

new futures

A Newsletter for Parents and Friends of Children's Health Council

Spring 2011

the autism issue

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Children's Health Council helps children, teens and families find the best ways to learn, develop and thrive.

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- Autism Spectrum Disorders
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One Family's Journey with Autism

A group of boys ages five to six are interacting in a therapeutic skill building group to strengthen classroom social skills. They take turns playing games, doing jobs and sharing their favorite toys. One boy stands out for his bubbly and friendly behavior – Johann García. He comforts his friends when they are sad, he doesn't hit back when other kids antagonize him and he happily tells the class about his favorite truck. However, Johann, the friendly, bubbly boy who loves Disney movies and chocolate ice cream, is not the Johann of several years ago. His family has struggled to get him to where he is today.

Three Years Ago

Three years ago, Johann was the kid hitting the other children in class and never uttering a word. His mother, Lucy García, says, "He'd line up his cars, yell, be aggressive with other kids and couldn't sit still."

Johann's father, Martin, and Lucy sought help and were told that Johann had a speech impediment as a result of learning both English and Spanish. It didn't make sense to them. Their daughter, also a bilingual learner, had none of the problems Johann was having. They tried speech therapy, but Johann didn't improve. Again they looked for answers but this time were told that their son's problems were the result of "bad parenting." Lucy was exasperated. Meanwhile, Johann's teachers reported that his aggression was escalating.

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Dear Friends,



As our cover story on the Garcías illustrates, when a child has autism, receiving coordinated care across multiple disciplines under one roof is essential for helping families help their children get the best care possible. Esther B. Clark was the first leader who understood the value of integrated care and made it attainable by founding Children's Health Council (CHC). Today, others in our community have attempted to replicate her vision with two or three disciplines, and yet, CHC stands as the only place that offers a truly integrated care model with nine disciplines under one roof. Why does integrated care across multiple disciplines matter?

Integrated care equals better care. Children with autism or ADHD, for example, need multiple services—evaluation, therapy and social skills groups—with multiple professionals—psychologists, speech-language pathologists, occupational therapists and family therapists. In other professional practices, when a child is evaluated by a psychologist and needs an occupational therapy evaluation, a speech-language evaluation and an educational evaluation, the parents are burdened with coordinating care. With three or more separate reports in hand, the parent is required to synthesize information, determine priorities and communicate new information among providers. It's a time-consuming and frustrating job.

At CHC, kids receive coordinated care with professionals who are able to easily talk with one another and not send mixed messages about what the child needs. This takes a huge burden off parents, freeing them to focus on the important work of helping and supporting their child.

Because CHC professionals work with a variety of disciplines, they are able to provide exceptional integrated care. CHC psychologists, for example, have more knowledge about specialists outside their specialty because they work with specialists from different disciplines on a daily basis. The interdisciplinary knowledge CHC clinicians and educators exchange while sitting in a team meeting to evaluate a child, while walking down the hall to discuss a therapy session or while co-facilitating an interdisciplinary group is unrivaled elsewhere in our community. With your new or ongoing support for CHC, you are taking a stand to get kids the best care possible when they are faced with a lifelong disorder like autism, ADHD, learning differences and more.

Thank you for making it possible for us to provide outstanding care for those in need.

Warmly,

Rosalie Whitlock, Ph.D.
Executive Director & Educational Specialist

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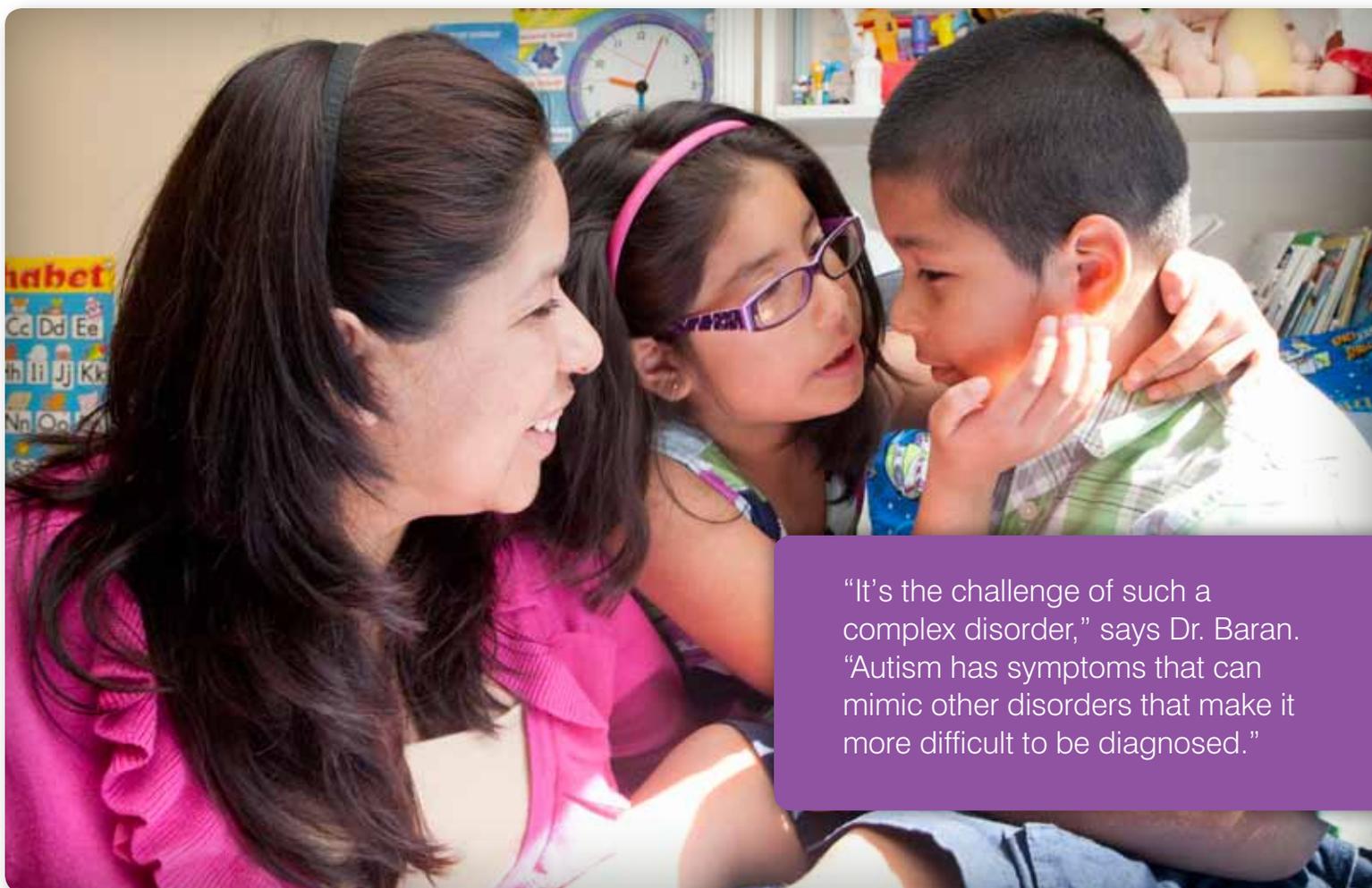
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“It’s the challenge of such a complex disorder,” says Dr. Baran. “Autism has symptoms that can mimic other disorders that make it more difficult to be diagnosed.”

Getting Help

It wasn’t until a relative recommended going to Children’s Health Council (CHC) that things began to change. Conducting the evaluation, in English and Spanish, Dr. Joan Baran found that Johann’s behaviors were consistent with autism.

Lucy cries as she remembers being told her son had autism. “It was so hard. When someone tells you that your son doesn’t have the capacity of other children, it’s sad,” she says. “My husband and I didn’t want to accept it.”

“The first thing I thought of,” says Martin, “was my son wasn’t going to be able to enjoy the normal things that we do—simple things like being a boy and enjoying his nephews and cousins and then becoming a man and meeting girls, becoming a father, and having a family.”

“Parents like Lucy and Martin go through something similar to a grieving process when they hear their child has a lifetime diagnosis like autism,” says family psychotherapist Dr. Carlos Konishi.

Why was it so difficult to diagnose Johann? “It’s the challenge of such a complex disorder,” says Dr. Baran. “Autism has symptoms that can mimic other disorders that make it more difficult to be diagnosed.” She also adds that Johann’s bilingualism added to the complexity.

Learning New Skills

When Beatrice Kirchhoff, a speech-language pathologist, began working with Johann, he needed to learn the back and forth nature of social interaction.

“Children with autism don’t understand the purpose of communicating with someone,” says Kirchhoff. “Even if you increase their vocabulary, they still struggle to use language to communicate.”

Once Johann’s language skills began to improve, he started receiving more individual and then group therapy with occupational therapists including Kianna Collier.

When Collier first met Johann, she described him as a sensory seeker as opposed to a sensory avoider (sensory avoidance is more typical of children with autism). Johann enjoyed the impact of crashing into people and the loud noises of pushing toys off the table, but he didn’t understand that these behaviors were problematic.

“Children with autism spectrum disorders don’t have an awareness of where their bodies are in space. When they crash into things, they are trying to learn the limits of their bodies,” Collier explains. Collier’s job was to teach Johann how to understand his limits more productively. In occupational therapy,

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— Dr. Baran



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she’d have Johann participate in “heavy work” activities such as crashing, climbing and jumping while building on imaginary play themes in order to help him feel calm and to increase his engagement in pretend play.

Collier also taught Lucy and Martin techniques to help them keep Johann regulated at home. She learned how to calm Johann when he got too energetic with techniques like sandwiching him between two pillows. “They’ve [CHC professionals] helped me so much,” says Lucy, acknowledging all of Johann’s therapists at CHC. From Collier’s perspective, what has helped Johann the

most is his family’s openness and willingness to take suggestions and try new things.

The collaboration between the Garcías and the clinicians enabled everyone to work with each other and learn from each other to help Johann progress. When Lucy told the therapists what they tried at home and what worked and what didn’t, Collier was able to apply Lucy’s experience to tailor her sessions with Johann and share the learning with the team of CHC professionals working with Johann.

To date Johann has received individual speech and occupational therapy and participated in two therapeutic skill building groups (DIR®/Floortime and SPOT: Speech, Psychology and Occupational Therapy).

Three Years Later

Perhaps the biggest change in Johann is his ability to show his love and affection for Lucy. With her daughter, this came naturally. “But with Johann,” she says, “it was hard. I had to wait two years longer for him to be able to give me a hug and say, ‘I love you, Mommy.’”

Lucy, Martin and their extended family are overjoyed by the amount of progress that Johann has made over the last three years. “Now,” she says, “Johann can sit in one spot and pay attention to an activity. He can follow my instructions, and when kids try and fight with him, he doesn’t respond, or he will say ‘Please don’t hit me.’”

Parties were a problem in the past because Johann had trouble being around other children. But now, Martin says, “He doesn’t want to leave the party.”

As difficult as it was for Lucy and Martin to accept that Johann had autism, Dr. Konishi says, “Families do adjust. They often discover new things that their child can excel in and gain new hopes.”

Lucy and Martin are finding ways to better support their whole family. To ease their ability to get Johann the help he needs, this month they are moving from their home in South San Francisco to an apartment in Palo Alto. “Melissa [their daughter] will have access to better schools,” says Martin, “and we’ll be closer to Children’s Health Council.”

Johann’s Future

Johann has more milestones to reach. “He might be in therapy at different stages throughout his whole life, but it will constantly be changing to challenge him to reach his full potential,” Kirchhoff says. While he no longer needs individual speech therapy, he now needs more skill building groups to learn to better interact with his peers.

Lucy and Martin’s goal is to help Johann as much as they can to ensure that he can live the most independent and “normal” life possible, and Kirchhoff believes this is a realistic goal.

Johann’s progress has been an inspiration for all of the clinicians. “Telling a parent that their child has autism is a huge responsibility,” says Dr. Baran. “I’ve had parents ask me, ‘How can you do this job?’ But when I see the progress a child like Johann can make, there’s no greater reward – it gives me hope.”



It's Not Autism. What Is It?

A Second Opinion Rules Out Autism Spectrum Disorders

Dr. Cheryl Klaiman stopped her evaluation of six-year-old Mia after 45 minutes and met Mia's parents on the other side of the one-way mirror where they were watching.

"It is very rare to see all these positive social behaviors so quickly and easily with kids who have autism spectrum disorders," she explained. "Mia doesn't have an autism spectrum disorder. She's behaving this way because she is a highly curious, smart and focused young girl." Dr. Klaiman gave the parents the option to continue the evaluation to assess for a social disability, but emphasized that she didn't want to waste their time or money that could be better spent on helping them manage Mia's challenging behaviors.

Rather than feeling relieved, Mia's parents were confused. They had traveled from Hong Kong to Children's Health Council for a 1-day evaluation to get a second opinion. In Hong Kong, Mia was diagnosed with an autism spectrum disorder. "But she doesn't come to me when I call her name," Mia's mother Judie protested. "She's not interested in playing with the other children in her class, and she seems lost in activities."

Dr. Klaiman helped the family understand the difference between Mia's behaviors and behaviors associated with autism spectrum disorder. Dr. Klaiman explained that Mia, even upon greeting her, an unfamiliar adult, interacted in a natural reciprocal manner.

Even more, Mia appeared to derive pleasure from Dr. Klaiman's attention and praise. Mia also showed sophisticated play skills not consistent with autism spectrum disorders. "Mia made connections with me that a child with autism isn't typically able to do—especially so readily and naturally," Klaiman said. "You cannot turn autism on and off."

Dr. Klaiman surmised that Mia's advanced capability was driving her difficult behaviors. "She's probably not interested in other children her age because their play and interests are not at the same level as hers," said Dr. Klaiman. Dr. Klaiman offered that Mia might be absorbed in her thoughts when her parents called her and thus was not tuning into their requests.

Once Mia's parents better understood why Dr. Klaiman dismissed the previous diagnosis, they were ready to hear Klaiman's advice for handling Mia's challenges. Klaiman recommended several tactics to get Mia to respond such as getting in Mia's line of sight when she is engaged with something and making sure Mia is looking at them before they make a request. Dr. Klaiman advised the parents to speak on Mia's level, involve her in decision making and capitalize on her intelligence by giving her the rationale for participating in a task. Klaiman also stressed the importance of Mia having friends who could keep up with her intellectual abilities and recommended ways to find gifted children whom Mia could befriend. As Dr. Klaiman offered more ideas, Mia's parents asked more questions.

Tristan, Mia's father, reflects, "I guess every child needs to be parented in a special way. We needed someone like Dr. Klaiman who could help us understand what Mia needed." 🍃

A Yearly Evaluation with the Autism Coach

"Dr. Baran is our coach," says Miles, father of 10-year-old Silas.

Eight years ago, Dr. Joan Baran, psychologist at Children's Health Council and pictured at right, diagnosed Silas with an autism spectrum disorder. Today, his parents do everything they can to help their son develop. On a weekly basis, Silas sees four specialists including a speech-language pathologist, occupational therapist, music therapist and reading specialist. He also attends a social skills group and receives special education.

"We have specialists who work with Silas on spot problems," says Miles, "but we need a coach like Dr. Baran to guide the

big picture."

Every year Silas' family has Dr. Baran and her team evaluate Silas' progress and develop new goals. Eva, Silas' mother, explains why a yearly check-in with their coach is important to them.

"Dr. Baran guides us. We take it one year at a time. It's like baking a cake. If we all work together and all of Silas' therapies are geared toward the same goal, we'll be successful."

Both parents are visibly excited as they share stories about their son's developmental advances. Showing a picture of Silas on skis, Eva says, "Three years ago, Silas couldn't ride a bike and had no coordination. Now he loves to ski and he's really good at it." 🍃



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