

The Kennedy Willis Center News & Updates

Spring 2016

Get to Know the Kennedy Willis Center (KWC)

Established in 1996, the Kennedy Willis Center (KWC) at Pathfinder Village links research-informed best practices regarding individuals with intellectual disabilities to professional practitioners, families, and policy makers throughout New York State. Collaborative Partners include OPWDD's Institute for Basic Research, AADMD's National Task Group on Aging and Dementia Practices, the Children's Hospital of Philadelphia, Colgate University, and many others. The KWC is dedicated to three specific areas in support of personalized and high quality services for individuals with disabilities and their families: research; community and professional education; and information and guidance for families, particularly in the areas life planning, post-secondary employment preparation, and aging supports for individuals with Down syndrome and related developmental disabilities.

KWC History

The KWC's goal when established was to offer education through experience, and over the last twenty years it has surpassed this goal. The Clark Lecture Hall has hosted thousands of participants in and training seminars on Down syndrome. The Nicholais Library is a resource for conferences, attendees, students, staff, and visiting professionals. And the Village has helped to change the public's perspective of and attitude toward people with disabilities.

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Research



New Growth Charts Developed for Children with Down Syndrome

As the result of a four-year study conducted by pediatric researchers at the Children's Hospital of Philadelphia, a new set of growth charts for US children with Down syndrome is now available. With the new charts, pediatricians will be able to compare the growth patterns of children with Down syndrome with peers of the same age and sex. Study leader Dr. Babette Zemel, PhD stated "Children with Down syndrome grow differently from other children, so it is important to have growth charts that reflect their unique growth pattern."

The study was looking to learn more about how body composition relates to the risks of developing heart disease and type two diabetes in children and adolescents with Down syndrome.

The study was conducted in response to growth charts for children with Down syndrome having not been updated in over

thirty years. The CDC recognized how desperately this information was needed and launched the study in 2009. *Down Syndrome Growing Up* worked with families from across the United States to measure the height and weight of 637 participants, ranging in age from infants to twenty years of age. Older children visited the clinic yearly, while younger children visited more often. The results produced the needed growth charts for children with Down syndrome, and the results are positive.

The study concluded that children with Down syndrome are healthier today than they were thirty years ago. Along with the growth charts, the study also released a body-mass index (BMI) chart; the first of its kind.

Pathfinder Village was pleased to be a participating site as part of the study, which was funded through a \$1.2 million grant from the Centers for Disease Control (CDC). To learn more about this study, see the growth charts and BMI chart, or see more of the research at CHOP, visit www.chop.edu.

Get to Know the Kennedy Willis Center (KWC), continued

Independent Research

In 2012 KWC commissioned a 12-month research study under the auspices of the Leadership Institute at Utica College. The study utilized a research based behavior conditioning model as the basis for a Delphi method interviewing 128 study participants (individuals with disabilities, family members, care providers, and policy makers) regarding quality of life outcomes including: individual decision making, choice, satisfaction, supports, personal change and growth.

Active Research Projects and Partners

Since 1996, KWC has been a partner in the Institute for Basic Research of OPWDD (IBR) continuing longitudinal research examination of aging in individuals with Down syndrome. KWC also offers experiential learning projects for undergraduate and graduate students from Utica College School of Health Professions and Education, Hartwick College and Colgate University.

Professional and Community Education through KWC

Did you know?

Over the past 30 years, the average life expectancy for an adult diagnosed with Down syndrome has increased an average of 1-1.5 years per year. Many children and adults living with Down syndrome today will live well into their 60's and early 70's.

Professional and community education activities of the KWC include regional conferences and training on current and emerging topics related to intellectual and developmental disabilities. Recent conferences with attendees from throughout the eastern US include: *Connecting the Threads: Celebrating Life with Down syndrome; Symposium on Aging, Dementia, and Intellectual Disabilities; Caring for Adults with Intellectual Disabilities and Dementia*. To learn more about KWC or Pathfinder Village visit our website at www.pathfindervillage.org.



Education

KWC Internships Build Tomorrow's Leaders

Academic internships are widely recognized as valuable opportunities for students to integrate academic learning with practical application in a real world setting. Not only do students develop improved workplace and social skills, but they also gain insights into the day-to-day operations and complexity of an organization or business.

Internship experiences at Pathfinder Village are varied and range from two weeks to as long as three months. During the past two years, we have welcomed special education majors from the State University of New York campuses at Geneseo and Oneonta and occupational therapy majors affiliated with Keuka College. Music majors from Hartwick College worked with our Enrichment department and Upstate Institute Field School Fellows from Colgate University conducted research that led to the development of Otsego Academy.

Graduate interns from the Cooperstown Graduate Program have brought a wealth of talent and expertise in nonprofit organizational development to the KWC and Pathfinder Village, contributing to projects such as the Pathfinder Village 2014 Symposium on Aging and Disabilities, design of marketing materials for Otsego Academy, and development of newsletter and informational materials for various stakeholders of the Village.

For Pathfinder Village, internships offer us the unique opportunity to see the Village through the eyes of an intern, an experience highlighted during each intern's required presentation of his/her learning experience to members of the senior leadership staff. As shared by Melissa during her reflection of her internship experience, "Working with Pathfinder Village and the KWC has been a truly remarkable experience. They reminded me how much joy can be found if you love what you do". For more information about internships contact the KWC at 607.965.8377.

Pathfinder Village

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Kennedy Willis Center

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Planning for a Longer Life

Who will care for my son or daughter when I am no longer here?

This is an overwhelming concern that people with disabilities and their families must address. A well designed life plan is a blueprint that addresses this concern and ensures that your loved one is cared for in the way that you wish.

Designing A Life Plan

- **Create a life plan document**—Outline what you want for your family member regarding a residential setting, employment, education, social activities, medical and dental care, religions activities and end of life care, supports and arrangements.
- **Write a letter of intent**—Discuss your hopes, desires and values for your family member. Mention personal friendships, daily routine preferences, and experiences that are meaningful to your loved one.
- **Decide if guardianship is needed**—Options to consider are power of attorney, guardianship, co-guardianship, or conservators.
- **Determine resources needed for the life plan**—Make a list of current and projected monthly expenses. Identify resources that can help to fund the plan. Sources may include government benefits, family resources, inheritances, savings, life insurance and investments.
- **Select an attorney and prepare legal documents**—Choose a qualified attorney who will assist you to prepare wills, trusts, power of attorney, guardianships, living will or other documents.
- **Consider establishing a special needs trust**—A special needs trust (SNT) holds assets for the benefit of people with disabilities and uses income from the trust to meet the supplemental needs.
- **Use a life plan binder**—Place all documents in a single binder that is clearly marked.
- **Hold a family meeting**—Schedule a family meeting and provide copies of documents and instructions.



Life Planning

Looking to the Future

Researchers at New York State's Institute for Basic Research (IBR) remind us that advances in medical and support services have resulted in dramatic increases in life expectancy of people with intellectual disabilities. While a longer life expectancy offers new opportunities and experiences for adults living with intellectual disabilities, it also presents challenges for family members and care providers. Researchers have paid particular attention to understanding how aging affects adults with Down syndrome, including studies of Alzheimer's disease, because people with Down syndrome are at an increased risk for age-related dementia.

As care providers face these lifespan challenges, it is important to plan ahead to anticipate the supports and services that will best meet the needs of an aging family member with a disability. Considerations include:

- Optimizing health and nutrition, including regular physical exercise.
- Early detection of signs of cognitive decline beginning at age 40 for adults with Down syndrome, using a recognized

screening tool such as the NTG-EDSD (aadmd.org/ntg).

- Simple environmental modifications to minimize the likelihood of falls and household accidents, and to provide helpful visual cues for mobility and navigation.
- Maintaining preferred activities and social relationships.
- Engaging with caregiver support networks such as those associated with the Alzheimer's Association and the National Task Group on Aging and Dementia Practices of the AADMD.

For more information about aging and disabilities:

The Kennedy Willis Center at Pathfinder Village at:

www.pathfindervillage.org

Did You Know?

In addition to resources found through the Kennedy Willis Center at Pathfinder Village, excellent information regarding supports and services for individuals with Down syndrome can be found through: NYS Office for Persons with Developmental Disabilities (OPWDD), the National Down Syndrome Society (NDSS) at www.ndss.org, and the National Task Group (NTG) of the American Academy of Developmental Medicine and Dentistry at www.aadmd.org/ntg.

In Our Next Issue

New Horizons: How post-secondary programs assist students with disabilities to transition from school to work and independent living.

My Life and Yours: Snapshots of daily life for students and adults with and without disabilities who live, work and play in rural upstate New York.

Emerging Research: Life with Down syndrome thirty-six years after Pathfinder Village opened its doors.

~ Save The Date ~

Bodies, Boundaries, and Behavior: Proactive Strategies for Addressing Sexuality Issues in People with Developmental Disabilities

This one day conference with Terri Couwenhoven, M.S. will help parents and professionals become more comfortable and confident addressing sexuality issues that commonly surface among individuals with developmental disabilities. Best practice for teaching sexuality to individuals with developmental disabilities will be shared.

April 12, 2016—9am-3:30pm @ Pathfinder Village
3 Chenango Road Edmeston, NY
Parents of OPWDD eligible individuals attend free
For More Information or to Register Visit:
www.familyrn.org

Calendar Of Events

Spring/Summer 2016

Bodies & Boundaries Conference
April 12, 8:30-3:30

Otsego Academy Open House
April 28, 4:30-6:30

Camp Pathfinder Registration Ends
May 16

PV Splash Path—2016
May 21

Otsego Academy Graduation
May 27

PV Annual Formal
June 10

PV Family Day—2016
June 11

Pathfinder School Graduation
June 22, 1pm

Camp Pathfinder
July 17—August 12

Kennedy Willis Center at Pathfinder Village

3 Chenango Road

Edmeston, NY 13335

www.pathfindervillage.org