All the News Worth Chirping About from Villa Esperanza Services

Fall 2018 Newsletter



Providing Love, Care and Hope for Individuals with Disabilities and their Families since 1961



Villa student Natalie is thriving at Villa School; she is pictured above smiling as her classmates wave colorful scarves to practice their social and motor skills.

# Natalie's Journey: It Takes a Villa

Articles by Katherine Evans, Villa Esperanza Services Grant Writer

atalie is a bright, mischievous 12-year-old. A girly girl through and through, she loves makeup and nail polish, Justin Timberlake, and the latest gossip. Natalie also has Rett Syndrome (RTT), a neurodevelopmental disorder that affects how she moves, speaks, and learns. Like most girls with Rett Syndrome, Natalie developed normally until she was 18 months old, when she rapidly lost speech, followed by the ability to use her hands. Natalie's mom Krystal explains, "She wasn't able to communicate and we would have to be guessing. At Villa I had a good first impression—they convinced me right away. All the staff made me feel at home."

One of those staff members was teacher Carol Cruz. Carol had never worked with a child with RTT before and recalls, "We did a lot of researching. We went to Children's Hospital and what we began to realize is girls with Rett are trapped in their bodies, but their brains are still typically developing. All the research said she's still this little girl inside."

Buoyed by this knowledge, Villa staff set to work developing learning and communication strategies for Natalie. They contacted Dynavox, the manufacturer of the Tobii eye gaze device that allows users to generate speech through eye tracking and control. "We convinced Dynavox to come out and loan us a Tobii device for 3 months and then we dragged it out a bit," says Carol, laughing. "When the loan ended, Natalie had gained some skill. Then we were able to convince her insurance company to purchase it for her and that was really exciting."



Natalie practices her motor skills by shaking a maraca with teacher Alexandra.

Natalie's Tobii has given her a voice and the freedom to express her opinion. During a recent occupational therapy session, Natalie used the device to choose the day's activity: rolling a pink ball to practice purposeful hand movement. Director of Occupational Therapy Amy Jensen uses the Developmental, Individual Differences, Relationship model (also known as DIR) to guide her sessions with Natalie. DIR is another tool in Villa's multidisciplinary approach to education and as Amy explains, "It's the idea of following a child's lead. It has given me a framework to be flexible in my thinking and how I can create an activity in the moment. I have in the back of my mind what Natalie's learning goals are, and I just have to be creative about how I can apply them based on what's going on for her on a given day."

Natalie's work ethic inspires her staff--Speech Language Pathology Assistant Barbi shares, "If you were to try to use her eye gaze device, you'd see it's really hard. It's a struggle. It's physically tiring and she has seizures, too. Some days she's just really fatigued." When that happens, Barbi offers alternatives, such as presenting Natalie with a field of four picture choices to help her communicate

and give her eyes a rest. "We don't give up. We try alternatives. We respect her... the big thing is we communicate with her like a teenager and not this child who doesn't have choice."

When Natalie's mom Krystal reflects on her progress, she can't help but remember the first days of her daughter's diagnosis. "The doctors told me she would regress—she's gonna stop doing this, stop doing that, but it's the opposite," says Krystal. "She's been having improvement. There's hope. She's getting stronger mentally, emotionally, physically. I want to tell parents don't give up. Find the help and motivation. Villa gave us that hope and motivation."



Panorama view of the new school campus.

October 23, 2018 marked the official Grand Opening of Villa's Phase I School Campus. 180 family members, clients, neighbors and dignitaries joined in celebration of this momentous occasion. "The students, families and especially the staff are all very excited to be in this new space," shared Kelly White, Villa's CEO. White went on to share comments from donors and teachers: "The Campus feels fresh, organized and so much more functional."/ "It finally feels like a real school." / "My favorite part of the new campus has been watching the students on the playground; there are just so many more chances for engagement!"

### **Senen Takes the Stage**



Microphone in hand, Senen serenades his peers at Dimensions Day Program.

t's a Friday afternoon at Dimensions Day Program, and 45-year-old Senen has taken center stage for a karaoke session. Program participants wait expectantly—Senen is known as a musical connoisseur. While he is particularly fond of '80s dance hits, today he chooses an old standby, "Volver, Volver." Senen takes a deep breath and the first notes draw rapturous applause. "Senen," his peers cheer, "Woohoo!" The applause subsides and Senen moves on to his next selection, "Kiss and Say Goodbye."

It's hard to imagine, but this confident crooner wasn't always so comfortable in a social setting. Before Senen began his Villa journey, the intensity of his behaviors made interactions with his peers difficult—so much so that the first day program he entered after aging out of the public school system asked him to leave. Senen's brother Hugo explains, "What Villa has done is nothing short of amazing. They've taken him from an aggressive guy to the guy I know. He's able to behave the way he is at home with

everybody now. They stuck with him even in difficult times, when others turned him away."

Dimensions Day Program Manager Claudia Cortez was Senen's first one-to-one aide at Villa 16 years ago. She credits his transformation to the fact that staff have developed a knowledge of Senen's preferred activities bowling, walking outdoors, anything to do with music or public transportation—and are able to redirect him when they see a behavior developing. They also provided Senen with routine and security. As Hugo puts it, "He'll say, 'I go to my program and you go to work.' Within that routine staff helped Senen learn tasks that give him a sense of purpose. I wish I could say he learned those skills at home, but he learned a lot of that at Villa. The one-to-one support is so important for people like my brother."

With the support of Villa and his loving family, Senen's confidence has grown. When he's not attending Dimensions he lives with his brother Hugo. "He has his own space and he knows it's his," says Hugo. "He used to say, 'We're at your house.' Now he says, 'We're home. 'I don't think he'd be the person he is today if we hadn't found Villa."

## ...and Grand Opening / Ribbon Cutting



Villa's Phase I Capital Campaign Cabinet performing the formal "ribbon cutting" of the new campus.

We are grateful for the generosity of all our donors who made our vision a reality. Special thank you to the Ayrshire Foundation and Wells Fargo, for each contributing lead gifts of \$1 million to the project. Cabinet Co-chair Jim McDemott added, "We are excited for the day when the rest of the campus embodies the passion and commitment we have to individuals with special needs. " Contact us for a tour!

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