Setting Up for School Success

A Roadmap to an Effective IEP for Students With Prader-Willi Syndrome

Dr. Destiny Pacha | 2026 FPWR Conference

Edited presentation transcript

This transcript has been edited for clarity and readability. Filler words, repeated phrases, false starts, and nonessential interruptions have been removed. The presentation and audience questions remain in their original order. Some audience questions and fragmented sentences have been lightly reconstructed from context; this is not a verbatim or recording-verified transcript. References to slides and the conference app refer to materials shared during the session.

The discussion reflects the speaker's experience and explanations at the time of the presentation. Education procedures vary by state and individual circumstances. As Dr. Pacha notes below, this presentation does not provide legal or medical advice.

Introduction

WILL GREENE:

My name is Will Greene. I'm a board member at the Foundation for Prader-Willi Research, and I'm here to introduce our next speaker, Dr. Destiny Pacha.

Her topic is of growing importance to me as the parent of a five-year-old entering what we call transitional kindergarten in California: navigating schools. Her session is Setting Up for School Success: A Roadmap to an Effective IEP for Students With Prader-Willi Syndrome.

Without further ado, I'll hand the microphone to Dr. Pacha.

DR. PACHA:

Thank you. He was so careful about my last name! I'm used to it being called all kinds of things, so as long as it's not a bad word, I don't mind.

There is a lot of information today. I don't expect you to take it all in. I believe this is being recorded, and you can reach out with questions. If you take away one piece of information, I consider that a win.

I'll watch the time so I can answer questions. If we run out of time, I'll stay outside and answer every question. Please come find me.

I'm Dr. Destiny Pacha, president of Empowered Solutions. We support families of children with PWS with IEPs, behavior, and training educators to understand PWS and support your children. I also authored It Starts With Hello: Katie's Story About Prader-Willi Syndrome. If you preordered a copy and haven't collected it, please stop by the table.

Today I hope you'll gain a basic understanding of IEP eligibility, how to map your child's individualized plan, and how to prepare for the future.

I created an infographic summarizing this information. Thank you to Melissa for uploading it to the conference app. If you don't take notes or photographs of every slide, that resource is available.

First, I am not an attorney. My husband is, so I get in trouble if I don't say that! We'll discuss law, including IDEA, but I cannot give legal advice. I'm also not a medical doctor. I can discuss ways school teams address health needs, but I cannot give medical advice.

Understanding IDEA

IDEA is the Individuals with Disabilities Education Act. I'll try to avoid acronyms because special education is alphabet soup.

There are four main parts. Part A contains the general provisions. Your procedural safeguards explain your rights and what to do if you disagree with the school district. At meetings, you'll be asked whether you need a copy or an explanation. Keep a copy, but you probably don't need another identical copy at every meeting.

Part C is early intervention, birth to three. Part B begins at age three and continues into young adulthood. States vary: some serve students until their 22nd birthday, and some offer transition services to age 26. At least, they have to go until the 21st birthday.

Part D concerns research, resources, and information. Today we'll mainly move from Part C to Part B, although not everyone takes that path.

Referral and evaluation

The process starts with referral and planning. A parent, physician, or someone at school may identify a child who might qualify under IDEA.

Schools have a responsibility called Child Find. If you explain that your child has PWS and may need support, they should help guide you through the process.

We'll discuss evaluations and eligibility because eligibility isn't automatic. Then we'll discuss whether you continue on to developing an IEP or take another route.

After referral, the team reviews existing information. At age three, that may include medical evaluations and reports rather than much school data. Together, you decide what additional evaluations would help.

The relevant professionals assess your child. Before age three, you may take your child to a district office, or someone may come to your home. For a child already in school, evaluations may happen there. These evaluations are provided at no cost to you under IDEA.

Evaluators consider development and pre-academic skills in younger children and academic skills in older students. Families arriving from another country may need assessments here because the educational systems differ. The team also gathers health information you provide and reviews the results together.

A diagnosis is different from educational eligibility

This can be difficult for families. You know your child has PWS and likely needs support, but a medical diagnosis doesn't automatically establish educational eligibility.

For comparison, a child can have an autism diagnosis without meeting school eligibility criteria. A school can also identify educational eligibility without a medical diagnosis.

Saying your child has PWS doesn't automatically produce an IEP. The evaluations still need to take place. When I worked in schools, parents sometimes brought a doctor's note saying the child needed an IEP. We could try to move the process along when needs were urgent, but it was still a process.

What evaluations may consider

This is not an exhaustive list. There are many areas a team might assess.

Cognitive scores in very young children may not reliably describe their longer-term abilities. Children with PWS also don't tend to test well. IQ measures can include processing speed and working memory, both areas that may be challenging in PWS.

A cognitive assessment may not fully show what a child knows. Yet some eligibility determinations require that assessment. Sometimes we need to understand that the test helps us move through the process, but it isn't the end of the road.

I don't believe an early cognitive score should determine a young child's educational path or automatically move them to an alternative curriculum. Preschool assessments don't accurately establish long-term potential.

Speech and language evaluations are common. Occupational and physical therapy assessments are also important for many reasons, not just handwriting later on. Think about playground access, sidewalks, and stairs needed to reach a classroom.

Depending on the child's needs, the team may assess social, emotional, behavioral, and developmental functioning. Some assessments involve surveys or questions for families.

Other health impairment is often relevant for students with PWS. States differ in the documentation they require. Some use a physician's signed form; others accept a letter or medical report. If the team is considering that category, the health information is important.

Eligibility and the possible alternative of a 504 plan

A student must meet criteria for a qualifying disability under IDEA and need special education.

If the student isn't eligible under IDEA, that doesn't necessarily mean they are ineligible under Section 504 of the Rehabilitation Act. That's a separate discussion.

Typically, children with PWS are found eligible for special education, and the next step is developing the IEP.

Eligibility categories and my cautions

Families sometimes ask why PWS isn't listed on the front of the IEP. It isn't one of the 13 disability categories described under IDEA. I have 13 plus one on this slide, and I'll explain the extra category shortly.

These cautions reflect my perspective when supporting families. I caution against autism as the primary category, but not necessarily as a secondary category. There is overlap, and co-occurring diagnoses absolutely happen. My concern is that staff may see autism, assume they know the approach, and overlook PWS-specific needs or training.

I also caution about emotional disturbance, called emotional or behavioral disability in some places, and intellectual disability.

Children with PWS can struggle with social interaction and emotional regulation. But I generally don't want emotional disturbance to become the primary category and lead the team toward a behavior-focused classroom that may not be the best fit. Some children do well in those settings, depending on the district and the classroom support; nothing is all or nothing.

Similarly, I don't prefer intellectual disability as the primary category. Children with PWS can have a spiky profile, with real strengths and areas of need that vary by subject and over time. I don't want cognitive disability to be the first explanation people assume for everything. As a secondary category, it may accurately describe a particular child.

Other health impairment is the broad umbrella I most often look to. People may associate it with ADHD, but other health conditions affecting access to education can fit there. That's where PWS often falls.

Developmental delay and state differences

The extra category is developmental delay. IDEA recognizes this beginning at age three, potentially through age nine, but states have flexibility.

I'm from Florida. For a long time, developmental delay was used only from three to five. A mistake or missed meeting near kindergarten could mean the category dropped off without another category in place and the child entered kindergarten without an IEP. Florida changed this a couple of years ago.

Many states go to about nine; a few don't use the category. New Jersey, for example, uses a preschool disability category and changes it before kindergarten. Developmental delay can provide a route to support when there are clear delays but the specific category isn't settled.

Not every child qualifying under developmental delay will need an IEP later. Outside PWS, some children make sufficient progress through early intervention. In PWS, the transition is often from developmental delay to other health impairment.

In research I discussed at a previous conference, most students with PWS were found eligible under other health impairment. About 20% were under developmental delay, which I marked with an asterisk because that category eventually ends.

States also differ in how they describe multiple eligibilities. Some identify primary and secondary categories; others use multiple disabilities. When you're in the process, return to this information and the recording because it may make more sense then.

Mapping the individual student

We'll move through present levels, special considerations, goals, accommodations, modifications, services, and placement. The infographic in the conference app summarizes these areas.

I developed a PWS spectrum tool for school training. A child's pattern of needs isn't linear. It isn't simply more or less PWS. Each student has a different combination of strengths and challenges.

I used to describe the completed map as a spiderweb. A mother told me it looked like the iris of an eye. Every iris is unique, like a fingerprint, which is a helpful way to think about this.

Knowing one person with PWS doesn't mean you know every person with PWS. We need to respect each student's strengths and needs, and recognize that they can change. I can discuss common patterns and supports, but your child's plan must be individualized.

Present levels are the starting line

The present levels of academic achievement and functional performance are often near the beginning of the IEP. This is where the plan should describe strengths, interests, and current abilities.

You may hear that something has to be educationally relevant. Functional abilities are educationally relevant too. IEPs address independent functioning, social skills, and communication as well as academics.

What is your child good at? What can they do? What motivates them? You should read this section and think, "That's my child."

I often see very little information here, yet it drives the entire IEP.

Your input belongs here. At meetings, families are asked their concerns, which can feel overwhelming. I prefer written input so all your thoughts, wishes, and concerns are available for the team to address.

Present levels should describe current performance and progress toward previous goals. Did the child meet the goal? How far did they get? You should receive IEP progress reports, and that information should help shape the next plan.

This section can explain PWS and how it affects learning, behavior, and communication. If you've disclosed the diagnosis in the IEP, describe the supports and protections needed as food seeking or other needs change over time.

Include strategies teachers know work. Does the student do well with individual support or in small groups? When I read that individual support works best in math, I look for that support later in the plan. If the child knows letters but struggles with consonant-vowel-consonant words, I expect to see that need addressed.

Everything here should help develop the rest of the IEP.

Special considerations and behavior

IEPs may arrange these sections differently, but IDEA outlines special factors the team needs to consider.

Does behavior impede the student's learning or others' learning? Families sometimes hesitate to say yes. But this isn't asking only whether a child is aggressive or leaves the classroom. Staying focused and remaining on task are behaviors that can affect education too.

If the answer is yes, the team needs to address it, whether through accommodations, a service, or another plan. I don't want families to fear this question; it can identify a need for support.

Other considerations include language needs and visual impairment. Communication needs are also important. I've seen teams mark that only for students who are nonspeaking or need an AAC device, but communication includes articulation, expressive and receptive language, and pragmatic skills.

If there are communication needs, the team should consider how to address them.

Assistive technology and health considerations

Assistive technology isn't only AAC or an iPad. It can include pencil grips, slant boards, specially lined paper, visuals, schedules, and checklists, as well as augmentative and alternative communication devices.

Sometimes, if the supports are clearly documented elsewhere, I won't make the checkbox the issue I focus on. But families should know the category is broader than electronic technology.

Some states include a health question in this section, asking whether medical or health conditions affect education. For a student with PWS, yes. It's a good place for a short description of relevant needs.

That might include emotional regulation, hypothalamic-related needs, temperature regulation, and thirst. It helps the next person reading the IEP understand the child and what support may be required.

Writing goals and monitoring progress

At this point, we know the student's strengths and needs and have considered additional supports. Now we develop goals.

Goals must be specific and measurable and connected to needs identified in present levels.

Families ask how many goals are too many or too few. I can't give one number because it depends on the child. But too many goals can lead to a great deal of monitoring without enough time for instruction, including instruction with peers.

Identify the skills most needed to get to the next step. Goals can address academics, pre-academics, independent functioning, communication, and social-emotional needs.

There should be a clear monitoring plan. A goal can't simply say the child won't elope. How will that be measured? What support prevents it? How will the team teach the skills the student needs? What does success mean: counting incidents, zero incidents, or a percentage?

The plan should explain how families will learn about progress. Often reports come with report cards. Where I live, that's every nine weeks.

If the report says no or limited progress, that's a reason to return to the team. Are the services right? Is the amount sufficient? Is more support needed in general education? What's preventing progress?

The IEP is fluid. Health can change; communication can suddenly expand. A student may meet goals and need new ones. The plan can be reviewed and revised.

Accommodations modifications and supplementary supports

I call these roadside assistance.

Accommodations address how: how the student is taught, responds, or is assessed. Is it a small group? Extra time? An additional day for a task? Those change the how.

Modifications change the what: curriculum, standards, or the assessment path.

Supplementary aids and services are another section. One-to-one support is a supplementary service. Visual schedules, checklists, and writing rubrics can also support access to education. Additional health, behavior, or food plans can be identified here too.

Health behavior and food security plans

An individualized health plan is one of my recurring soapboxes. I've given a separate webinar on this topic. If a child qualifies under other health impairment, I generally think they need a health plan, but that doesn't always happen.

Schools may think only about hyperphagia and overlook temperature regulation, encouragement to drink, or a higher pain threshold. Those concerns should be outlined so someone knows what to monitor and how to respond.

A behavior intervention plan may also help. It describes what adults do to support the student, with proactive, teaching, and response strategies.

If a child puts their head down, is that an early sign of difficulty? Does it indicate something may be building? If that information isn't written down, staff may not know. I want adults to understand what works and how to respond.

Food security and meal plans are another common need. Many schools don't understand what food security means in PWS. It can be outlined in a health plan; the heading matters less than the content.

Where does food come from? How much is provided? Who provides it? One of my non-negotiables is direct adult supervision at every meal, both for access to food and choking concerns.

These are supporting plans that can be referenced in the supplementary aids and services section. My concern is making them part of the IEP's documented support. If they aren't part of the IEP, IDEA procedural safeguards don't apply to them.

Document the existence of the plan, whether in the health section, parent concerns, or another appropriate place, so anyone reading the IEP knows there is another plan to follow.

Special education and related services

The types of services can be confusing. Special education may address academics or social skills. Speech-language services may be special education or a related service, depending on the state and district.

Occupational therapy, physical therapy, and transportation are related services. You can't have an IEP for occupational therapy alone; it supports the child's access to special education.

Speech and language are more complicated because how they are classified depends on the jurisdiction. The point is to understand what support the student needs to access their education.

Supports for school personnel

This section can be hidden, and parents may not know about it. It's a gold mine: supports for school personnel.

It asks what staff need to understand the disability and support the child. This is where PWS training can be included in the IEP.

I typically try to include training at the start of each year, sometimes a midyear refresher, and training for new staff.

A district may push back because they aren't used to using the section. I worked for more than 20 years in a very large district, and we were often told not to touch it. This may be new for the team.

We can work collaboratively, share resources, meet, and discuss it. The goal is to document the support while working with the school.

Transitions from elementary to middle school or middle to high school bring a new team, school, and therapists. They need to understand PWS and the individual child, including how to respond in specific situations.

If your child already has an IEP, look for this section. It may be a small line within supplementary aids or services, sometimes marked "team considered; no needs." Don't overlook it.

Services do not automatically determine placement

Services aren't placement. An eligibility category or service doesn't automatically move the student to a particular classroom.

Every child needs their least restrictive environment. This can be difficult to explain because the general education classroom is often described as the least restrictive end of the continuum, but the decision has to be individual.

A student may do well in general education with a speech therapist coming in or someone supporting math. Another may need 30 minutes of reading instruction elsewhere, perhaps during independent work, or separate speech sessions for articulation. There are many points along the continuum, not rigid steps.

An autism category doesn't automatically mean an autism classroom. Intellectual disability doesn't automatically mean a particular disability classroom.

Not every child needs general education all day, and that's okay. Needs change with age. Speech may shift from articulation to language or pragmatics. The amount and setting can change in either direction.

The continuum includes hospital or homebound instruction and residential settings. I've spoken with districts or specialized schools that say they cannot meet PWS needs, often food security. Sometimes more intensive options need consideration, depending on the child.

Most students with PWS are in the part of the continuum shown on this slide, but not all. Where the student is educated depends on their needs and the support required.

Preparing for an IEP meeting

Request a draft. I can't emphasize that enough. IDEA doesn't require a school to create a draft, but if one exists, parents have a right to it.

I've seen teams use slideshows or PowerPoints rather than draft documents. Whatever you can obtain ahead of time gives you time to process the information and participate meaningfully.

This isn't about coming in confrontationally. I've been in meetings with more than 40 people. Imagine hearing new information about your child in that setting while managing emotions, interpreting terminology, taking notes, and advocating. You're wearing many hats.

With a draft, you can arrive with questions or a section you disagree with. If a teacher reports the child knows three letters but you know they know more, your observations can be included as parent input.

Request evaluation reports and assessment information in advance too. You are required to get evaluations ahead of time; you shouldn't be expected to process them for the first time as someone reads them aloud in the meeting.

Schools often schedule 30 minutes. I generally allow at least two hours for a well-developed IEP meeting. Having a draft may help, but you need time to understand the document before agreeing to it.

Bring documentation and written input

Document what is and isn't working. If the school asks you to collect your child once a week, keep track. Repeated pickups mean something isn't working. You shouldn't be asked to pick up your child for behavior; that is a placement change they can't simply make.

Bring data. If the draft describes three known letters and you have work showing more, share it. The school may say they don't see that skill there, but your evidence and observations can still be documented.

Provide written concerns ahead of time. That helps the team arrange for the right people. If handwriting concerns are known in advance, the occupational therapist can attend. Without notice, the response may be that the OT isn't there and another meeting is needed.

Writing also gives you time to consider your goals and concerns. Describe roadblocks and what isn't working.

If you request something, the team must address it, either agreeing or refusing. They can refuse, but there are procedures to follow and the refusal needs documentation.

Your concerns and preferences must be considered. Decisions should not be predetermined before you participate. You are a team member.

Resources to bring to the team

Bring your packing list. I have free resources on my website, although not everything I've written is posted. If something specific is happening, I may have a resource for it. I try to keep materials to one page because I was a teacher and know what happens when people receive too much information.

There is a trifold introduction for teachers and staff, fact and awareness information, and materials on hyperphagia, food security, and questions for schools.

I also coauthored a primer for school psychologists with Dr. Bédard and Stacy Ward. This is useful for people assessing your child. It focuses less on genetics and more on how PWS may present during assessment, including executive functioning needs that should be considered.

Review revise and return to the team

Once the IEP is written, the process isn't over. The infographic has a U-turn because you continuously review and revise.

Sometimes an amendment is enough; sometimes you need to remap the whole plan. Review progress reports and work coming home. If necessary, request another IEP meeting. You can ask the team to revisit it.

That's the presentation. I know it's a lot of information to process at once, but I'm here for questions.

Audience question on goals that feel too low

AUDIENCE QUESTION:

My daughter has an IEP, but the goals seem to set very low expectations. We asked the team to raise them, and they said no. What do we do?

DR. PACHA:

They shouldn't simply say no. If a progress report shows strong gains, you can return to the team and write new goals.

Disagreement doesn't have to be adversarial. I usually recommend first talking to the administrator or district representative. School staff don't always have all the answers, and district staff may better understand available options and how to write the goals.

I was recently in a meeting where we rewrote the entire IEP. Sometimes someone from the district can help the team reach common ground.

Goals should be achievable, but we also want to push. If you know the child can do more, discuss increasing the measurable expectation. If you're getting nowhere with the school, ask for the district's special education director.

Did they provide prior written notice of refusal? The notice should explain why they refused. There are specific requirements for what it contains. If you'd like to email it to me, I'm happy to review it and offer guidance.

Audience question on additional speech and language services

AUDIENCE QUESTION:

My son is three and has moved from early intervention to school district services. He gets only 20 minutes of speech each week in a group, which doesn't seem enough. How can we advocate for more time?

DR. PACHA:

Similarly, ask for the data and make sure any refusal is properly explained.

Does he have speech goals, language goals, or both? We need to separate those. There may be receptive language goals for understanding, expressive goals for communication, and pragmatic goals. Those goals need services to support them. If there are multiple goals, I agree that 20 minutes a week may not be enough.

Ask for progress reports and therapy notes. Speech-language pathologists, OTs, and PTs may maintain detailed records, partly because of Medicaid billing. Ask for documentation of progress monitoring. That shows you want to understand the details.

Sometimes we can agree on a trial. If you request an hour and they propose 20 minutes, could you start with 40 and review progress after two marking periods? If progress is still insufficient, perhaps more time is needed.

For a support the family sees as essential, can the team try it for six weeks, nine weeks, or two months and then review? A defined trial can help the school see the need and gives everyone an end date for reassessment.

Several families here have worked with me that way. We start, review, and the team sees that the student did need the support. Sometimes we have to guide them through it.

District-level support may help, particularly with speech-language services. There is a therapist shortage, which may explain limited availability, but that cannot be the reason to refuse needed services. A district can contract for additional therapists.

Missed services and compensatory education

If your child isn't receiving services because no therapist is available, that is time owed to your child.

In the district where I live, one of the largest in the country, contract speech-language pathologists were dropped because of funding. Some schools now have no language therapist. They document the missed time and send a letter every ten days saying the child has not received therapy and time is owed.

There are measures families can pursue. Some service schedules build in flexibility for illness, absence, or monitoring, such as providing services three weeks out of four. But when missed services are ongoing, compensatory education may be owed.