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## Finally, they find a place to be heard; With round-the-clock support, deaf-blind adults live and learn in Port Washington duplex, called a model for fostering independent living

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One in a row of brown and beige look-alike buildings, Destiny Home appears as any other 1960s duplex in Port Washington. But inside, five residents are cocooned in an environment geared for people who are blind - or almost so - and deaf.

Deaf-blindness is an unusual disability that presents a number of challenges. There are mobility problems as a result of the blindness. It is more difficult to navigate with low or no vision. Being hearing-impaired complicates communication. An estimated 85 percent of what anyone knows about the surrounding world is perceived through vision and hearing. When both senses are impaired, affected individuals are extraordinarily disadvantaged.

The home - a first of its kind in New York that is expected to become a model for other states - is an uber-supportive environment. The passport into it is a knowledge of American Sign Language. Designers of the home's interior took into consideration what it's like to be cut off from the world of sights and sounds.

Beds vibrate to signal an emergency. Kitchen cabinet knobs are oversized. One resident with low vision has a computerized relay system for telephone conversations, which features a live operator who appears on screen to translate a caller's spoken words into sign language. The resident's signed words are translated into spoken ones for the person with both senses.

### Buzz of activity

Roland, David, Damali, Tanisha and Linda are Destiny Home's five residents. (Administrators of the home asked that residents' last names not be published to protect their families' privacy.) They range in age from early 20s through early 40s. They moved in last summer, each having waited for years to live in a supportive atmosphere.

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Eavesdropping on this world, it's easy to discover a community abuzz with activity though nary a word is heard.

While Roland donned a wide-brimmed hat on a recent chilly afternoon, as he prepared to escort a visitor around Destiny Home's backyard, David busied himself at his computer.

A Braille version of a Nancy Drew novel, the size of a major city's Yellow Pages, captured Tanisha's attention, as Damali helped herself to milk and a cookie in the kitchen. Linda dressed for visitors: a purple dress and matching purple necklace.

This makeshift family has been molded from a common disability. They are among about 70,000 deaf-blind people nationwide, though that figure may be as high as 1.5 million, some say, when adults who lose hearing and vision due to age and medical disorders are counted.

All three women are completely blind; the two men are legally blind. "When we talk about legal blindness, that's 20/200 in the good eye with correction," said Joseph McNulty, executive director of the Helen Keller National Center for Deaf-Blind Youths and Adults, which administers the residence. All Destiny Home residents are deaf.

Most people who are deaf-blind from childhood, as is the case with Destiny Home's residents, lose their hearing and eyesight to one of two causes: Usher's syndrome, a rare genetic condition; or congenital rubella syndrome, which occurs during the fetal stage.

High marks for facility

None of the residents had been successful living independently on Long Island despite training at the Helen Keller center in Sands Point, McNulty said. The region is expensive, a job is necessary and a support system is vital. Organizers hope Destiny Home's emphasis on job training will give residents stronger financial footing.

State-funded, the duplex has a staff of 15 people who work in shifts around the clock. It costs \$1 million annually to run. The state's support for Destiny Home includes "life coaches" who serve as constant companions to each resident. They help with tasks such as choosing clothing and dressing, as well as explaining what's going on, moment by moment, using American Sign Language.

For those with low vision, sign language is performed as it would be for someone who is deaf. For residents with no eyesight, words are "finger spelled" into their hand. Helen Keller famously learned to understand the world through the same technique more than 120 years ago.

Destiny Home is winning high marks from experts outside New York. "We are excited to see that Destiny Home is available for deaf-blind people and they are living in an environment where they can be independent and still receive the support they need to be fully independent," said Elizabeth Spiers, who is deaf-blind and spokeswoman for the American Association of the Deaf-Blind in Silver Spring, Md. Spiers was interviewed by e-mail. She is legally blind but can read large type on screen.

Signs of hope

In the general population, the deaf-blind are often cut off from communication, even within their own families, often because of an unwillingness among parents to learn sign language, said Suzanne Ressa, marketing and development director at Helen Keller.

"They're very vulnerable to abuse because they're a silent population," Ressa said. "How would they communicate to authorities if something happened - to say they need help?"

One Destiny Home resident (whom neither Ressa nor other administrators would name) is a survivor of the notorious Willowbrook State School, whose long and sullied history resulted in a spate of lawsuits against the state of

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New York.

The Staten Island institution, closed in 1987, served as a home for mentally disabled and deaf-blind children. Many were subjected to a series of abuses, including the intentional injection of the hepatitis virus in a bizarre scientific experiment, a state commission later found.

Whatever their past traumas, the residents indicate they view Destiny Home as a safe haven and a place to grow.

David has a job at La Piccola Angelina, an Italian restaurant in Port Washington. He works in the kitchen. The opportunity came after a group from the Helen Keller center - communicating at its table in sign language - lunched there last year.

Tanisha has an internship at the Stop & Shop in Port Washington. "She unrolls the cookie dough and puts the dough on [baking] trays." said Laura Rocchio, of the Helen Keller center. "She also does the bread. ... She can do a good number of trays in 55 minutes."

Tanisha signs a response.

And Rocchio interprets: "I love the smell of baked goods."

Bridging the communication gap

Many methods, new and old, are used to communicate with people who are deaf and blind.

**HAND SIGNING.** American Sign Language is "spoken" in the palm of a deaf-blind person's hand. This is the time-tested method made famous by Helen Keller, who learned to communicate this way with her teacher Annie Sullivan.

**COMMUNICATION BOOKS.** These laptops have Braille keyboards. The deaf-blind person types in a message, which is conveyed in standard type to a sighted person or a poorly sighted person. Devices such as this can help the person navigate shopping or ordering in a restaurant.

**PORTABLE TRANSLATORS.** A computer carried by a blind person that allows them to type in Braille and have the message reproduced in voice output.

**TADOMA.** Developed in the 1920s, this technique has a deaf-blind person place a thumb on a speaker's lips and spread his or her remaining fingers along the speaker's face and neck. Communication is transmitted through vibrations, jaw movements and the speaker's facial expressions. Some Tadoma users can understand 40 words a minute.

**VIDEO PHONES.** Allows the two people communicating to see each other. In one system, a hearing-impaired person and someone with limited vision can see each other and communicate via sign language. In another system, a person who is not disabled speaks into the phone and his or her words are translated by a sign-language communicator, who is seen by the disabled person on the video screen.

What causes deaf-blindness?

The unusual disability has more than 70 causes. Here are a few.

**USHER SYNDROME.** A genetic condition caused by a DNA flaw on any one of nearly a dozen genes. It is the most common cause of deaf-blindness and is incurable. The loss of eyesight is gradually caused by retinitis pigmentosa, a devastating degenerative condition that affects both eyes. Night vision is the first to go, followed by peripheral vision, which progressively narrows. Hearing loss is attributed to defective inner ear structures.

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**CONGENITAL RUBELLA SYNDROME.** The condition has been nearly eliminated in the United States as a result of maternal vaccination against rubella (also called German measles), but is still a problem in underdeveloped countries. Pregnant women exposed to the rubella virus during pregnancy can pass the infection along to the fetus, causing damage to both the eyes and nerves cells in the ears.

**JUVENILE ALPORT SYNDROME.** This rare disorder is largely one of the kidneys, but in some children with it, the surface of the eye's lens may be cone-shaped and clouded by cataracts. White flecks may be prevalent on the retina. Doctors divide the condition into several subtypes, all of which are characterized by kidney disease, nerve deafness and eye abnormalities.

**CYTOMEGALOVIRUS (HERPES) INFECTION.** Exposure to herpes can occur congenitally or after birth - or at any age. Sensory loss in infants has been associated with severe herpes infections, which can cause scarring in the eyes and damage to hair cells in the ears.

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**GRAPHIC:** Newsday photos / Ken Sawchuk - 1) Laura Rocchio, right, of the Helen Keller center, signs into Tanisha's palm as Destiny Home staffer Jeannette Plavsky, center, looks on at the deaf-blind residence in Port Washington. 2) **UNIVERSAL LANGUAGE.** Destiny Home resident David gives a thumbs-up after communicating through the Sorenson Video Relay System in his room 3) **Friendly Design.** Interior features of the home allow Damali to navigate in the kitchen 4) **The Great Outdoors.** Roland uses a strategically placed fence to guide him on a walk outside the home. Charts - 1) Bridging the communication gap 2) What causes deaf-blindness? (SEE END OF TEXT)

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