22

Can you step back and talk a little more broadly about why it's so important for clinicians to know the etiology of ID, whether it be a genetic condition, FASD, TBI, prematurity, etc? What are some of the differences in prognosis and intervention?

**Jennifer Huffman** 52:41

Sure. So this is important for understanding prognosis or what's expected. If we are making a diagnosis of intellectual disability and it's based on fetal alcohol syndrome, then, for example, we may expect increased behavioral problems during puberty. We know that there may be certain risks as a child goes on. Another example is Prader-Willi. These children are often friendly and affectionate as very young kids, but we can see increased temper tantrums, stubbornness, impulsivity, food stealing, and compulsive behaviors once that onset of the excessive hunger hits in the older children. So knowing that helps parents get ready for what may be coming. For example, I once saw an individual with Prader-Willi in an inpatient unit and parents had locked the refrigerator and locked the cupboards - this is a pretty common finding when you are working with these kids given how much time they'll spend foraging for food and trying to get food. So letting families know that that's okay and that's one of the ways that people deal with that is important.



It may be important also to discuss genetic recurrence risks. If you have a child born with Angelman syndrome, and this is the firstborn child and parents are wondering, was this something that happens spontaneously? Is this because I was a carrier? What was the specific cause of this? It can help us understand and provide genetic counseling for future children. There may be certain complications expected for certain conditions and sometimes it's just helpful for parents to be able to understand the "why?" and have an explanation. So instead of wondering, why is this happening? For example, the child I was talking about with the chromosome 15 microdeletion, he presented with some really unusual hypotonia. It was the physical therapist and occupational therapist who were quite puzzled by that level of hypotonia and had recommended a neurology consultation, and that led to the chromosomal analysis that identified the microdeletion. Now the family has a better understanding of why. Now they're starting to sort out, is there some autism going

on as well? Or what do we make of some of those symptoms? I think it can provide some explanation, not just for parents, but also providers, when they encounter some of these behavioral difficulties. And, you know, why isn't this child responding in the expected way to the interventions that I'm providing? It was really an "aha moment" when that genetic disorder was discovered.

**John Bellone** 56:17



The mention of autism makes me think that there are comorbidities that are quite common in kids with ID. Autism is one, ADHD, learning disorders, mood and anxiety disorders. Can you tell us about the ID and autism comorbidity first, and what many of these children look like cognitively, emotionally, behaviorally?

**Jennifer Huffman** 56:39



Ah, this is such an important question.

**John Bellone** 56:42



I'm glad I got to ask it and not Ryan. [laughs]

**Ryan Van Patten** 56:45



[laughs]

**Jennifer Huffman** 56:45



Yeah, such a difficult differential diagnosis to make for so many complex reasons. It's important to talk about this comorbidity. In my training in the early 2000s, I first learned through research that about 75% of individuals with autistic disorder had ID. With increased attention given to the range of the spectrum, we call it the autism spectrum disorder, ASD, now, these numbers are changing. More recent research suggests about 30 to 40% of individuals with ASD also have ID. But research methodology actually may lower the actual rates due to exclusionary criteria. It's not uncommon for these studies and autism centers to exclude low functioning individuals or individuals with ID. So they have a much narrower group that they're studying.

Another interesting research trend has found that, with the increasing rates of ASD diagnoses, we've seen a pretty equal decline of ID diagnosis. So that's interesting, and it may just be that we're moving kids from one bucket into another bucket. We don't have the best understanding, as we're focusing on this ASD group and excluding some of the ID folks within that group, and as our research focuses there,

we're developing measures that are great for assessing ASD, but oftentimes those measures don't include ID kids as part of the standardization sample. So we may actually be creating tools, we are creating tools that aren't really well-validated in kids with ID. Something like the Social Communication Questionnaire, SCQ, that I find very helpful in understanding diagnoses is not validated for use with some of those ID kids. So we have to be pretty careful when we're using these tools. We know there's a good deal of overlap in the symptoms between ASD and ID as well as causes. So we're making this distinction between primary, or idiopathic, and secondary ASD. So there tends to be a high rate of ASD in secondary or non-idiopathic cases of ID where specific genetic causes are identified. So, for example, [in] individuals with Fragile X and Williams syndrome, we see increasing rates of ASD diagnoses.

One of the great resources I've found recently is a paper by Thurm and Cathy Lord and others in 2019 that really addresses this in detail. It's an open access article and outlines specific guidelines for looking at the DSM -5 ASD criterion E. This is the criterion that requires that symptoms of autism are not better explained by an ID or global developmental delay. We know that all kids with ID have global developmental delays, but a diagnosis of ASD implies that these social communication deficits are particularly impairing relative to that level of intellectual disability. This is something I mentioned earlier. It's really important to assess cognitive ability against which you then make comparisons. So at that point, you can make determinations about what falls below a child's developmental level. If you're expecting a mild level of ID, for example, yet we see severely impaired social functioning, then that might be a sign that we have the comorbid ASD and ID diagnosis here. Now, this is really hard to do in young children. If you've got a very young child with severe ID then what would you expect in terms of their social communications? It becomes really hard when you've got kids functioning at the floor to think about what would be lower than the floor. [laughs] So those kids at the very low level are very difficult to assess.

Sometimes it's hard because there's a lot of pressure in some cases and in some areas to give that comorbid ASD diagnosis. I think researchers like Thurm and others would argue that we have to be very careful about assigning a diagnosis of ASD in these kids who are so low functioning, but sometimes services are only available for kids with an ASD diagnosis. So then it can become a matter of, "Well, if applied behavior analysis services are only paid for by insurance in my area with a diagnosis of ASD, then gosh, maybe we should just assign that diagnosis."

I think another huge complication is that some of these ASD focused research centers and training centers, because the research is excluding some of these ID kids, then they really develop a skewed sense of autism and they don't really have a good way of recognizing and/or understanding the kids who also have ID. So I've seen, at least in my area, a lot of ASD evaluations that don't even include cognitive assessment. I had the opportunity to train with Cathy Lord for a brief period when she was at the University of Michigan on my fellowship and I know that she's a strong believer in cognitive assessment as part of these evaluations. So it's really surprising to me to see so many of these evaluations excluding cognitive assessment. They include the ADOS or the ADI-R as a means for both determining the need for autism specific services and also for reassessing on a yearly basis using these tools. I don't really think that's what they were meant for necessarily. So there are certainly some concerns.

One of the things, I think, when it comes down to actual symptoms that can help differentiate ASD and ID, we really have to consider nonverbal communication behaviors like eye contact, facial expressions, gestures, the capacity to share enjoyment, and participate in simple games like peekaboo. We know that kids with ID show a greater capacity for joint attention, showing and directing their attention. They have a range of directed affect. They use socially-appropriate eye gaze for social communication purposes. Kids with ID are often very interested in social functioning. They have friendships, often with younger kids, but you'll see that real interest, whereas children with ASD and ID may be disengaged, watching peers from afar, not coordinating that eye gaze.

We also often see kids with ASD and ID having some of those more serious maladaptive behaviors, limited communication and social impairment. They tend not to grow out of those challenging behaviors, rather those can persist over time. But one of the diagnostic dilemmas here, too, is that we know kids with lower IQ have more stereotyped behavior and self-injury. So sometimes those symptoms alone can get mistaken for the overall ASD package when, in fact, it might just be a function of the ID.

**John Bellone** 1:05:57



Those were good tips for differentiating. It sounds like a good take home is for clinicians to consider both and assess for both ID and ASD in their evaluations. And then to be aware of which diagnoses receive which interventions and to just have that on your radar as well.

**Jennifer Huffman** 1:06:16



Right. And, you know, seek supervision. If your background is in ASD, and you're seeing a really low functioning individual, it may be important for you to seek supervision in making that differential diagnosis because it's often very hard. I mentioned that the child I've been working with, with the rare genetic disorder, and it's tricky. There are so many - there are language impairments, there are motor impairments, and there are challenges with social engagement that I'm seeing. But there are also some strengths as well. Like there is some capacity for shared enjoyment and sharing things and joint attention, but it looks a little bit different. So teasing it out can be very tricky.

**Ryan Van Patten** 1:07:14



Great. Let's move into talking more explicitly about treatments. The ideal here would be primary prevention, meaning that we use public health interventions that reduce the incidence of ID in the first place. This could be something like education related to alcohol use during pregnancy. It could be reducing the prevalence of TBI in infants. Better screening and diet for children with phenylketonuria, and there are many others. What can you tell us about efforts such as these in the US?

**Jennifer Huffman** 1:07:45

Well, this is important. Since there is no cure for ID, we have to focus on prevention of course. One example of a leading preventable cause in developing countries in the world is iodine deficiency. This is why you find iodine added to our table salt, because most people are salting their food. So we get the iodine, and we really have eliminated that as a factor here.



Other prevention efforts - I distinctly remember attending a seminar on fetal alcohol syndrome by a leading researcher in the field and she acknowledged drinking alcohol during her pregnancy because she really, at the time, didn't know that alcohol would be bad to the developing fetus. I've even once evaluated a young man whose father admitted, "Hey, yeah, mom drank a lot during your pregnancy." The young man was shocked. The father had actually disclosed this to me separately, but this was a man in his 30s or 40s and I suspected may have had some of the effects of this. The father had never disclosed to his son that mom had been a heavy drinker, so we had to have a conversation about why that might be important to discuss. It's an example of the effect that prevention efforts can have because I think as you sit here, as earlier career folks, you're probably thinking, "Wow! Somebody was drinking and didn't know that was bad?" [laughs] It probably sounds absurd. But that's because of all of the efforts we've made and the

advances we've made in pushing this narrative until it becomes part of generally accepted culture. I know there's a recent billboard that's gone up on my commute that speaks specifically to the risks of marijuana to the unborn child and breastfeeding mothers. So that's something that's new that we're trying to be educating about. But in all of our prevention efforts, I always feel like we have more room to go. Do people really understand the importance of, for example, taking a prenatal vitamin if they're of childbearing age and aren't really great at taking a birth control pill consistently? You know, "Hey, you might want to be taking prenatal vitamins because without that folic acid really bad things can happen to your baby's brain in those very early stages." And what about binge drinking in those early weeks before you even realize you're pregnant? That can have pretty significant effects on neural tube development. I think people don't know as much about that as they could.

We do have a standard set of newborn screening tests. Although they vary by state, there's a core set of 34 tests for all states. Things like PKU, galactosemia, congenital hypothyroidism - these are tests that every state gives to assess for these conditions that may be modifiable by diet or other treatments. In certain areas, there are conditions that are not part of the newborn screening and I bet people don't always know there's a difference in that by state. So it's interesting to me, I think we hit some of the major ones, but why is it that one state would test for more things than another state? I think there's room for improvement and consistency in the messaging that we're sending, but we'll see where things go from here.

**John Bellone** 1:12:01



Primary prevention is obviously incredibly important, but some children still do develop ID as we've been talking about. Can you tell us about special education services in the US? I'm also interested in, for the children with mild ID, the pros and cons of opting for special education versus so-called "mainstreaming" for these children. So if you [could] talk about that briefly.

**Jennifer Huffman** 1:12:25



Right. As to the latter question, that just came up [for] a colleague of mine in a case conference this past week. So certainly very relevant every day of our practice, really. We know, in the United States, children from birth to age 3 are eligible for early intervention services. That's maybe called different things in different places. In my area, it's Early On. These are service providers who develop what's known as an Individualized Family Service Plan, or IFSP. They may send providers into the

home or in some cases have a child come to a classroom to receive some group-based services. Then once children are age 3, they end up qualifying under special education services. Those services are federally mandated through age 21, although some states do offer services for longer. For example, in Michigan, where I practice, it's through age 26. There are a whole set of laws that regulate the provision of what they call a free and appropriate education, or public education, including special education services for individuals with ID.

To get to your latter question, mainstreaming is often preferred for children with ID and we hear parents really pushing for this. They want their children to have an opportunity to engage with children with normally developing social and emotional skills. In the case I was talking about, that parent was concerned because the child had developed some bad habits when the child was in a special education self-contained classroom with other children who had more severe forms of ID and who are engaging in some self-injurious behavior. So that can be one potential risk. At the same time, the pace of programming might not be best suited for a child with ID especially as they get older where that child may need to have tasks broken down into small sequential steps. They may need hands on, concrete approaches with visuals and immediate feedback. This is really hard to do in a general education classroom setting with 30 other students, perhaps even with a paraprofessional. I think sometimes these choices get down to the type of classroom that's available, the quality of educators at a given school or in a given classroom, and what kind of kids are in that special classroom or self-contained classroom. For example, if a child with mild ID is going to be placed into a classroom with kids with severe or profound ID, that might not be the best program. But if a child with mild ID could be placed in a basic classroom where there were other students with learning disabilities, for example, and it allowed more one-on-one time with a skilled educator who is familiar with certain programs, like the Edmark Reading Program that's specifically designed with these kids in mind, would that be potentially a better fit to get more individualized instruction? I think you've really got to weigh the pros and cons. There is no one right or wrong answer here. Sometimes you have to look at the whole picture, which might include behavioral problems that are difficult to manage in the general education setting, for example.

**Ryan Van Patten** 1:16:45



Moving forward in time, from education to employment. As we've mentioned, people with severe or profound ID are very unlikely to work, but people with mild to moderate ID can sometimes work. You mentioned supported employment earlier. Tell us more about this program.

**Jennifer Huffman** 1:17:03



Right. Various vocational programs exist and have different levels of support, whether it's on the job training, supervision, or job coaching. The goal here is to match the environment to the individuals with ID. Supported employment often occurs in specialized settings where they may have certain tasks or they may contract with other governmental agencies or local companies to provide a particular kind of service. For example, if there's a hospitality program that is serving banquets at a university and they need silverware rolled and prepared for the banquet, or dishwashing services, or folding linen, that might be an example where individuals with ID could be placed with a direct supervisor to perform some of these more basic tasks. They can be quite complex - they can be sewing or answering calls at a call center, something like that. But it's really about these kinds of jobs that are fairly rote and repetitive and don't require a lot of problem... - Well, limited problem solving or conceptual thinking, as part of that.

**John Bellone** 1:18:32



Did you want to say anything about psychological or emotional sorts of interventions? The comorbidities can be pretty high. I think the rates of psychological diagnoses are like four times higher in these children or it's definitely higher. There is also potential for behavioral disruption and being more gullible and more susceptible to scams and things like that. I'm wondering if you wanted to comment about interventions in any of these symptoms.

**Jennifer Huffman** 1:19:00



Sure. Oftentimes, you see these kids requiring and benefiting from psychiatric services, so that could include medication. I think when it comes to some of the behavioral problems, the primary work happens with parents and these kids also can benefit from direct intervention services like applied behavior analysis. Big surprise to some of our insurance companies who want to limit these services only to individuals with autism spectrum disorder, [but] we know that kids with ID often benefit from these intensive treatment plans as well. There are some folks really making some gains with some particular maladaptive behavior problems with some of these programs that are really rooted in ABA techniques and principles. Here in Michigan, I think we're starting to see a shift where individuals with ID are on the cusp of also getting some of these supports. I think that's appropriate because some of these behaviors can be very limiting. If a child is spending so much time injuring himself or herself or others, then we know learning is not taking place.

I think it used to be that individuals with ID were excluded from being considered for other diagnoses like ADHD, for example. But I think we've all seen individuals with ID, who may be at a mild level, but they cannot pay attention for more than two, three seconds at a time. The attention problems are clearly limiting their ability to learn. While we can implement some ABA techniques, for example, to help improve or increase or lengthen their attention, we may not be able to do that as effectively as possible without medications to improve attentional functioning. So it's important that when we do see these comorbid diagnoses, that we're paying attention to them.

I gave the example earlier of the young lady with Down syndrome who began to develop more symptoms of depression and anxiety as an adult, and it really created some concerning symptoms. Things like withdrawn behavior, acting out more, not being able to participate in some of those structured social programs because of that apathy and orneriness, I guess for lack of a better word. So I think medications were an important part of her overall treatment plan in order to reduce that depression [and] anxiety level, so that she could engage appropriately and effectively in those social situations and outings that she really did enjoy.

**John Bellone** 1:22:19



When you're conducting an evaluation and find that ID is present, the feedback sessions, I'd imagine, can be sometimes challenging. Obviously, your approach to feedback is going to vary on factors like the severity of the ID, the child's age, and the parents level of education and familiarity. But can you give us a few tips on how you approach these types of feedback sessions?

**Jennifer Huffman** 1:22:44



Well, thank you for asking this question. Honestly, I think learning to provide feedback to parents of children with ID was probably one of the most difficult aspects of my training. At the time, I found very few resources available to me. Now we have Postal and Armstrong's wonderful "Feedback that Sticks" book, which I think is great in helping us to think more proactively about this subject. I think earlier on, we did these evaluations and in the adult world sometimes feedback never even happened. The reports just went back to the referring [physician]. I mean, that's still the case sometimes. But the reports go back to the referring [physician] as kind of like, "Well, just let the doctors handle it." Well, I think what child-focused folks realized pretty quickly is that the doctors weren't handling it. [laughs] They tend to avoid these subjects. They really do look to us to be the bad guy, if you will, and be able to deliver these diagnoses honestly. I think this is a really important

piece of training that deserves more attention. When I was first learning about this, I really resonated with that "Welcome to Holland" poem. I don't know if you've seen it, but it's a story about a long planned vacation to Italy when the vacationer suddenly finds themselves in Holland, which is a nice place as it turns out, but not what was expected. I think you really have to understand the hopes and dreams a parent holds for what they believe to be their "typically developing child" and those hopes are often dashed when we have to deliver an ID diagnosis. So I think you need to come to this with a really empathetic framework, with a clear understanding of your findings.

In neuropsychology, the reality is that we do a lot of hemming and hawing. You know, as I think about my case that I'm working on, there are certain aspects of this child's functioning that I think "Yes, that's ASD. No, that's not." We kind of go back and forth. I think, ultimately, we've got to be able to be clear in our own minds about what's going on and what our opinions are, and then be ready to be clear and firm when we can. And maybe we can't, and we have to say that. But if we're clear with some of those early diagnostic tools - if we see, let's say, a nonverbal IQ less than 70, for even a very young child, we know that that tends to hold up over time. Research tells us there's some stability in those findings. So when we see impairment early on, assuming we can't explain it away by some sensory or motor limitation, we have to really be thinking that this is a sign of ID and be prepared to tell parents that this is an impairment, or a deficit, or disorder, rather than using wishy washy terms like "delay" that imply the child's just [going to] grow out of it or get better. We need to be telling parents, if we're sure that this is a lifelong condition, that recovery is not expected.

At the same time, you have to instill a sense of hope in these families. We have to focus on what a child can do and their strengths and their capabilities. Hopefully, you find something about this child that was enjoyable and that you can highlight and highlight the parents' strengths as well. You know, "Gosh, you're so invested. I can see how much you care." "This child has such a sunny disposition and wide smile." Pointing out these things they think really can help set up a positive framework and a framework of hope. Another reference I like is that Eichenstein book, Eichenstein, I'm not sure how she says her name, but "Not What I Expected: Help and Hope for Parents of Atypical Children." I think it really takes that poem and those features of hope and puts that together in that reference, which I think is really helpful. You've got to use lots of examples about what a child was able to do, what they were not able to do, and what children their age are expected to do because you, as the expert - Remember, the value you bring to the table is those norms, that normative data. When you're making comparisons, you're saying,

"Okay, well, a child who is 24 months of age is expected to do X, Y, and Z, but your child is not able to do those things. And so that's what tells us there is an impairment there." Because, remember, they don't have that normative set of data in their head. They haven't worked with hundreds of 2 year olds, so they don't know what those comparisons should look like.

I think it's important, too, to incorporate their own adaptive ratings, assume those match and support your findings, you can use those. "You told me your child is not capable of X. I saw that in my evaluation as well." I always have a laminated copy of the normal curve at the ready. Or now I've got a quick and handy file folder that I can reference and throw it on the screen with my telehealth feedbacks. But you really need to show these parents what you mean when you say "IQ of 65." You need to give them a visual and help them understand what that percentile really means in reference to typically developing children so that they can understand because otherwise they're left thinking that they're just going to catch up. You've got to have an understanding of those differences between those categories of mild, moderate, severe, and profound. If the child is in that mild range, you can say that and say why you believe the child fits in that category.

These parents asked tons of questions about the future. So be prepared to answer questions about those and the limitations. You need to be able to say things like, "Look, these kids surprise us all the time. And we need to be hopeful about what they can and will do." But you may know, if you've got a child with an IQ of 35, something about the likelihood that they're going to live independently and go to college and work on their own. You can answer some of those questions realistically and help paint that realistic picture. You may encounter some of the most extreme denial that you've ever encountered in your professional career. I can tell you, I'm sure that some of my reports leave my office and find their way quickly into File 13. Just know that sometimes that's okay. You may have planted a seed that over time parents will learn to understand. I think it may not be until down the road. So, for example, I remember doing an evaluation of a really severely impaired child. The parents were certain that the child just wasn't able to communicate. That they were so much more capable than what they were able to communicate or get out. And that's oftentimes some of their sense. And they may be right, but part of what we're testing is that ability to see what they can get out. I ran into an attorney, a special education attorney, some years later who was defending a school district, and they referenced that case and said, "Thanks for just doing an accurate assessment, because you set the foundation for what we needed to help push that conversation along down the way." Although I viewed that evaluation and feedback

as a failure in some sense, I was able to learn that it had been helpful in the grand scheme of things.

I think one of the most important things to learn about this work is to always have the box of Kleenex nearby because that simple act of getting up to push the box of Kleenex and giving the parents that moment, that time to process. I mean, they'll openly weep in front of you and give them space to do that and sit quietly. You don't have to fidget or ask questions. You can just let that quiet be there. Unless you really understand it, and I know some of us have lived it with our own family members, and they may or may be able to have a certain understanding and empathy that others won't. Unless you've lived it, don't try to tell them you understand how they feel. You don't understand how they feel. You understand nothing about how they feel. You just say, "I can see this is really hard for you."



**Ryan Van Patten** 1:33:24

Sharing the Kleenex is one of the first skills we learned as a psychologist.



**Jennifer Huffman** 1:33:29

Right.



**Ryan Van Patten** 1:33:30

It's amazing how much power it has.



**Jennifer Huffman** 1:33:33

Yeah.

**Ryan Van Patten** 1:33:33



Well, thank you for the great tips regarding feedback. Before we let you go, there's just a couple more clinically -relevant questions we'd love to get to. One of them is: I'm thinking about working with adolescents who have ID and the importance of their transition from childhood to adulthood. This happens in multiple areas, socially, sexually, academically, and in other domains. How can we help with transitions?



**Jennifer Huffman** 1:34:03

Well, I think highlighting these transitions and encouraging open conversations about them really allows families to begin preparing for them rather than simply avoiding them. With kids with ID, or with all kids, it's easiest for parents to avoid

conversations about sexual activity, for example, even masturbation or other intimate relationships between young adults. But we have to let parents know that for kids with ID these conversations are especially important. It's important to have conversations about touch and acceptable touch, and to be thinking about how a child may deal with their sexual urges as it's a part of typical development. They may be especially confused or unprepared. Another example is menstruation for females and the onset of that and being prepared to deal with that. These are things we really need to talk about directly and preferably before they happen, and not after, because sometimes it's too late to alter the course. I like to say "The train has already left the station." That's not when it's best to have those conversations. In my work with transition planning, I saw how important it was to catch these kids early and have these conversations early because it was so hard once, say, a plan had been put in place for a child to attend college, then that course was very difficult to change with data. Sometimes you had to catch them before, in those early planning stages, before they enrolled and went for the placement testing or whatever it was. So just being open and being willing to have those conversations I think is pretty key.

**John Bellone** 1:36:20



I know you're a pediatric clinician, but I'm curious if you have any tips for adult neuropsychologists, like us, who might evaluate people with mild ID where the referral question is whether or not there's also a neurodegenerative process going on?

**Jennifer Huffman** 1:36:37



Well, to be clear, I'm a lifespan person.

**John Bellone** 1:36:40



Gotcha. Thanks for clarifying.

**Ryan Van Patten** 1:36:41



Whoops, John. Do your homework. [laughs]

**John Bellone** 1:36:45



I know there are a few of those out there. You're right.



**Jennifer Huffman** 1:36:47

Yeah. Interestingly enough, you know, my board cases were presented on prematurity and Alzheimer disease. So I will really cover the bases. [laughs]



**John Bellone** 1:37:03

Well, the bar is even higher now to answer this question. [laughs]

**Jennifer Huffman** 1:37:05

[laughs] Exactly. Yeah, as we were talking, I was thinking about a case I saw several years ago. It was a woman in her 50s who had gone back to college and was looking for accommodations for her learning disability, and came to me and had tested in that mild ID range. It was incredible. I mean, she was able to be successful in certain college courses that really relied heavily on rote learning and struggled in those upper level courses where more conceptual thinking was required. This woman just worked her tail off. She was very socially engaging and I think professors just wanted her to be successful. She was able to do things like get attendance points and homework to get credit to pass these classes. But, obviously, she really struggled when the course material got harder. So that was really interesting.



I think one of the key things that we have to keep in mind as clinicians working with these adults is records - obtain and review records. This is key. I think, for example, if you're working on a forensic case, and you're wondering if this person's low score is consistent with the way they've always been, getting educational records can be really illuminating and not always possible. We also want to make sure we're not relying on one source of information. We know that collateral informants can be biased for one reason or another. So, when possible, we need to try to get other people involved. Sometimes that means getting a group home supervisor, where an individual is living, to complete an ABAS, for example. Or maybe it's a sister of a young adult whose parents recently died. Maybe that sister is the one who can provide some helpful collateral information.

We also really need to pay close attention to changes in behavior. If we see new onset irritability, or aggressive outbursts, or any changes in adaptive functioning. If we see changes in eating habits, grooming, driving, work, performance, social withdrawal - that might be an example of an individual with ID who is experiencing a neurodegenerative disorder. As I said, those internalizing problems like depression or anxiety might be more of a problem with adults with Down syndrome, the acting out behavior would be less common. You should take a look at the available

research and instruments like the ones the mother highlighted for me. There's the Down Syndrome Dementia Questionnaire\* or Dementia Screening Questionnaire for Individuals with Intellectual Disabilities. So there are these formal measures out there that you can give caregivers to help you understand this. These are tools really trying to take a careful look at episodic memory, orientation, aggressive behaviors, household habits - you know, are these young adults who were clearing the table and helping with dishes before and now they're not doing those kinds of things? Are you seeing changes in their dressing behavior? Are they now requiring more assistance or prompting with eating? Are they suddenly not continent with their urine? Are they less likely to help around the house? Of course, if you've got access to prior evaluation reports, like school records, that would document IQ or functioning to compare current results to that can be key, because these are hard diagnoses to make.

My experience has been with Down syndrome. Again, when you're dealing with individuals who may be in the moderate or even severe ID range, and now you're trying to assess for a decline in functioning, you have a real problem. When these individuals are at the floor [of the test], how do they do worse? If you've got someone scoring at the lowest level on your IQ testing, how do you see that they're scoring lower? It's really as tricky as some of those ID/ASD differentials at the lower levels of functioning. You see the same problem. So it really becomes again more about that adaptive behavior and those sudden changes there.

[\* Transcriber's note: The Dementia Scale for Down Syndrome]

**Ryan Van Patten** 1:42:27



Well, this has been a great discussion of ID. Thank you for taking the time to answer all of our questions. Before we let you go [laughs], just two more. These are bonus questions about the field of neuropsychology more broadly. They don't necessarily need to apply to ID, although of course they might. So the first one is, if you can improve one thing about neuropsychology, what would it be?

**Jennifer Huffman** 1:42:51



I think relative to our conversation today, I would really like to see providers in the field getting experience with a wide range of conditions in their training. Obviously, as a lifespan person, I'm thinking about this more than other people because I have had a wide range of experiences. But I want to see that we're paying attention to how individuals grow and develop across the lifespan. Not just for the people we see who are biased, but also typically developing people too. I think it is a concern if you're studying one condition, or one patient population so narrowly that you lose

sight of behaviors that can occur outside that condition. For example, if you're studying individuals with ASD without ID, and you're focusing on that group, then you really may not be able to recognize or understand some of those differences when you see someone with ASD and ID. Evaluating people in a range of settings - like if you're seeing people in an inpatient setting in a general hospital where people are coming in from the community, maybe because they broke their leg or they needed some type of surgery, and you're evaluating them and you're seeing signs of ID. But these were people who were, before they came to the hospital, living independently and driving and working. I think some people are shocked about that when they're used to seeing maybe individuals with ID who are much lower functioning. So I think you really need to know what these people are capable of - what people can do with limitations. Because I think, as neuropsychologists, we often focus on what people can't do and that leads some people in the field to have very negativistic and just low expectations for what people are capable of. So I want to make sure that decisions about things like capacity for decision making are really based on our data. That we're understanding [that] these decisions are complicated and we're recognizing that sometimes individuals with ID are more capable of certain decision making than we give them credit for. I want to make sure that we focus as much on what folks can do as what they can't do.

**John Bellone** 1:46:03



Excellent. I love that positive approach. For the last bonus question, what is one bit of advice that you wish someone had told you when you were training, or maybe someone did tell you, that really made the difference? Just an actionable step that trainees can take.

**Jennifer Huffman** 1:46:17



This is a great question. I think that one of the most powerful pieces of advice that came from my mentor early on in my career was pretty simple. It was to learn how to say "no."

**John Bellone** 1:46:33



[laughs]

**Jennifer Huffman** 1:46:33



I learned this as an early career psychologist. He told me, "I'm terrible at this, don't do what I do. Learn how to say no." I really think it's important to prevent burnout. Our services are in such high demand. I feel the pressure growing every day. As we keep going in this pandemic, I think there are so many folks who have such high

needs. Those needs get bigger once you've established yourself in a certain area of practice because people keep coming back for their revaluations. Now you feel like you've got this relationship, and you must help them. So once you develop a reputation for helping others, that just begets more work. We have to keep in mind that the work we do is rarely an emergency. We're not good to our patients if we don't have that appropriate work-life balance. I just wrapped up a huge case that was all time consuming, and what I kept thinking toward the end was, "Why didn't I just say no?" [laughs]



**Ryan Van Patten** 1:48:02

[laughs]



**John Bellone** 1:48:02

[laughs] That's great advice. Although we are glad that you didn't say no to our request to have you on this episode.



**Jennifer Huffman** 1:48:07

Right. [laughs]



**Ryan Van Patten** 1:48:08

[laughs]



**John Bellone** 1:48:08

This has been fantastic.



**Ryan Van Patten** 1:48:09

Say no to anything except podcast invitations. [laughs]



**John Bellone** 1:48:12

[laughs]



**Jennifer Huffman** 1:48:12

Right. There you go. [laughs] Yeah, well, you know, it's like anything. It's like studying for the board exam. It's good every once in a while to force yourself to do some research and think about questions and prepare in a way that helps sharpen your skill set and knowledge. So I enjoyed preparing for this. And I enjoy listening to

your podcasts on my commute, too. So thanks for the work you guys are doing. I think it's great.



**Ryan Van Patten** 1:48:42

Well, thank you.



**John Bellone** 1:48:43

That's nice of you to say.



**Ryan Van Patten** 1:48:44

Yeah, thank you for the time. Any advice for us regarding the podcast?

**Jennifer Huffman** 1:48:49

Well, I'm excited that you're doing more case studies with kids - that that's coming. I've enjoyed the case study format. I think it's especially useful to someone like myself in private practice. I often feel starved for clinical collaboration. I've managed to put together a group of colleagues that I consult with regularly, but it's nice to think about things in new ways. You know, we can get stuck in surrounding ourselves with people who think the way we do or train the way we trained, and so I think it's really helpful to keep a broad perspective. I think that's what that offers. So keep up the good work.



**Ryan Van Patten** 1:49:35

Great. Thank you. We will try. Thanks, Jennifer.



**Transition Music** 1:49:38

**John Bellone** 1:49:42

Well, that does it for our conversation with Jennifer. A quick reminder to register for the upcoming INS conference. Ryan and I are both planning to attend in-person unless there are any COVID-related changes, in which case we would attend the digital conference. But we very much hope to see you in New Orleans. And, as always, thanks so much for listening, and join us next time as we continue to navigate the brain and behavior.





**Exit Music** 1:50:09

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**John Bellone** 1:50:33

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**Ryan Van Patten** 1:50:44

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**End of Audio** 1:51:03