

Like countless 4-year-olds across the country, Jaxson Pennington is attending a new preschool this fall. Typically, this is a challenging experience for most kids as well as their families. What makes Jaxson special, however, is that he has autism and was in a school for children with special needs last year. This year, he is attending a public school in a classroom with typically developing peers.

Jaxson's successful transition from a special needs classroom to a typical classroom would not have been possible without intensive early intervention and effective behavioral therapy, as well as the support of his school district and his mother, Tracy, who played an important role during the development of his Individualized Education Program (IEP).

The Penningtons live near Camp Geiger in North Carolina, where Jaxson's father, Staff Sargent Brandon Pennington, has been stationed with his family for the past two years. The family's move to North Carolina from Hawaii, where Brandon was previously stationed, occurred just before Jaxson was diagnosed with autism in June 2009.

A lively and loveable child, Jaxson appeared to be developing typically—waving, pointing, interacting, and saying “Mama” and “Dada”—until he was about a year old. Then Tracy and Brandon began to notice changes in their son. When Brandon returned from his first deployment, he observed that Jaxson was acting just like a neighbor's son who had previously been diagnosed with autism.

An initial evaluation by a developmental pediatrician in Hawaii confirmed that Jaxson had a number of the “red flags” for autism. Because the family was preparing for their move to North Carolina, Tracy arranged for an assessment to be conducted through the Child Development Services Agency (CDSA) in that state.

By this time, Jaxson was not speaking at all. “He would just scream and we would have to try and figure out what he wanted,” says Tracy.



# Active Duty Helping parents become effective members of their child's IEP team

By Adam Feinberg, Ph.D., BCBA-D, and Patricia Ladew, May Institute

In North Carolina, Jaxson had a play-based assessment as well as speech, hearing, and occupational therapy (OT) evaluations. After receiving an “official” diagnosis of autism, he began receiving in-home OT and participating in a speech program twice a week. CDSA provided Jaxson with a play therapist, and once a week he participated in a playgroup.

### TRICARE, ECHO, and ABA

It was after Tracy and Brandon enrolled in the Exceptional Family Member Program (EFMP), and Jaxson qualified for services through TRICARE's Extended Care Health Option (ECHO) program, that the Penningtons met Anne Stull, M.A., LPA, a board certified behavior analyst (BCBA). Anne is the Clinical Director of May Institute's Center for Autism

Spectrum Disorders in Jacksonville, N.C. In December of 2009, Anne began providing Jaxson with in-home applied behavior analysis therapy (ABA).

[After a military dependent receives an autism spectrum disorder (ASD) diagnosis, he or she is eligible to receive \$36,000 per fiscal year for ABA services. ABA uses effective, evidenced-based interventions to increase skills and appropriate behaviors and decrease inappropriate behaviors. It is the only treatment reimbursed by TRICARE's ECHO and Enhanced Access to Autism Services Demonstration ("tutor") programs for military families who have children with ASD.]

Anne immediately went to work addressing Jaxson's lack of language. She applied basic behavioral practices such as positive reinforcement, teaching in small steps, prompting, and repeated practice to help him develop communication skills.

"We started with picture cards and he learned to exchange a picture card for an item he wanted," Anne explains. After he mastered the picture exchange system, Anne taught Jaxson to hand her the card and say the name of the item on the card. From there, they worked on pronunciation, adding descriptive words, and finally, putting sentences together.

Since then, Jaxson has made tremendous progress developing language skills. "He was not talking at all when I first met him," Anne says, "and now he cannot be stopped! In January 2010, his verbal repertoire consisted of only five words. By April 2010, he had mastered 182 words and 13 phrases."

Jaxson also benefitted from the speech, OT, and other services that were provided as part of North Carolina's Early Intervention program. When he turned 3, however, Jaxson was no longer eligible to participate in those state-funded programs.

### Developing an Individualized Education Program

Before Jaxson's third birthday—the date on which he "aged out" of state-funded early intervention services—Tracy attended her first IEP meeting. An IEP is a document that outlines special education and related services school districts must provide to eligible children. IEPs are developed in accordance with the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA), which mandates that every child in the United



States with a diagnosed disability and who requires special education services will receive those services free of charge.

The professionals on an IEP team must include general and special education teachers, along with other staff such as therapists, a psychologist, vision or hearing specialists, and others, depending upon the specific needs of the child. Parents are also critical members of any IEP team.

At the meeting that was held to discuss and develop Jaxson's first IEP, Tracy was joined by a case manager, occupational and speech therapists, a school director, and a special needs teacher. She quickly learned how involved a process

it would be. "I didn't really understand everything that went into creating an IEP," says Tracy.

An IEP team meeting commonly begins by reviewing any assessments and evaluations that have been conducted. This helps team members determine if the student qualifies for special education, and if there are recommendations for specific services. After reviewing all relevant information, the team decides whether the student meets the criteria for a "child with a disability" as outlined by IDEIA. It is possible that the initial qualification determination and the IEP development can occur at the same meeting.

This is what happened during the first IEP meeting for Jaxson. "They did the assessment while we were doing the meeting," Tracy remembers. "I could have asked for separate meetings, but I didn't know that. So I was trying to watch him plus participate in the meeting."

During an IEP planning meeting, participants discuss the strengths and needs of the student in order to identify his or her learning profile and a set of appropriate educational supports. The professionals on the team use the information obtained at the meeting to draft a document that outlines the services the student will receive. This document includes specific components—accommodations and modifications, goals and objectives, as well as a grid outlining services provided to and for the student. This becomes the student's IEP.

After an IEP plan is in place, parents receive progress notes on a quarterly basis. These are designed to update parents about their child's progress relative to the specific goals and objectives set out in the IEP. The IEP team reconvenes annually to update the child's services and goals for the upcoming school year.



## How to Prepare for an IEP Meeting

By Anne Stull, M.A., LPA, BCBA, May Institute

Parents are a very important part of the Individualized Education Program (IEP) planning process. When they are fully informed and prepared for IEP meetings, they can be more effective members of a team that comes together in the spirit of collaboration and cooperation to develop a program that will best meet their child's unique needs. Here are some tips for parents who are new to this process.

- Do some research. Learn about the Individuals with Disabilities Education Improvement Act (IDEIA), and find out what goes into creating an Individualized Education Program (see resources listed below).
- Know your rights. You have many rights as a parent, and your child is entitled to a free, appropriate public education in the least restrictive environment (LRE).
- The school should provide you with a list of parental rights (also referred to as Procedural Safeguards) when an IEP meeting has been scheduled. If you do not receive this document, request a copy.
- Gather data from your child's progress summaries or evaluations, from therapists, and from the school.

- Prepare what you will say before the meeting.
  - What would you like to see your child achieve over the next year?
  - What are his/her preferences and communication skills?
  - What type of classroom do you think will be the best fit for your child?
  - Be prepared to provide support for your answers to these questions.

Be realistic and base your request on objective data (written reports/evaluations).

- Write down any questions you may have for other IEP team members.
- Be prepared to be open to listening to the other members of the IEP team. If their recommendations are different from your suggestions, provide support for your suggestions and ask them to provide support for their recommendations.

Remember: decisions should be based on objective data and in accordance with the Individuals with Disabilities Education Improvement Act (IDEIA), not based on emotional or otherwise subjective data.

- Have a third-party join you for the meeting, if possible.
  - a therapist or professional who is familiar with your child
  - a family member
- Remain calm and don't argue. The other IEP team members are more likely to listen to what you have prepared to say if you are calm, respectful, and politely assertive.

### Coming to consensus

One important objective for an IEP meeting is for all participants to come to consensus regarding the student's needs. Sometimes the team may determine that the student needs additional services and supports; sometimes they may agree that the student is ready for a less restrictive environment. When all team members are in agreement, the IEP document can be finalized. Parents receive a copy of the

completed document to review and sign. They can disagree with any aspect of the IEP at any time. If they do have concerns, they should request that the educational team reconvene to discuss all concerns with them.

"I wasn't prepared [for that first meeting] at all," says Tracy, who attended it without Anne or Brandon by her side, as they would be during subsequent meetings. "I think I was just so happy that he got into the

school that I was in a daze for the rest of it. I would have said 'yes' to anything."

She signed the required paperwork and left the meeting believing that Jaxson would be in a "mixed" classroom with some special needs students and some typically developing students. Based on the results of the assessment, however, he was placed in a self-contained classroom with other children with special needs. Tracy did not realize this until she took him to school the first day and noticed "that there was not one kid in the class who was typical." When she called the director to ask about Jaxson's placement, the director explained that his placement had been decided in the IEP meeting. Sure enough, the IEP document stated that Jaxson would be in a self-contained classroom.

Many families are not entirely clear about what will happen the first time they go through the IEP process. With the support and encouragement of the other team members and regular communication with the school, most parents find the process becomes easier.

### Addressing problem behaviors, improving language skills

As it turned out, Jaxson initially did very well in the self-contained classroom. But soon thereafter, Tracy noticed that he started acting out at home. He began engaging in problem behaviors—such as hitting, pushing, and scratching—that she had not seen previously.

"These types of behaviors are common with children who cannot otherwise communicate," explains Anne. "The other children in his classroom did not have the verbal repertoire that Jaxson had."

Anne addressed Jaxson's new problem behaviors during their sessions. He quickly abandoned them when he learned better ways to get the attention he wanted.

"Another early challenge for Jaxson was that when he was at school he did not use his words to express his wants needs and he stopped requesting or describing things using full sentences," says Anne. "Most of the other children in the class did not communicate verbally, so they were learning different ways to

communicate their needs." As is common with young children, Jaxson was picking up cues from the children around him."

But along with the challenges came successes. Within a few months, Jaxson began making great strides in developing his language skills thanks to his in-home ABA therapy, the speech and language interventions at school, and the reinforcing efforts of his family. By January of 2011, his verbal repertoire consisted of 578 words, 60 phrases, and 17 simple sentences.

### **An emergency IEP meeting**

Believing that it was time to move Jaxson to a more challenging environment, Tracy requested an emergency IEP meeting to discuss a move.

Prior to the meeting Anne encouraged Tracy to learn more about the IEP process and prepare for the meeting [see related sidebar]. "She listed the reasons why Jaxson should be in a typical classroom," Anne explains. These reasons were based on the teachers' assessments, Anne's assessments, and those of his private OT and speech therapists.

After several months, Jaxson was moved to a typical class. At first, he was in the typical class for just a few hours a week, then three days a week for two hours at a time. Finally, he was moved to the class all day, every day because he was doing so well.

### **Changes at school, changes at home**

It was about this time that Jaxson's baby brother John Mason was born. "A lot of factors changed at home, so Jaxson was dealing with a lot of change at once," says Tracy. "At first he did really well (in the typical classroom). He had stopped some of the behaviors he was doing in the other class. And then the baby was born right around the time they moved him into the typical classroom all day long. He started acting out."

"Jaxson's home environment changed drastically when the baby was born," confirms Anne. "He began engaging in some attention-seeking behaviors, crying when the baby cried, and having toileting accidents." They worked on these things at home, and the attention-seeking

behaviors decreased. At school, however, his teachers noticed that his attention-seeking behaviors were increasing.

Sometimes there can be discrepancies between what parents see at home and what educators see at school. When this occurs, it can be challenging for the two parties to communicate. It is therefore very important to record clear and valid data both at home and at school to help determine whether there are differences in expectations and/or in performance in the different environments. If there are differences in performance across settings, the next step is to determine why this is occurring. Then parents and educators have the information they need to work together and best support the child.

### **Planning pays off**

The next IEP meeting was held to discuss Jaxson's classroom placement for the 2011-2012 school year. Based on his recent attention-seeking behaviors, Jaxson's teachers recommended that he return to a self-contained classroom so that he could receive additional supports.

"Anne and I had a meeting before the meeting to prepare," says Tracy. "We had all the data and made it into a chart. We also prepared a list of points to discuss at the meeting."

"We shared the data that showed Jaxson was at grade level in almost every area and above grade-level in the majority of academic areas," Anne explains. The team also discussed Jaxson's recent attention-seeking behaviors, and how they might be connected to sudden changes at home.

Ultimately, the IEP team came to a consensus that Jaxson's best interests would be served by being in a less restrictive environment. It was determined that he should attend a typical preschool class in a public school near his home this fall.

Anne and Tracy spent the summer preparing Jaxson for his new school, working on community outings, social skills, and communication skills. They also focused on helping him learn to communicate appropriately when he is frustrated or upset. In addition, they

requested the curriculum for the upcoming year to make sure he would be up to speed with the rest of the class.

A team working towards a shared goal of success for Jaxson, and data to help make informed decisions each step of the way, are key factors contributing to this next stage of Jaxson's life. The close collaboration between his family, his IEP team, and his therapists will be pivotal in ensuring his continued success.

"Jaxson is super smart and I am confident that he has all the prerequisites he needs for his new typical preschool class," says Anne. "We all wanted to make sure he was ready for his new 'big boy' school. We wanted to be sure to set Jaxson up for success." •

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### **Additional Resources:**

#### **About IEPs:**

[www.wrightslaw.com/info/iep.index.htm](http://www.wrightslaw.com/info/iep.index.htm)

#### **About IDEA:**

[www.wrightslaw.com/idea/index.htm](http://www.wrightslaw.com/idea/index.htm)

#### **Exceptional Family Member Program (EFMP):**

[http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF\\_HOME\\_1?section\\_id=20.80.500.165.0.0.0.0](http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_HOME_1?section_id=20.80.500.165.0.0.0.0)

#### **Specialized Training of Military Parents (STOMP):**

<http://www.stompproject.org/services.asp>

#### **"A Parent's Guide to Autism and Evidence-based Practice,"**

the National Autism Center's new manual for parents is available free of charge from the organization's website:

<http://www.nationalautismcenter.org/>