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H.A.L.O. Reports

A Foundation for Children with Neurological Impairment



Renovation can be functional AND attractive

Laurie and Bruce Rabe could host one of those design programs on the House and Garden TV network.

Not *House Hunters* -- because there was no thirty minute resolution to their quest. They explored number of historic homes before Bruce discovered a 134-year-old Victorian the couple could cherish.

Not *Design On A Dime* -- because retrofitting the three-story, mansard-roofed manor for accessibility has been expensive.

Certainly not *Weekend Warriors* -- because it's five years and counting since Laurie and Bruce began their transformation of a former boarding house into their own small piece of Dedham, Massachusetts.

Something like *Real Family Rooms* might be more apropos. Laurie, an historic preservationist by profession, was determined to preserve AND to renovate her home for the enjoyment of all family members, including 9-year-old Elloise, who has special needs, and Olivia, 11, who is a busy preteen.

"Everyone kept trying to tell me function should rule, but shouldn't aesthetics matter, too?" asked Laurie. "A home shouldn't look like a hospital. We all have to live here together, enjoy it and feel comfortable."



Olivia and Elloise relax in the kitchen

In some ways, the home was a perfect fit. Elloise's wheelchair and stroller maneuver easily through the large double doorways. The high ceilings and tall windows let in lots of light so that Elloise, who is blind and neurologically impaired, can bask in the sunshine, and the rest of the family can enjoy the large, bright vines and flowers Laurie hand-painted on the walls.

Nearly every room has a window seat or nook for a stylish daybed so that Elloise can lounge in the midst of daily turmoil, rather than be isolated in her bedroom when her wheelchair becomes too confining.

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Northampton emphasizes ties to family, friends

Family ties are very important to children -- especially when the children live in a pediatric nursing home.

Northampton Nursing Home has placed a high priority on nurturing relationships between residents and extended family members, and is reaching out to the community to bridge any gaps.

"Caregivers may be skilled and well meaning, but they are not a substitute for family and friends," said Lisa Foster, Director of Pediatric Social Work at the

dual pediatric/geriatric facility in Western Massachusetts.

The staff strives to create a loving, homelike atmosphere, and often becomes very attached to the children, she said, but it is critical for the young residents to bond with people who are not paid to be there.



Lisa Foster

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Founder's Message: Facing Hobson's Choice

Dear Friends,

In America, we are fortunate to have freedom of choice.

We choose our President every four years. We choose where to live and which car to drive. We select our preferred entertainment from hundreds of satellite and cable television stations. Sometimes we are offered the proverbial Hobson's choice -- which is really no choice at all.

John Bartlett's Familiar Quotations 10th Edition explains that "Tobias Hobson (died 1630) was the first man in England that let out hackney horses. When a man came for a horse he was led into the stable, where there was a great choice, but he obliged him to take the horse which stood next to the stable-door; so that every customer was alike well served according to his chance, —from whence it became a proverb when what ought to be your election was forced upon you, to say, 'Hobson's choice.' "

Children with neurological impairment, and their families, have been dealt Hobson's choice. The Help A Little One Foundation has chosen to address their needs and enhance their quality of life.

In this edition of H.A.L.O. Reports we share two stories about positive choices. The Rabe family chose to ignore conventional wisdom about "handicapped-accessible" living. Instead they sought renovation solutions to meet the needs of all family members. Our second story is about Northampton Nursing Home, where the staff is finding compassion and friendship for residents in the surrounding community.

Illness robbed our daughter Sarah of her choices more than a dozen years ago. We choose to help others, rather than despair over her lost potential.

As always, we thank you for your continued support in this endeavor and wish you peace and happiness.

Sincerely yours,

Alan Pinshaw

***"Where to elect
there is but one,
'Tis Hobson's choice,
— take that or none."***

N.E.P.C. arranges medically-supported vacations

New England Pediatric Care is implementing a unique family vacation program to enable residents and their families to take perhaps their first vacation ever with full nursing support.

The not-for-profit, long and short term skilled nursing facility in North Billerica, Massachusetts has been awarded a \$30,000 grant from the Massachusetts Department of Public Health to enhance quality of life, broaden horizons and stimulate cognitive development outside the confines of the home.

"Due to the severity of N.E.P.C. children's disabilities, many families have never taken a total family vacation," said Executive Director Ellen O'Gorman. "We wanted to give them quality time and the opportunity to go on a vacation with the security of full medical backup."

The plan is to rent a handicapped-accessible domain for three days and two nights at a vacation spot – the beach, for instance – and fully support three residents and their families on each trip.

A total of 15 residents will benefit from the program. Depending on location and individual needs, up to two additional residents and their families, might make a day trip with them, as well.

The staff/resident ratio will be one to one, and will include medical, nursing and therapeutic support. The staff will take care of tube feedings, catheter kits, special diets, tracheostomy, ventilator and other respiratory needs 24-hours a day.

"From a social service perspective this will be amazing," said Ms. O'Gorman. "We already provide many day trips within the community to enhance the recreational and educational process, but this short vacation will allow parents and siblings to plan activities, learn how community interaction can be accomplished, and perhaps gain enough problem solving confidence to take the children on outings alone."

The vacation project also aims to improve parent-child communication, introduce and reinforce sensory awareness, and demonstrate and build the importance of vital family interaction.

"It is another piece of N.E.P.C.'s effort to help residents achieve their maximum degree of independence within the framework of their habilitation potential, said Ms. O'Gorman.

Contact Ellen O'Gorman at 978-667-5123.

Apply common sense to decorating challenges

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When her frequent seizures occur, or when family members want to cuddle, they are just a few steps away.

The kitchen renovation had a high price tag, but the family was willing to live with short-term inconveniences such as poorly heated rooms and a leaky roof until they saved up for improvements "done the right way." The couple knocked down walls to transform an inconvenient warren of three tiny rooms into a combination family room-kitchen.

The work island faces the family area – so Laurie can observe Elloise when she takes a break in the giant suspended swing she found in a catalogue. The Air Chair® swings neatly out of sight when parties inevitably end up in the kitchen.

"Resist the impulse to accept a solution, just because it appears to be the only solution available."

The home's central staircase sweeps gracefully up to the second story bedrooms and an unused apartment on the third floor. Its structure doesn't work with standard chairlifts, however, and even the smallest elevators seemed ridiculously expensive and space consuming. Laurie conducted exhaustive research until she found the less obtrusive and less costly Minivator®.

The Minivator® is reminiscent of a glass telephone booth. The family had it installed in a corner of the dining room, where Elloise and one adult can rise through the ceiling directly into the extra large bedroom suite above. Guests hardly notice the inconspicuous track climbing the dining room wall, or the attractively concealed trap door ten and a half feet up.

Families in the Rabe's support group have been impressed with Laurie's innovative approach, and sometimes ask how they can customize their own family cocoons.

"Resist the impulse to accept a solution, just because it appears to be the *only* solution available," Laurie said. She advises parents to

think creatively and look beyond the hospital industry to camping, decorating, or even hardware catalogues for products to save money and sanity.

For instance, Bruce designed inexpensive bed risers similar to those college students use to create space under dormitory beds to raise Elloise's queen-size bed to an ideal height for diaper changes. He added guardrails for safety, but otherwise avoided the look of a hospital bed, the expense of an adult size-changing table, and the back pain associated with yet another set of transfers from the wheelchair.

The family also installed a small refrigerator and coffee station in Elloise's room. Now they begin the day minus the stress of running up and down stairs for forgotten medicines, milk and sugar. For convenience, they located Elloise's bathroom in her bedroom. Someday they hope to install a barrier-free lift to transfer their daughter directly from bed to bathtub.

The winding brick walk to the front door cost more than double the price of a wooden ramp, but Laurie said it is less obtrusive, much more beautiful and won't need to be replaced nearly as often. The Rabes re-situated the driveway and main door from the west to the east side of the house to provide easier access. The original "front" door was probably convenient when horse-and-carriage transit was the rule, she said, but challenging because it involved carrying Elloise up another flight of stairs.

Virtually no agency or advisor exists to offer assistance or financing to integrate special needs with conventional family living, Laurie said. She recommends blending a common sense with knowledge about how you want your family to interact.

Those will be real family rooms, she says. Perhaps you'll see them on TV soon.

Contact the Rabe family through Family Circle, 781-551-0405.



Laurie and Elloise demonstrate the Minivator



The Rabe home was built in 1870.

Residents need friends 'not paid to be there'

(Continued from page 1)

At one time, social service agencies encouraged families to place their children in institutions and 'go on with their lives.' Today, the extended family is urged to bond and maintain relationships with their children. Northampton facilitates this in several ways.



Jenny Salzman

Jenny Salzman, Director of Recreation, expanded family involvement this year by restructuring activities so that they parallel typical family gatherings. She organized themed family picnics and holiday parties to provide comfortable, more typical settings for get-togethers. Soon, she will introduce age-appropriate events such as movie nights to help siblings find common ground with their resident brother or sister.

When families revealed that a lack of transportation or a need for translation was a barrier to staying in touch, the professional staff found solutions to ease the way.

Staffers started taking turns on a Welcome Committee, greeting visitors and addressing their needs and questions during visits. Lisa Jakshitis, the new education administrator, invited parents to participate on the school's new Advisory Council.

Families can be traumatized by their child's complicated medical conditions and needs, and distressed when they need to relinquish care to the professionals. The Northampton staff tries to tailor support to each family's unique situation, Lisa Foster said.

Hillary Clinton popularized an African adage in one of her books: *It Takes a Village to Raise a Child*. Northampton takes this maxim to heart by inviting the community at large to expand residents' lives.

Staff members have long browsed the shops with small groups of children, and interacted with neighbors in the parks and other public spaces, but Jenny, the recreation director, recognizes that they benefit most from more lasting relationships. Building on existing associations such as the 30 year old University of Massachusetts' Boltwood Project, she is

creating both structured and relaxed opportunities to match volunteer interests with activities. Some of them are a story reading group, grandparent "adoptions" and music and pet programs.

This year, she hired part-time outreach worker Judy Ingham to cultivate relationships with area schools, colleges, churches, temples, and youth and service groups. The nursing home is particularly fortunate in its proximity to the five-college consortium -- Amherst, Hampshire, Mount Holyoke, Smith and UMass -- which is especially rich in 20-somethings who might serve as companions to 20 to 30 year-old residents. The long-term goal is to establish a corps of caring visitors who can maintain a friendship long enough to know residents as individuals, despite the roadblocks presented by their impairments.

Cognizant that unfamiliar sights, sounds and machines such as respirators, g-tubes and orthopedic devices can be unsettling to first time visitors, Assistant Recreation Director Isis Feliciano has developed an informal orientation and tour to sensitize volunteers to the nursing home environment and dispel any myths about relating to the residents.

"It's our job to heighten community awareness, to educate people about the existence of our kids and -- very importantly -- encourage them to interact and enrich their lives," said Jenny Salzman. This team is making steady progress toward that goal.

Northampton Nursing Home is located at 737 Bridge Road, Northampton, MA. Contact Jenny Salzman at 413-586-3300.



Northampton residents visit a petting zoo.

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