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INTELLECTUALLY DISABLED IN VIRGINIA



At 15 months old, Dylan was diagnosed with Angelman syndrome, a genetic disorder characterized by developmental delay and neurological problems

WHEN A CHILD STARTS OUT BEHIND



ROB OSTERMAIER/DAILY PRESS PHOTOS

Speech pathologist Nancy Hawfield, right, gets Dylan Trinkle safely strapped onto a horse at the Dream Catchers Therapeutic Riding Center in James City County. **Top:** Dylan greets his horse Lark.

BY VERONICA CHUFO
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Part one of a five-day series

Dylan Trinkle is 3 years old, and he has yet to say his first word or walk on his own.

Instead, his parents celebrate other milestones. Sitting up. Pulling up to stand. Taking a few steps.

At 15 months old, Dylan was diagnosed with Angelman syndrome, a genetic disorder characterized by developmental delay and neurological problems that occurs in one in 15,000 births.



Online video

Watch Dylan and his horse Lark during a therapy session at dailypress.com/therapyride

Dylan's pediatrician first noticed something wrong with the child's eye when he was 6 months old and referred him to specialists. Blood work led to an electroencephalogram — an EEG — which studies electrical activity in the brain. The test found that Dylan has Angelman syndrome.

"Through early intervention, he got a real solid foundation," his mother, Jennifer Trinkle, said.

Dylan's pediatrician first noticed something wrong with the child's eye when he was 6 months old and referred him to specialists. Blood work led to an electroencephalogram — an EEG — which studies electrical activity in the brain. The test found that Dylan has Angelman syndrome.

See **DETECTION/Page 7**

About this series

After a three-year investigation, the Justice Department criticized the state for needlessly housing people with intellectual and developmental disabilities (formerly known as mental retardation) in training centers, a violation of their civil rights, and for failing to invest in an adequate system of community-based care. Though the state plans to fund 275 additional waiver slots that would provide community-based services to people with intellectual disabilities, it's not enough to address an urgent waiting list of more than 3,200 statewide and help discharge people from training centers, it said. The Justice Department threatened legal action if the state didn't address those matters. State officials have been in negotiations with the Justice Department to work out an agreement.

This series aims to highlight what services are available in the community and point out shortcomings in the state's disabilities system.
TODAY: The importance of early intervention.
Monday: The cost of rebuilding a state facility outpaces investment in community-based services.
Tuesday: Nearly 5,800 people statewide are on the Medicaid waiver waiting list.
Wednesday: Community-based services: A place to live and work.
Thursday: Volunteers provide recreation for people with intellectual and developmental disabilities. Plus, what can the state do when budgets are tight?

Hampton's Town Center weathers the recession

After more than a year, the mostly full shopping center looks to deals

BY DAVID MACAULAY
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HAMPTON — More than a year after Peninsula Town Center's grand opening, Merchant Lane remains quiet on a Tuesday morning and there still are a number of empty storefronts.

General Manager Raymond Tripp says the recession has lasted longer than anyone imagined when the center opened at a high profile ceremony in March 2010, but he says it continues to weather the downturn and is adapting well to the austere climate.

He said Merchant Lane is set to benefit from a new influx of tenants expected at Peninsula Town Center later this year.

"They would be lined up down this street," Tripp says.

"This is one of the areas that really has high-end retailers," he said. "We want to keep that clientele in this market. We are right outside Macy's, which is our higher-end department store."

Tripp is not yet saying how

See **TOWN CENTER/Page 6**

Fast facts

- The Peninsula Town Center celebrated its formal opening in March 2010.
- It has now leased 69 of just under 100 storefronts.
- It generated taxable sales exceeding \$134 million in its first 12 months of operation.
- The town center has rented all of its available residential units.
- About 50 percent of office space has been leased.

Hampton news to go

Text **HAMPTON** to **71593** to get alerts of the latest news in Hampton.

NEWS NATION & WORLD

Rover rivalry ignites in mission to study Mars

NASA's rover Opportunity has been roaming Mars for seven years. As NASA prepares to launch its newest rover, it's a race to see which rover can reach rocks called phyllosilicates first. The discovery could provide evidence of possible life on Mars. Read more on **Page 13 of News**.

SPORTS

Hungry senior runners named Athletes of Year

After running to glory at state meets during their senior seasons, Grafton High's Kyle King and Tabb's Kiara Porter are honored as the Daily Press Athletes of the Year before they head off to compete in college. **Page 1 of Sports**

GOODLIFE

Peter Pittman readies his new Hampton restaurant

Peter Pittman enjoys creating restaurants as much as running them. His latest project is the Conch & Bucket, set to open up next month in downtown Hampton in the space once occupied by Goodfellas. **Page 1 of Good Life**

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“I would love for him to be able to speak, be able to learn how to communicate with gesturing — his fine motor skills would have to improve to do that.”

— Jennifer Trinkle, Dylan's mother



ROB OSTERMAIER/DAILY PRESS PHOTOS

Speech pathologist Nancy Hawfield helps Dylan Trinkle put his equipment away after a recent riding session. Dylan goes through the whole process of getting the horse ready to feed in order to teach him basic life skills. Part of the therapy is teaching Dylan that a horse is a living creature that needs care and affection.

Early intervention may keep people from needing more services later

Detection

Continued from 1

Haven't heard of it? "We hadn't, either," Dylan's mother said. "We were stunned. You're learning how to be a parent, and you're given a diagnosis like that."

And so began the Newport News family's journey into Virginia's intellectual and developmental disabilities system.

It's a system that has recently come under fire by the U.S. Department of Justice for housing people in state institutions needlessly, a violation of their civil rights. The reason many are housed in state institutions is that there isn't enough funding for services in the community to meet the need. This is the first in a series of five stories exploring the services available in the community for people with intellectual and developmental disabilities and identifying the system's shortcomings.

Starting early

Early intervention is important because it may keep people from needing more services — such as state institutions — later on, which can save taxpayers' money, said Julie Palmer, children's services director for The Arc of the Virginia Peninsula.

The Arc's Early Prevention and Intervention for Children program, known as EPIC, is responsible for coordinating early intervention services for Newport News and Hampton children up to age 3 whose families do not qualify for Medicaid. Case management of Medicaid-eligible families is handled by the Hampton-Newport News Community Services Board.

The brain is very impressionable during the first three years of life, Palmer said.

"If we push them as far as they can go with their skill development now, they will need fewer services later on," she said.

The program coordinates therapies tailored to each child and helps connect parents to resources, such as where to find adaptive carseats and developmental playgroups, she said.

One of the biggest problems with the early intervention system is paying for in-home assistance that may be needed to keep the child living at home. About 55 percent of the families EPIC works with are military families, who often make too much money to qualify for Medicaid. Although the child may have significant disabilities, the families may not have access to needed resources,



Dylan has a close relationship with Hawfield.

Web chat Wednesday

Have questions about early intervention and the state's intellectual and developmental disabilities system? Ask them Wednesday at noon at dailypress.com during a live Web chat. We'll have Julie Palmer, director of children's services, and Linda Kerns, director of community living, both of The Arc of the Virginia Peninsula, available to answer your questions. Can't make the chat? Email questions in advance to vchufu@dailypress.com.

she said.

Another problem is that children aren't being referred to early intervention promptly. Sometimes, pediatricians tell parents who are worried that their 18-month-old isn't speaking to wait until the child turns 2. That delays intervention and often results in the child needing more intensive and costly services later, Palmer said.

"If you think your child has a developmental concern, please call. We can do a free developmental screening. We can do that anytime, as often as they need us to," Palmer said.

Therapy for Dylan

Even before Dylan's Angelman syndrome was diagnosed, a neurologist at Children's Hospital of The King's Daughters gave the Trinkles the phone number for



Working with horses has improved Dylan's strength and coordination, and with time it is hoped he will speak.

The Arc, and Dylan started physical therapy. He's now receiving physical and speech therapy at CHKD and horse therapy at Dream Catchers at The Cori Siskich Therapeutic Riding Center in Toano.

Horse therapy takes what's learned in the clinical setting and puts it to use in a real-world environment, said Nancy Hawfield, a speech pathologist who works with Dylan at Dream Catchers.

During a recent session, Hawfield helped Dylan brush down a brown horse named Lark. Dylan giggled and flashed a wide, toothy grin when he was placed in the saddle. Hawfield helped him sign "walk on" to indicate he was ready to go. They practiced standing up and sitting down in the saddle. They practiced signing stop and bringing the horse to a halt and signing "walk on" to get Lark moving again.

Dylan giggles and grins a lot.

"He is very happy. Everybody who sees him says he is the happiest child they've ever seen," Jennifer Trinkle said.

Dylan loves Curious George, Elmo and toys that are animated or light up. He loves people, enjoys the outdoors and is drawn to water — a typical characteristic of people with Angelman syndrome.

"There's not much he doesn't like," his mother said.

"Except brushing his teeth," his father quipped.

Making progress

Dylan's parents have noticed some progress since he started therapy.

At first, Dylan's doctors were skeptical about Dylan's ability to walk, but they went ahead with physical therapy anyway. Now, he's able to take a few shaky steps.

He's able to communicate better using electronic communica-

tions devices and he's learning some sign language.

Insurance has covered most of the cost of Dylan's therapies. But his parents were told to expect a denial for a claim for \$1,500 worth of push-button communications devices that will help them communicate with their son. They plan to appeal.

Mark Trinkle already has started the process of applying for Medicaid waivers, which open the door to financial assistance for many of Dylan's needs. With a waiver, Medicaid would help pay for services such as in-home care and transportation to appointments or work. Dylan doesn't sleep well at night, and an aide once or twice a week would allow them to get a full night's sleep. Without a waiver, they'll do what they can.

"He'll need care for his entire life of some sort," Jennifer Trinkle said.

They don't think it'll be too hard to get an Elderly and Disabled with Consumer Direction (EDCD) waiver, which will pay for some services. But the waiting list is long for the intellectually disabled waiver, which pays for about \$80,000 to \$90,000 worth of services per year, said Carol McCarthy, of IDD case management for the Hampton-Newport News CSB.

As of June 13, there were 5,790 people on the state's intellectual disability waiver waiting list; of those, 3,216 are on an urgent needs waiting list, according to the State Department of Behavioral Health and Developmental Services.

In Hampton and Newport News, about 275 names are on the waiting list, about 100 of them classified as "urgent," McCarthy said.

The Trinkles want to enable Dylan to live as independently as he can. "Not that I don't want him with me. I want him as an adult to be as much like other adults as possible," she said. "We're not always going to be here."

They hope to expand their family so that one of Dylan's siblings can see to his care when they're unable to. They're also doing estate planning to make sure he's taken care of if something happens.

In the fall, he'll enter the Program for Educating Exceptional Preschoolers — known as PEEP — a special-education program provided by Newport News public schools.

They hope he'll graduate high school one day, and maybe hold a job.

"I would love for him to be able to speak, be able to learn how to communicate with gesturing — his fine motor skills would have to improve to do that," Jennifer Trinkle said.