MY LIFE NOW⁷



A Shared Journey: Shannon and Anna Marie's Path to Community Living



MY LIFE NOW 7

Spotlighting individuals who have transitioned from developmental centers, nursing homes, and family homes to vibrant community settings. **Celebrating their journeys.**

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"Disability should never disqualify anyone from accessing every aspect of life."

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ABOUT US

The Community Living Education Project, usually referred to as CLEP, works with individuals with intellectual and developmental disabilities and their families and caregivers to explore the possibilities of community living.

Our mission is to assist individuals with intellectual and developmental disabilities in New Jersey to live lives of choice within their communities.

WHAT IS COMMUNITY LIVING?

Community living values each person's strengths and abilities and supports them in pursuing their own goals and aspirations. Person-centered supports and services enable people to establish a valued presence in their communities.

Community living offers opportunities to people with intellectual and developmental disabilities to choose where they live and explore their hopes and dreams. A valued presence in a community is something we all strive for, and why should a person with an intellectual or developmental disability be any different? It allows us to be recognized as contributors to our community as neighbors, friends, volunteers, and taxpayers.

MESSAGE FROM THE EDITOR

Welcome to the second edition of My Life Now.

After a successful decade as a print magazine, The Community Living Education Project (CLEP) re-launched this publication last year an online format.

Our mission remains the same: to spotlight individuals who have transitioned from developmental centers, nursing homes, or family homes to vibrant community settings. We celebrate their journeys of empowerment and self-discovery and share how they have embraced choice and control in their lives.

At CLEP, we believe that everyone deserves a life of choice and control. Yet, we also recognize that for many individuals with intellectual and/or developmental disabilities, this concept remains elusive. Through our work, we strive to instill the principles of person-centered planning, empowering individuals to shape their destinies.

In this edition, we shine a spotlight on Shannon Lewis, whose story highlights how the path to community living is often taken as a family. Parents and siblings are often integral to the process, and it can be a substantial adjustment for all who are involved. In this edition of *My Life Now*, we share the story of Shannon and her mother, Anna Marie. CLEP was fortunate to be able to support them both as they explored different home options, made plans for Shannon's move, and adjusted to Shannon's new life in a group home.



We are grateful to every person who turns to us for assistance while making these important decisions. We never lose sight of the honor it is to walk alongside them and share their stories.

An Marinelli





to read our July 2024 issue of *My Life Now*, which tells the story of Carmelys Vincent

A SHARED JOURNEY

Shannon and Anna Marie's Path to Community Living

BY ANN MARTINELLI



Shannon (left) and her mother, Anna Marie

Shannon Lewis grew up in Williamstown, New Jersey with her mother, stepfather, and younger brother, Jake. Her radiant smile brightens any room, a reflection of her joyful spirit. After graduating high school in 2013, Shannon remained active, attending a day program through Arc Gloucester, and participating in Special Olympics basketball and a Washington Township Parks and Recreation bowling league. She also began attending Camp Sun-N-Fun through Arc Gloucester, starting with the day camp before transitioning to the residential program and weekend respites throughout the year.



Shannon with her brother, Jake

Routine has always been vital to Shannon, making holidays like Thanksgiving and Christmas especially meaningful. Weekly church services at Our Lady of Peace parish in Williamstown, followed by lunch with her grandparents, were essential traditions. However, life changed significantly when her stepfather, Christopher, passed away.

Christopher's passing in July 2022 profoundly affected both Shannon and her mother, Anna Marie Perrone. Chris had been a steady presence, providing support in ways Shannon deeply relied on. His absence left a void that Shannon struggled to express, leading to her refusal to attend her day program. As a full-time middle school teacher, Anna Marie faced challenges balancing work with Shannon's new needs. Their relationship shifted, making it clear that a change was necessary.

Thus began their 18-month journey to transition Shannon to living in a group home. In the fall of 2022, Anna Marie reached out to Shannon's support coordinator to discuss possible living arrangements. In the meantime, Shannon's support coordinator and the day program director urged Shannon to return to her old routine and attend her day program. However, Shannon's reluctance continued. Shannon's support coordinator helped secure direct support staff to come to Shannon's home through Shannon's Division of Developmental Disabilities (DDD) budget, allowing Anna Marie to continue working. Additionally, they worked to move Shannon onto the Community Care Program waiver, paving the way for her transition to a new home.



Shannon, her grandparents, and her mother

"[MELANIE] KNEW WHAT TO LOOK FOR, WHAT QUESTIONS TO ASK — THINGS I DIDN'T KNOW. YOU DON'T KNOW WHAT YOU DON'T KNOW."

Anna Marie Perrone

Through a colleague, Anna Marie connected with Melanie McGackin of the Community Living Education Project (CLEP), who helped create a One-Page Profile for Shannon. This person-centered document detailed Shannon's preferences, needs, and personality traits, and is often a first step towards a transition into a supportive home environment. The One-Page Profile balances "what is important to" someone (what Shannon likes, her preferences, interests, what makes her happy) and "what is important for" someone (her support needs, including medical and behavioral). A DDD case manager was also assigned to begin the search for a provider-managed setting that would be able to support Shannon.

Anna Marie and the DDD case manager worked closely with CLEP. One provider agency showed interest, and Shannon visited the proposed home a few times, including a solo dinner visit to meet future housemates. Initially, the agency suggested she move in before Christmas with a 30-day no-visit period, but after further consideration, they decided to wait until after the holidays. However, in the new year, the provider declined Shannon's move, citing difficulties in meeting her behavioral needs. Disappointed but determined, Anna Marie resumed her search with CLEP's support.

What makes CLEP unique is that its team members are both professionals and mothers of adult children with intellectual and developmental disabilities. This dual perspective provided Anna Marie with invaluable guidance. When a second housing option became available, Melanie helped Anna Marie assess its suitability, emphasizing the importance of housemate compatibility and proximity in age. Reflecting on this, Anna Marie shared, "She knew what to look for, what questions to ask — things I didn't know. You don't know what you don't know."

Preparing Shannon for the move was a gradual process. In conversations with Shannon, Anna Marie used her son's engagement and move out as an analogy, framing Shannon's transition as a natural step toward independence. She frequently reassured Shannon, telling her "You're getting older, and it's time for you to move out on your own. You'll still see me, and we'll still spend time together." Shannon embraced the idea, often telling others she was moving into a group home.

Once the final decision was made, Anna Marie helped Shannon acclimate by visiting the new house together. Though unoccupied at the time, the house was furnished, and Shannon was delighted by the setup. Anna Marie shared the One-Page Profile with the staff to ensure person-centered support. She also decorated Shannon's new room with her favorite colors and items, including a tie-dye bedspread, unicorn Squishmallow, and a cherished Anne Geddes Ladybug doll named "Pooper." The agency provided the main furniture, while Anna Marie contributed personal touches, including a TV and Shannon's desk from home.





to view a video of Anna Marie talking about the value of Shannon's One-Page Profile

CLICK HERE



to view a video of Anna Marie talking about the process of looking at different homes for Shannon

"ARE YOU PROUD OF ME? I DID IT!"

Shannon Lewis

Shannon and her favorite doll, Pooper





MOVING DAY

Shannon's move was carefully planned to maintain her sense of routine. Anna Marie reassured her that a familiar direct support person would stay with her while she finalized arrangements at the new home. Close family friends, Andrea and Stan, picked Shannon up, making the transition smoother. Initially hesitant, Shannon followed their encouragement. Upon arriving, Shannon proudly declared, "Are you proud of me? I did it!"

Though there were some tears, Shannon's transition was smoother than expected. She briefly expressed a desire to return home but was comforted by her favorite mealsomething the staff knew about thanks to the One-Page Profile. That evening, she attended a Valentine's Day party, where she sang, danced, and met new people, ending the day on a joyful note.

ADJUSTING TO HER NEW HOME

Since Shannon's move, Anna Marie has had concerns about staff consistency, but the house manager has remained stable, and the direct support staff has become more consistent since summer 2024. She speaks to Shannon every night, and their weekly visits continue. Saturdays are spent shopping, dining at favorite restaurants (Applebee's, Chick-fil-A, Friendly's), bowling, watching movies, or attending church. Sometimes, Shannon's grandparents or family friends join, and even her brother, Jake, has visited from Florida.

Over the past year, Shannon has grown remarkably, referring to the group home as "home" and her mother's house as "Mommy's house." This linguistic shift reflects her growing independence and comfort in her new environment. Anna Marie noted that Shannon has become more outgoing and has formed friendships with her housemates. They attend different day programs but enjoy evenings together playing Connect Four (Shannon's favorite game) karaoke, and dance parties. One housemate created beaded necklaces for Shannon, a small gesture that brings them both joy. A structured lifestyle has also improved her overall well-being, leading to better health and increased activity.

RETURNING TO THE FAMILY HOME

Anna Marie was initially concerned about Shannon's reaction to visiting her old home. Thanksgiving was the first major test, with a gathering of twelve family and friends. While Shannon enjoyed the visit and festivities, by Saturday, she displayed restlessness and surprised Anna Marie by saying, "I want to go home now." Her desire to return to the group home reassured Anna Marie that she had truly settled into her new life. Reflecting on the visit, Anna Marie admitted to mixed emotions. "First, I thought" wow, this is a lot of work. How did I ever do this and go to work? It reminded me why she is where she is - I just can't do it by myself. But I was happy she wanted to return."

Christmas was another milestone. Shannon attended holiday events with family and friends before Christmas Day including a Grinch Santa dinner with Andrea, Stan and Meaghan. She also spent Christmas Day with them and family members and again stayed overnight before comfortably transitioning back to her group home after the celebrations. This demonstrated how well she had adjusted to her routine and new environment.

(Left) Shannon in her new bedroom (Below) Shannon and her mom at Christmas

to view a video of Anna Marie talking about the support she received during Shannon's move



ONGOING SUPPORT FROM CLEP

CLEP remains a resource even after a transition. Shortly after Shannon's move, one of her housemates called Anna Marie to say Shannon was crying. Concerned but unsure of how to proceed, Anna Marie reached out to Melanie, who guided her through contacting the house manager. A quick response reassured Anna Marie, and Shannon confirmed she was fine.

Shannon's move has been transformative, positively impacting her physical health, emotional well-being, and social engagement. Her journey highlights the importance of person-centered planning, individualized support, and a strong network of care. The combined efforts of Shannon, her family, and dedicated support staff have made her transition a success, paving the way for a fulfilling, independent future. This support reinforced the vital role CLEP plays in easing people and their families through transitions and ensuring long-term success.



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