

The Kennedy Willis Center News & Updates



Fall 2022

KWC Intern shares insights on COVID-19 through I/DD survey



Sarah Shelton of Greenwood Village, Colo., a senior at Colgate University, completed an eight-week internship with The Kennedy Willis Center on Down Syndrome at Pathfinder Village this summer. With little information available on the effects of the pandemic for people with developmental disabilities, Ms. Shelton was tasked with devising an accessible survey to gain a better understanding of COVID's impacts on Village residents.

An educational studies and psychological sciences double-major, Sarah's internship was coordinated through the university's Upstate Field School summer program and focused on the implications of COVID-19 on the intellectual and developmental disabilities (I/DD) community.

Colgate University's Sarah Shelton '23 talks to Shaun R. about his experiences during the COVID-19 pandemic.

"Doing research with the Kennedy Willis Center was one of the best internships I've had! Not only was my supervisor, Brittany Goodrich, extremely helpful but I was also inspired by the tight knit community of employees who supported me in multidimensional ways throughout my project," said Ms. Shelton. "Further, working with the residents to share their experiences taught me more than I can express. My internship gave me insights into creating a holistic research project using quantitative and qualitative data—that has been super helpful as I write my senior thesis this fall!"

"I also was fortunate to attend the board meetings for the Village and Center, which showed me how much work and thought goes into creating amazing organizations," she added. "I hope to apply the research and community-based skills that I've learned in all of my future endeavors."

Shelton's electronic survey was developed through the Qualtrics platform and was organized into three sections. Questions were aligned with three dimensions of wellness (physical, social and emotional) as defined by the National Wellness Institute. Twenty Village residents provided their answers using a touch-screen tablet. The use of icon-based responses, varied question formats to support diverse thinking and learning styles, and a peer-review of the draft survey by self-advocates with disabilities contributed to the accessible functioning of the survey.

Section one focused on capturing individuals' feelings on specific words associated with COVID-19, including "masks," "vaccine," and "quarantine." Section two included objective questions with "yes," "no" or "I don't know" response choices. Section three encouraged free expression through written or drawn answers related to COVID-19 and pandemic safety measures.

The KWC survey found 1.3% of Pathfinder residents were hospitalized for COVID-19.

In the general population, 1.6 % of the population was hospitalized. Those with Down Syndrome were four times more likely to be hospitalized.

*Rothwell & Witters, 2022;
Macmillan, 2021*



Interviewer Shelton and Lloyd P. work through the survey together. Questions were organized around physical, social and emotional impacts, and included icons and other strategies to facilitate responses from individuals who rely on different communication methods.

Along with completing the resident surveys, Ms. Shelton reviewed health data for all Village residents, including re-occurring and acute medical appointments, behavioral incidents, and social engagement opportunities during community lockdown and reopening phases. This information was provided by the Village’s clinical and enrichment staff and was substantiated by residential team members who are well-acquainted with the survey participants.

There were key positive findings identified through the project. Foremost, Pathfinder residents experienced far less severe effects from COVID-19, regardless of age. This finding is in stark contrast to the medical community’s projections for individuals with Down syndrome given immune dysregulation and health co-morbidities associated with Trisomy 21 that increase risks for respiratory infections. Researchers determined that those with Down syndrome typically experienced heightened medical implications and are four-times more likely to be hospitalized due to COVID-19’s effects as compared to the general population (Hüls et al., 2022).

“I don’t like COVID, it’s getting hard. But, I jump and I land, and I like when I land.”
Lloyd P.

Ms. Shelton’s findings concluded that only 1.3% of Pathfinder residents were admitted to the hospital for advanced medical treatment, which is below the general population’s admission rate of 1.6%. Pathfinder residents were proactive with general safety protocols and vaccinations. By March 2021, over 98.6% were fully vaccinated while only 91% of the general population in December 2021 had received the first dose of a two-dose vaccine (Hüls et al., 2022).

Beyond physical health data, Ms. Shelton also analyzed behavioral incidents both pre- and post-lockdown. Her findings revealed fewer episodes among Village residents during quarantine periods, including specific county- or statewide restrictions. This finding counters a majority of scholarly articles that surmised that individuals with I/DD would experience higher occurrences of maladaptive behaviors due to dramatic routine changes. At Pathfinder, campus-wide planning and segmented program schedules during quarantine phases were implemented to help maintain individuals’ mental wellness and social engagement.

Through the survey, Village residents stated that while life during lockdown was challenging, they were able to exercise and had access to reliable enrichment activities in their homes or in small campus-based groups, including art, music and fitness activities. Residents expressed a heightened understanding and application of web-based communication platforms such as Zoom and FaceTime, which were widely used during the pandemic to visit with their friends and family members.

“We live in the most inclusive period in history for individuals with Down syndrome,” said Center Board Member Elisabeth Fournier while reviewing this summer’s study. “Research conducted by emerging professionals through the Kennedy Willis Center provides insights and perspectives on the challenges and opportunities impacting individuals with Down syndrome and can offer improvements to the systems in which they operate. This type of research prepares these future leaders for impactful interventions throughout their careers.”

2022 KWC SUMMER WEBINAR SERIES RECAP

The Kennedy Willis Center on Down Syndrome offered a four-part webinar series on aging and dementia during June and July. Facilitated by Director Brittany Goodrich and Board Member E. Adel Herge, OTD, OTR/L, FAOTA of Jefferson Elder Care, Thomas Jefferson University, webinar participants were presented with best-practice strategies in caring for older adults with intellectual disabilities and dementia.

Discussion topics included the differences between typical aging and signs of dementia, determining the benefits of assessment tools as part of early screening processes, and discussing stress mitigation strategies to help caregivers. The Early Detection Screen for Dementia (EDSD) developed by the National Task Group on Intellectual Disabilities and Dementia Practices was shared as a ready-to-use tool to help care providers record changes in the daily functioning of loved ones.

Over 125 participants were registered for the hour-long sessions, with equal attendance from family members and direct care staff. Four guest speakers, Jane Boyle of Monmouth Co., NJ, Board Member Hut Beall of Amherst, Mass., and Job Coach Rose Davis and Staff Support Specialist Michelle Banks, both of Pathfinder Village, presented hands-on advice and engaging moments from their care experiences at the close of the series. All participants received links to the recorded online sessions and an electronic resource tool kit.

Participants were asked to complete a brief survey after the series and provided excellent feedback and information that will help the Center plan future trainings. Responses indicated that over 70 percent of participants strongly agreed they can discuss the value of early screening for dementia in at-risk individuals, and 80 percent strongly agreed that following the webinar, they are able to describe the benefits of using the EDSD tool as part of the screening process.

In one response, one attendee said, “I am a care manager, and have worked in a group home, I wish that I had seen this when I was [working] in the home. I did send the information to past supervisors to perhaps help new Direct Support Professionals and house staff.” Other attendees said, “The special guests with personal experiences were fantastic,” and “[I] loved this series and was glad to attend. Lots of great back-and-forth among presenters and attendees.”

“The response to the webinar series shows that there is great value in reaching out to families and care providers,” said Director Goodrich. “So much good information was shared, and new connections were made with families throughout the country. With so many parents, siblings and care staff needing resources, any opportunity the Center has to advocate and inform best practices in aging is worthwhile. We look forward to planning our next webinar series soon.”

Following the completion of this online series, several service providers in New York State have reached out to the Center’s staff for case-specific consultations, early assessment screenings, staff trainings, and environmental scans and home visits. If you are a family member or staff member who provides care to aging individuals with Down syndrome, please reach out to the Kennedy Willis Center to learn more about available support and resources.



Dr. Herge and Director Goodrich

“I loved this series and was glad to attend. Lots of great back-and-forth among presenters and attendees.”

Post-series survey comment

The Kennedy Willis Center
★
ON DOWN SYNDROME

To request a consultation, please contact
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The Aging Info Exchange: Collaborating with DPV Peers

The Kennedy Willis Center on Down Syndrome welcomed new visitors from Divine Providence Village (DPV) from Springfield, Penn. this August. DPV is an intermediate care facility for people with intellectual and developmental disabilities that is under the division of Catholic Social Services of the Archdiocese of Philadelphia.

On their 20-acre inclusive campus, DPV provides residential and day habilitation services, specialized therapies, recreation opportunities, and spiritual and social services. Five members of DPV's leadership enjoyed a two-day visit to the Center and Pathfinder Village to learn more about our aging and other program initiatives. Their visit included a campus tour, hands-on dementia experiences, and problem-solving discussions with the Village's senior leadership team and aging committee.

Looking ahead, the Center and DPV will collaborate on projects to sustain the development of quality care and best-practices for older individuals with Down syndrome living with dementia. Working together and learning together with other providers is a top priority for the Center.

In summarizing the information-packed visit, DPV's RN Administrator Lorrie Skelly said, "We are eternally grateful for the experience and absolutely know that it will help us with our future endeavors."



Pathfinder Village CEO Paul Landers and Center Director Brittany Goodrich share the Center's world connections map with professional staff from Divine Providence Village.