When Pathfinder Village was founded over three decades ago, most individuals living with intellectual disabilities, particularly those with Down syndrome, had life expectancies of about 30 years. Due to improved healthcare, more active lifestyles, and other factors, those with Down syndrome are now living well into their 60s and those with intellectual disabilities are experiencing life expectancy rates similar to the non-disabled population. Pathfinder has embarked on a new initiative over the past several years: To create quality programs and housing options that will support and nurture the Village’s oldest residents, so that they may age with dignity, in-place, and continue to enjoy the bonds of friendship, opportunities for independence, and the comforts of our close-knit community.

The Pathfinder Village Aging Initiative is a comprehensive project that includes specific capital projects, residential and day program enhancements, and workforce training and support. Pathfinder’s administrative team and governing boards are presently seeking the financial support and guidance from families, private donors, community members, corporate partners, and affiliated agencies to accomplish these goals. The Village is also a member of the National Task Group on Intellectual Disabilities and Dementia Practices of The American Academy of Developmental Medicine and Dentistry, to help craft national standards for the care of older persons with developmental disabilities.

As a human service agency committed to lifetime care, we are compelled to provide these enhancements and supports for our oldest residents. As founding Chief Executive Officer Marian Mullet said, “We don’t love them any less when they grow old.”
Especially of concern is the risk that Alzheimer’s disease poses to adults with Down syndrome, who are much more prone to being affected if they live past age 50. Various studies indicate that over 60% of adults with Down syndrome will be affected as they age. The tragedy is that as adults with Down syndrome are also increasing their life expectancy, their longevity is compromised by such a terrible disease.

The consequences of dementias are memory loss, personality changes, diminished self-care abilities and the eventual impairment of cognitive and adaptive skills necessary for successful personal, occupational, and community functioning.

There is agreement in the disability community that adults with intellectual and developmental disabilities, as they are affected by Alzheimer’s disease and related dementias, should be treated with respect and provided opportunities to remain in their community with sufficient and appropriate supports and services to compensate for personal losses in function and decline.


EMERGING BEST PRACTICES

Nationally, there are no universal Standards of Care or practice guidelines for agencies supporting older adult populations with intellectual or developmental disabilities. Services for these individuals have traditionally focused on skill building, independence and self-determination. As the course of aging and associated dementias progress, the focus shifts to maintaining skills, ensuring quality of life and care, and providing psycho-social supports to individuals, their families, and their carers.

The Aging Initiative Campaign at Pathfinder Village establishes Best Practices, based on years of practical experience and the latest aging research. In 2011, Pathfinder adopted the Five Tenets of Aging Care for persons with Down syndrome and other developmental disabilities. These guidelines include:

1. Early identification of dementia and tracking of other aging indicators.
2. Providing appropriate day programming and residential care environments.
3. Optimizing supports and services that allow individuals to remain within their communities.
4. Enhancing staff training and continuing education in the area of aging and dementia.
5. Providing available diagnostic assessment and intervention services to meet individuals’ current needs and to plan for enhanced individualized care.

These Village guidelines are aligned with those of the Edinburgh Principles, which were developed by a consortium of researchers and care providers at the Edinburgh Working Group on Dementia Care Practices in 2001. Chief among the principles is for agencies:

To adopt an operational philosophy that promotes the utmost quality of life of persons with intellectual disabilities affected by dementia and, whenever possible, base services and support practices on a person-centered approach. ¹

Pathfinder Village has adopted a two-pronged approach to answer our aging population’s needs: The first, linear, is to “age in place.” Care is directed to supporting a particular individual according to the unique progression of his needs. The other, segmented, is to identify specialty care settings in which all individuals receive personalized, long-term dementia-support services. This model has been referred to as “in-place progression.”

Built in 1989, Chenango House has brought comfort and care to many older residents until such time that they required specialized nursing supports. Village staff with care and expertise coordinated these transitions, but believed better outcomes for all would result if the aging process could fully be met within Chenango’s walls.

After the turn of the millennium, Village policies and training shifted so that aging residents could remain at home longer, despite their advancing symptoms. The need for environmental modifications and enhanced support services was clear. This strengthened commitment came to the fore in early 2011, when the Village received the Jane Davey Hamilton Endowment, established by Jane Warriner and Edward Klees, in memory of Jane’s mother, and brother Peter, a Village resident.

The Hamilton Endowment represents a threshold that permits Pathfinder to “do, and not just dream.” We are now positioned to start work on the Aging Initiative, which will lead to additional specialized care, enhanced training and continued research in aging and Down syndrome.

It is vital that we gain the help of community partners, foundations, families and individuals to provide an appropriate home and program environment to meet the needs of elders, both in the near future and in decades to come.

**Chenango House Renovations & Additions**

- Replace existing atrium with a 580 sq. ft. activities room. This will be done in concert with improved drainage and water damage repairs to the foundation.
- Replace the existing pressure-treated deck with a wood-alternative deck that has even surfaces, is more durable and easier to navigate. The deck is used extensively in leisure hours and planned recreational sessions, and provides a safe outdoor space for those who may get disoriented.
- Replace carpeting in common areas with non-porous materials, to assist with cleaning and respiratory particulates/infection control.
- Enhance home lighting in all common areas for easier navigation.
- Replace door hardware/floor sills to comply with ADA standards.
- Convert a multi-use area to a private medication room/staff office to enhance privacy and provide a secure setting for confidential records.
- Fully renovate bathrooms for ADA compliance with environmental modifications and improved lighting. These measures will enhance safety and independent personal care.
- Upgrade original fire suppression and alarm systems.
- Replace original windows and siding, and upgrade the kitchen.
- Purchase a DOT-certified wheelchair van to facilitate community outings.
- Install a video security system to monitor points of egress.
- Provide appropriate medical beds, furnishings, and room treatments that employ strategies consistent with Green House Project principles. These are strategies that enhance residents’ home experiences and encourage elders to participate in meaningful social and independence-enhancing activities (www.greenhouseproject.org).
On any given day, the Village Adult Day Program is busy: John is researching Native cultures on the internet, while Eric gets ready to frost a freshly baked cake. Liz and Lisa visit as they have their nails done. Dave and his friends are playing games, as Clark and George get ready to visit a local farm.

The Village Adult Day Program offers older residents rewarding activities with varied social and community opportunities, goal exercises and skills practice, all with the benefit of being close to home. This new program, initiated in 2011, has been successful in offering “failure free” activities, enhancing residents’ physical and mental wellness, and providing increased staff supports by caring, trained professionals.

A cooperative venture between Pathfinder and The Arc Otsego, the program provides ongoing cognitive assessments, nursing oversight, and other services that assure optimum support and compassionate care for individuals who may be experiencing age-related dementias and physical impairments. The welcoming atmosphere of the program places older residents at ease, and gives them something to look forward to each and every day.
Adult Day Program Renovations

The Adult Day Program will be housed in an existing single-level home on Village property, which dates to the 1960s. The building is structurally sound, but needs a total interior renovation to meet modern standards. The home will be upgraded with additional insulation, energy-efficient windows and doors, siding, and a new roof. Specific renovations include:

• Creating a new Activities Room in the former garage by raising the floor to grade.
• Opening up the front of the house to create an airy and inviting program area, flooded with light from south-facing windows.
• Installing a new kitchen with modern appliances that can be used for daily programs and cooking activities.
• Replacing all flooring with non-slip, non-porous surfaces.
• Creating a gently sloping “earth ramp” to facilitate access into the building for those with mobility concerns. Expand parking areas to accommodate staff and program vehicles.
• Upgrading all electrical services, including smoke and heat detectors, wall outlets and main service panel. Installing new lighting throughout the space to enhance navigation.
• Replace door hardware, hand rails and floor sills to comply with ADA standards.
• Renovate one full bathroom and install a new half bath, compliant with ADA standards.
• Create a backyard garden area with sun and shade features that can be used regularly as part of program activities.
It takes a very special type of person to work with older individuals with intellectual disabilities, and at the Village, we recognize that frontline staff — who come to their roles with great compassion — need specialized training to fully support our loved ones as they age. To help our staff succeed, we have effected training in:

- Aging and Dementia
- Healthcare Oversight and Tracking
- Physical Management Strategies
- Behavioral Supports
- Effective Communications with Healthcare Providers
- Palliative and Hospice Care

We will expand training in these and other areas to fulfill our commitment to total lifetime care and staff professional attainment.

As part of our Aging Initiative enhancements for Chenango House, we have adopted increased staffing ratios on all shifts, hired an on-site clinical house manager, and offer direct nursing services, regular monitoring of individuals by a community-based medical director, and ready access to a range of therapeutic services (PT, OT, speech and behavior). For those medically fragile individuals who are no longer able to attend other options, we have developed in-home day programming, to keep them mentally engaged, physically active, and among friends.
AGING INITIATIVE BUDGET

CHENANGO HOUSE RENOVATIONS AND ADDITION $300,000
- New Activities Room
- New outdoor deck
- New flooring
- Enhanced home lighting in common areas
- New hardware and floor transitions comply with ADA standards
- New private medication room and staff office.
- Bathroom renovations
- Upgrade fire suppression and alarm systems.
- Kitchen renovations
- New medical beds, appropriate furnishings, and room treatments

ADULT DAY PROGRAM RENOVATIONS $150,000
- New Activities Room
- New Kitchen
- New windows, doors, siding, roof, and flooring
- New parking area, sidewalks, earth ramp
- Upgrade of electrical service, lighting, heat/smoke detectors
- Upgrade door hardware, hand rails, sills
- ADA compliant bathroom renovations, hand rails
- Backyard garden landscaping

STAFFING, EDUCATION & PROGRAM ENHANCEMENTS $500,000

DOT-CERTIFIED WHEEL CHAIR VAN $50,000

AGING INITIATIVE TOTAL $1,000,000
For more information on the Pathfinder Village Aging Initiative, please contact:
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