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**Spreading Happiness Through Socks**

Hear from the father-son duo changing  
the sock industry, Page 12

**Holleran Family**

Meet Jim, Mary, and Katie

Read about the whole family and their  
involvement in the community, Page 10

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Conan's journey to  
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**Transitions**

MAGAZINE

2019 ISSUE



*They just need  
to be about you.*

*Family portraits  
don't need  
to be perfect.*



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# *Transitions*

## MAGAZINE

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# NOTE FROM THE PRESIDENT



Disability is part of the human condition. While some individuals are born with an intellectual or developmental disability; others' acquire a disability through an injury or an accident. We have met individuals who developed their disability through the onset of a mental illness or the diagnosis of a chronic health care condition later in life. As one self-advocate told me at a conference this summer: "we are all temporarily able bodied."

In our second edition of Transitions Magazine we are highlighting steps necessary to create and maintain a meaningful life; however that is defined. When a child is born with a disability a family may have several years to develop a strategy for life after high school. Other clients have to make adjustments more quickly as an illness or injury caused them to redefine independence. The common objective between these experiences is that everyone wants to have a meaningful life and we all may need a little guidance to get there.

The access and availability of information has made perspective and reliable expertise that much more critical to informed decision making. We hope that you will find the following pages useful as you chart your course.

Hope to see you in our new space,

James Traylor

A handwritten signature in black ink, appearing to read "James Traylor".



**James was recognized by Investment News Magazine as a 40 Under 40**



**James & Nicole reading to a group at the YMCA Lewis Street**



**End of the year trip to New York City**



**The Upstate team at the Miracle Field Fete**



**New space grand opening! Attendees included Senator Joe Robach, Assembly member Harry Bronson, Rochester City Councilmember Elaine Spaull, and Greater Rochester Chamber CEO Bob Duffy**



**Annual staff pool day outing**



**James at the Flower City Down Syndrome Buddy Walk**



**Nicole was a speaker at the Rochester Chamber's Women in Leadership panel**



## Article by Lisa Meyer Fertal, CEO East End Disability Associates

Organizational success is dependent upon maintaining successful partnerships on many levels. East End Disability Associates (EEDA) has learned that with shrinking governmental funding and other changes within our industry, successful partnerships are vital for growth and sustainability. EEDA partnered with L'Arche Long Island to establish a home for eight individuals in downtown Riverhead in 2016. Using the Self-Direction model to provide for staff costs and other expenses, the residents of the home pooled their resources in order to allow them to afford this chosen lifestyle. The families who form L'Arche Long Island conducted fundraising to allow them to purchase and renovate the house. The Community Leader responsible for managing the house is also paid with self-direction funding and L'Arche Long Island fundraising.

EEDA and L'Arche entered into a contract wherein L'Arche Long Island purchases services from EEDA. There is a huge commitment of time and resources on both sides, and this is the first time that L'Arche has partnered with another nonprofit in this way. The contract specifies that EEDA serves as the sole provider of Fiscal Intermediary Services for the residents, which ensures a consistent and coordinated approach to managing individual budgets. This year EEDA invited L'Arche to partner in its annual gala fundraiser, which increased opportunity for both organizations to raise more funds to support enhancement to services. EEDA is excited to work with L'Arche and encouraged by the opportunity to experience another model of success and true organizational commitment.

To learn more you can reach Lisa at  
631-369-7345, [www.larchelongisland.org](http://www.larchelongisland.org)



# Inclusion in the Media

"a spotlight on WXXI Rochester"



## Article by Norm Silverstein, President of WXXI Public Media

It all started with a phone call from Dan Meyers, head of the Al Sigl Community of Agencies. Dan had a proposition for WXXI. Every year Al Sigl received a grant to hold a lecture about the abilities of those with special needs. Dan said it was well attended (several hundred people), but he felt he was always reaching the same audience. What if Al Sigl gave the grant to WXXI, to see what we could do with media? It was a modest grant, but we were intrigued by the idea of using media to promote understanding and inclusion. Thus, Dialogue on Disability was born.

That first year we launched the effort with radio talk shows about disability issues, a television documentary, news coverage and other programming. Over the course of a week, we reached about 30,000 people. It convinced us to keep trying and to keep building, using all of our media – television, radio, news and digital content and eventually the Little Theatre.

Fifteen years later, with the Golisano Foundation joining us as a funder and a partner, Dialogue on Disability has evolved from one week of special programming into a year-round effort called Move to Include: It's Up to You!

We are reaching about a million people with programming that makes a difference. It includes PBS Kids shows on inclusion, prime-time television programs, news features, radio talk shows, films and discussion at the Little Theatre, and the list goes on-and-on.

Support from the Golisano Foundation made it possible for WXXI to expand our work with schools. We're adding over a hundred Move to Include video segments for distribution on PBS LearningMedia, a site used by students and teachers throughout the country. The video segments are designed to encourage students to be more inclusive and to motivate classrooms to embrace the concept of "different abilities."

We've also established an "Inclusion Desk." This supports our reporting on people and issues related to disabilities. Another important goal of the Inclusion Desk is to "give voice" to people with disabilities, along with a place for them to tell their own stories. We intend to expand access to this reporting through on-demand and social media.

We're proud that a recent five-part podcast, "Exited", produced by our Inclusion Desk, is getting national attention. "Exited" tells the story of eight young people as they navigate transitions in their lives, especially as they "age out" of traditional support services.

We're proud that WXXI has become one of the leading public media stations in the nation on the topic of inclusion. We like to say that telling stories about disability issues has become "part



of the DNA" at our station. You hear it reflected in topics on our radio talk show, on our news stations, on social media, and in the work we do with schools.

The work we're doing here in Rochester is having an impact and gaining national attention. A video segment we produced, "Positive Exposure," about the work of a photographer and his exhibit at the Eastman Museum featuring the beauty of people with disabilities, received 40,000 views when shared on the PBS Facebook page. When the segment was shown at a PBS meeting, station managers and colleagues I had known for years approached me to talk about their families, how they're dealing with

many of the same issues, and to thank WXXI for sharing our initiative.

Most recently, we've been asked to participate in a "webinar" with PBS stations to share our success stories and to encourage other public stations to do more programming on this topic. Our ultimate goal is a national initiative on disabilities and inclusion, led by public television stations across the country. Stay tuned!



## Article by Patricia H. Beaudrie, Mother and Advocate

Aidan Beaudrie has always had an outgoing personality. He just needs the extra support to gain independence in a world that doesn't always have the patience for individuals with other abilities.



Aidan's mom found out about Best Buddies by sheer chance and contacted Lindsay Jewett to see if it was something that she could get implemented in Aidan's school. The process was slow, and while they waited Lindsay suggested that Aidan join the college chapter. Success!

Aidan has been included with young adults who really care and want to include him. Not because it is their job, but because they truly care. They see Aidan's strengths and his talent at art.

Aidan feels the connection and cannot wait until there is another Best Buddies event. His comment recently to his mother was that "Best Buddies is really cool, and all the people there are nice! See mom, you were right, I can do anything!"

# A Star IS BORN



## Article by Georgia Csont, Mother and Advocate

Maddie started gymnastics at the age of three at the Perinton Recreation Center. We didn't qualify for PT and OT services, so we signed her up for gymnastics. The sport was initially meant to help Maddie work on gross and fine motor skills, as well as social skills.

Fast forward to 9th grade, Maddie joined the Fairport JV team. Her coach knew about the Special Olympics at the Gymnastics Training Center, and the rest is history.

Maddie has participated in local, regional, and state games since then. Maddie placed 5th



in the nation and received gold in the vault, beam, uneven bars, and floor in her division.

On top of her Special Olympics success, she also was a member of the Fairport Varsity team and received awards for Section 5 gymnast of the week, the spark plug award for team spirit, and much more! Maddie was also chosen to attend healthy ambassador training to teach her fellow teammates about creating healthy habits. To top it all off, she is going to New York City to be honored during the Women in Sports Foundation representing New York Special Olympics.

Maddie is a busy woman. Who would have guessed at 3 years old, that a rec center class could shape her future!

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# Q&A

What is one thing in your child's life that creates meaning?



**Emily** • Our furry "kids" would say long walks together out in the woods. My niece and nephew would say quality time together. I don't think it matters if we play outside with rocks or plan an elaborate adventure. They just want our full attention and love.

**Luisa** • At 4 months old Chloe gets the most happiness when we go for walks in the fresh air, read books, and when Mommy & Daddy make a fool of themselves. She loves the simple things already.

**Margaret** • My kids are college and post college age... I think they would all say the unconditional love of their mother and their siblings. (They've told me as much, I'm not vain. Lol)



**Colleen** • Once a month, my husband and I will take turns taking our son or daughter out on a special date. It gives us one on one time with each kiddo that we normally don't have during the week, and it always resonates with them as something special and memorable!

**Erika** • My daughter will be 6 years old in two weeks. Her life is full because of the sense of belonging she receives from her community. At age 3, she tragically lost her Father but our church community, her school community, her cheer team, and our family and friends have been such an instrumental part of her happiness and development. Every time I ask her what she is grateful for she says her "family" and continues to name endless members of her different communities as her family.

**Becky** • Having the continuous support that helps him feel / be empowered and independent = fulfilled

**Shlynn** • Relationships.

**Tracy** • Art, Olivia can express herself in different ways, and I can learn what is important to her without directing her answer with verbal communication.



**Catherine** • Relationships with friends and family.

**Sarah** • Relationships, arts , crafts, and experiments (the messier, the better)

**Juana** • Marianna said her "family and getting a good education" brings meaning to her life.

**Ruth** • Relationships that provide positive role models, provides a faith based foundation, love and security, encouragement and empowerment that helps the child then develop into a happy, healthy adult who believes in themselves and their purpose in this world.



**Mindy** • No matter what age, I suppose meaning is always created through relationships and interactions with the earth. I think right now something as simple as a big smile when Leonardo looks into the eyes of a stranger at the store creates more meaning than we will ever know. It brightens everyone's day, and lord knows we all need some light in our lives these days. This is his current way of "helping others".



# MEET THE Holleran FAMILY

Jim and Mary Holleran have lived in Rochester since 1984. Mary is the Vice President for Communications at the Rochester Area Community Foundation. Jim is a Registrar for Schools 3, 7, 20, 33 and 46 in the Rochester City School District.

## Tell us about your family?

The Hollerans are a family of five – Jim, Katie, Liam, Claire, and myself, Mary. If a child's birth changes the course of your lives, Kathleen Barbara's arrival impacted us tremendously on Nov. 9, 1985. As we learned about the ramifications of Down syndrome, we were opened to an entirely new world of possibilities, acceptance and advocacy. We have moved beyond the tears of joy at her first Special Olympics meet as a 5-year-old to the satisfaction and pride we feel today as we watch her negotiate the world, living independently in the Corn Hill neighborhood with her roommate.

## How has having a child with special needs changed your family?

Katie's birth immediately raised a lot of questions and uncertainties. Will she ever go to school? Will she go to her prom? Will she become independent? Yes, yes and yes.

Instead of taking everything for granted, we reveled in her minor milestones such as learning to roll over, learning sign language at 6 months to bridge the span until her speech arrived, and jumping on the school bus at 22 months for early intervention classes at BOCES I in Fairport.

## What is your favorite thing to do as a family?

We love the holidays. Who could forget Katie crawling into our bed on Christmas morning, lifting our eyelids and asking, "Awake?" We would not miss the journey to Doylestown, Ohio, each year for a Christmas reunion with the Dannemiller cousins, or the summer pilgrimage to Morristown, NY, where the Irish mafia, that is the Holleran clan, gathers for the village July Fourth parade, fireworks, and cookouts at Aunt Maureen's cottage on the St. Lawrence River.

The annual highlight is St. Patrick's Day when we throw open the doors to 100 or so guests with 35 pounds of corned beef. Katie dons something green, usually outrageous with a boa or a cowboy hat, and takes up her front-door post as official greeter and coatcheck girl.

## Are you involved in any community activities?

The list is lengthy and has changed as our children have grown. It began with Special Olympics volunteering and fundraising, helping in classrooms, driving children to events, and looking for new opportunities for Katie and her friends. She has danced in Las Vegas, read books to School 42 kindergarten classes, participated as an altar server, took classes on the University of Rochester campus, competed in local, state and national gymnastics, and joined a volunteer team serving food at the Blessed Sacrament Supper Program.

Jim wrote a book about the founding of Heritage Christian Services, and I serve on the board



of Catholic Charities Community Services, which supports individuals with disabilities and those with significant health issues.

In spring 2018, Jim, Katie and myself served as honorary chairs of the fundraising gala for the Miracle Field of Greater Rochester, the region's

first level, cushioned athletic field for persons of all ages and abilities.

We continue as founding members of the Developmental Disabilities Giving Circle at Rochester Area Community Foundation, a group of parents and siblings who raise and distribute money for projects that promote independence and improve the quality of life for adult individuals with intellectual/developmental disabilities. This grass-roots group has distributed more than \$134,000 since 2015.

#### How has Upstate Special Needs helped you?

We thought we had our affairs in order until we met with James Traylor and his team. We learned about the tax implications of trusts vs. insurance strategies, and how to maximize Katie's inheritance while balancing the needs of Liam and Claire. A crucial piece of advice from James was how to better plan for our retirement.

We considered ourselves insightful persons given our background as newspaper editors and professionals, but James guided us through the nuances of teacher retirement benefits, IRA disbursements and Social Security payouts.

#### What prompted you to do future planning?

Our will was 15 years old and our children had com-

pleted college. We weren't dwelling on where they would live, but on how to divide and direct our assets. James worked closely with our estate attorney to ensure the financial plans aligned with the intent of our new Will.

#### What are your hopes and dreams for Katie?

Katie insists she has a "great life." She does. We hope she continues to live independently, travel, enjoy time with her family, and build memories with her friends in the community. Whether sister or brother, or extended family members, we hope there will be someone to love and watch over her.

#### What advice would you give to parents when planning for the future?

Easy – call James. James' sincere interest in helping families with special needs stems from his devotion to his sister, Nathalie. He has taken care of us just as he looks out for the best interests of his sister. His expertise about state policy issues and mastery of planning strategies are invaluable.



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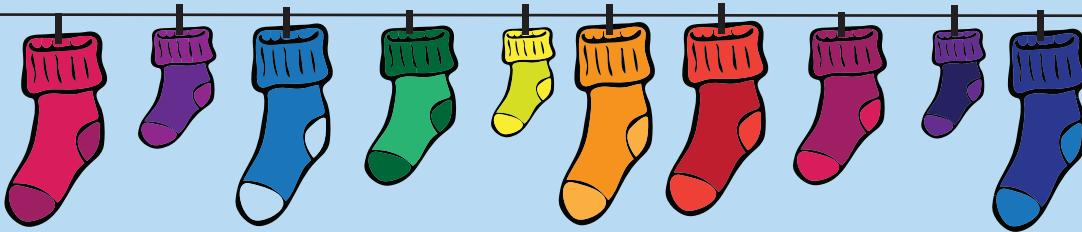
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# Spreading Happiness through Socks



You may have seen them on The Mighty, CBS or Money magazine. The father-son duo called 'John's Crazy Socks' out of Huntington Beach, Long Island is taking over the sock community with their fun and creative style. George W. Bush is even a fan! Nicole VanGorder had the chance to sit down with the dynamic duo to learn about their business, mission and why they do what they do. The interview wasn't short of candor and laughs. Continue reading to learn more about this booming business!

Nicole: John & Mark, thanks so much for speaking with me today. Let's start with the most basic question, what is the main mission of your business?

John: Spreading happiness!

Mark: Our core mission is to show people what is possible. We want to show everyday what people with differing abilities can do. We have created this social enterprise so we have a social and ecommerce mission. The two are indivisible.

Nicole: I was reading some recent articles covering the business and it sounds like to me that this idea really came out of the need and lack of desirable job opportunities once high school had ended for you John. So tell me what was that like going through that transition?

Mark: The context was back in the fall of 2016.

John: We started in a small log cabin! (laughs)

Mark: There were two things going on simultaneously. I had started an online business and John was in his last year of school.

John: I was 21 and I was trying to figure out what I was going to do.

Mark: We were looking at job training programs, workshops, and certificate programs. John had worked with me in an office before where he had real assignments. He liked working with me.

John: I loved going to school but I wasn't happy with the options for after high school

Mark: Not a lot of great opportunities for individuals with differing abilities after school. The idea came out of frustration. Our school system was great. I know this varies from state to state and county to county but we were blessed with a great experience. But then you hit this cliff and you're on your own! We have these people who are willing, educated, and ready to work.

John: I said to my dad. I want to do something fun and I want to go into business with my dad!

Mark: It was natural for John to be entrepreneurial. He does not see obstacles and barriers. There are lots of people who think about going into their own business but are taken over by fear of failure. We went through a few ideas about different businesses, eventually we came up with socks!

John: We had some non starter ideas! I wanted a fun store, and then a food truck! The problem with the food truck was me and my dad. We can't cook! (laughs)

Mark: Hey speak for yourself, I can cook!

John: Its fun. It's colorful. It's creative. I love all crazy socks! I've always loved crazy socks.

**Mark:** We didn't really do any market research or planning but we decided here is what we are going to do. We decided to run with it. We decided to set up a store online and start with some inventory.

**Nicole:** John, I love your fearless attitude. I know a lot of people who are too scared of failure and never end up taking that leap. Any advice for young adults starting their own business?

**John:** Just go do it! Stop overthinking.

**Mark:** Don't wait for it to be perfect, just do it. People will vote with their dollars. At the same time, you have to be thorough and careful. Whatever you do, it has to work as a business. We have a social and business mission, they feed off of each other but we can't just focus on one. If we focused on just one aspect, we wouldn't have the same impact.

**Nicole:** I totally get that. When we started our business we knew we couldn't and didn't want to be everything to everybody. We wanted to be able to provide value. Many people thought we should be a nonprofit but we knew that was not the right model for us at the time. Like you, we wanted to have a social and business enterprise that reflected each other.

**Mark:** Exactly. It's important for us to be a for profit and for us to succeed because if I am going to stand up in front of a group and saying hiring people with differing abilities is not charity, it's good business, then we have to show that we are successful as a business. We must be living testimony to the message, saying we succeed because of whom we hire.



**It's our second year of business and we have over 5 million in revenue. It's because of this social enterprise model that we are successful.**

**Nicole:** I read you have 35 employees and counting. What are some of the things you do in your workplace to get people to get excited about coming to work every day?

**John:** Thank you videos, pictures, tours, speaking engagements, meeting with new suppliers, and picking new socks. I work with the sock wranglers!

**Mark:** Sock wranglers are our stock pickers at our pick and pack warehouse. We have a certain approach to employee engagement. One, you want to give people a mission that they can believe. This applies to all of our employees-differing abilities and neurotypical. Make sure that everyone knows what they do fits into that mission. Our sock wranglers know that when they get those orders right they are creating happiness. What they do matters. Put people in positions where they can succeed. Ask people to do what they can do and give them the support they need. We all want to be recognized. Just as simple as saying thank you. Every Wednesday is 'Bagel Wednesday'- every Friday Facebook videos-everyone gets to do a little acting. We have social events every month outside of work, maybe a dinner or a Mets game. Everyone gets a John's Crazy Socks email address



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whether you're on the computer working or not, everyone has a business card. It's teaching people how to be a professional. Everyone gets their own personal discount code and they can share their business card code! It helps us get the word out.

Nicole: I am in awe. I think what you have is really special and I can tell you really care about your employees.

Mark: People perform better. When working with people who have differing abilities, it gives us a competitive advantage because we can tap into a labor pool that most people don't touch. Businesses have come here to us to understand what we are doing because many businesses do not know how to make it happen.

Me: John do you pick out the socks? What is your favorite sock?

John: My favorite is the Down Syndrome Superhero sock. I pick and draw the pictures of the designs I like. I drew the picture of me in the super hero sock! I love drawing!

Nicole: Mark, what are some of your hopes and dreams for John's future?

Mark: We set this business up so John would have meaningful work for the rest of his life. It has grown faster than one could have predicted.

John: I love doing what I do!

Mark: I've watched John grow tremendously in the past year and a half. I feel a very strong sense of obligation. We have set up and made a promise to people and now we have to make good on that promise. We made a promise to our employees, to potential employees and many others. It is imperative that we succeed. We plan to add more products, long term we want to be a destination. We host school groups and work groups, visitors, we want people to tour our facility. We want to have a store and café. We want people to come here and know that we have a unified workplace and that this is a different place.

## IDENTITY IN THE WORLD OF POST ADOPTION



### Article by Nicole VanGorder

Two years ago I decided to start engaging post adoption services through the agency I was adopted and it would start a journey that was more than I could hope for. I was always a curious child and as an adult that curiosity didn't go away but over time it was met with fear. Fear of the unknown. Fear of what I may or may not really want to know. Too many 'what ifs' clouded my mind. I didn't want to open pandoras box.

I came to America when I was a baby and was adopted into a blue collar family in Buffalo, NY. I grew up to be your typical young adult. More concerned with who was taking me to prom and worrying about what college might accept me, I gave little thought as to where I was from and how I got here. When I was 22 I had the urge to begin my search but was not emotionally ready for what was to come so I stopped the process. Years later, I decided to revisit the idea. I started writing my birth mother and with not much hope

or anticipation of a response back, about a month later I was notified the agency found her and she had written me back.

This correspondence went on for about year when I was then encouraged to apply for a program where the Korean government would pay for me to fly over and meet my birth parent(s). It was a competitive process with only 5 people being selected from around the world. I submitted my application without much thought or expectation that I would be chosen. Sure enough, on the day of my birthday I was notified that I had in fact been chosen. I had to make my decision quickly since the trip would be barely three months later not lending me much time for hesitation or thought.

My husband being the great trooper he is, agreed to come. After a full day of traveling we got off the plane only to be met with confusion. We were grossly underprepared. Immediately, the language barrier and getting around proved to be more difficult than expected. We spent the next week exploring Korea and preparing for my family meeting. Due to the nature of our situation, I had to meet my mother in secret. James and I went on a high-speed train down to the city where she lived. We would meet on the other side of town and a social worker would meet us the day of to be our translator. The day came when we would finally meet. It was a day I will never forget. It surprised me how quickly it was as if we never left one another. It felt as if we knew one another and despite the feelings of being separated for almost thirty years the history and distance quickly faded into the background. We walked arm in arm to lunch like many Korean mother and daughters do. We looked like every other mother daughter pair on the street. Our time finally came to an end and I nor James were prepared for goodbye. We both struggled the rest of the trip and had a very hard time coming back stateside adjusting to what had just happened. So many questions had been answered but also opened so many other questions and scenarios.

Post adoption services provided me an outlet to explore things I had always wanted to know but didn't know how. Mostly, the experience provided me the following:

- Closure and opening: There were things I was not prepared for including the profound grief I felt afterward. After returning stateside I was grieving a living person. So much disappointment, lost time and uncertainty moving forward. Yet so many of my questions answered allowed me to move forward in different ways.
- Meeting other people: It was reassuring to meet other people in my situation and who were similar in age and experiences. For as different as we all were, we had such similar personality traits. It was like meeting sisters I never knew. We keep in touch to this day and I am so grateful to have them on this journey.
- Cultural understanding: Korea is still a very conservative place. In being able to go overseas and experience things myself allowed me to be immersed and understand why things are the way they are and helped me to develop an appreciation for where I am from.
- A new understanding of my own personal identity: Perhaps the most important take away was the clarity that came to me about half way through the trip. Despite coming back with more questions than probably answers, I left Korea feeling a deep sense of understanding about the type of person I am. This is probably the most important reason I would tell anyone to consider engaging post adoption services.



# ORGANIZED ON THE GO



As a parent and caregiver you wear many hats! Here are a list of my favorite items to keep you in check as you go about your day.

**The Moleskine Voyageur Notebook** is built for travel with a canvas cover, rounded corners and elastic closure. I like it because of the three ribbon bookmarks, expandable inner pocket in cardboard and cloth, budget pages to note down expenses, journaling section to record memories from each day, and the detachable packing lists & detachable to-do lists.

**Vera Bradley Iconic Large Cosmetic Bag** is great for keeping personal items organized on the go! It keeps things from rolling around when I inevitably drop my purse wide open in the middle of a meeting! I keep items like Band-Aids, a sewing kit, Tylenol, and Chapstick in mine. I recommend a washable or vinyl wipe material bag for ease.

**Re-marks Breakfast Treats Magnetic Page Clips** are absolutely adorable. They're better than your average bookmark and can be used on documents as well as books. They are small and firmly stay in place, even though my purse is always in a state of disarray.

**Do It All Tool by Zootility** always comes in handy when I need it most. It's lightweight and fits in with my credit cards. The design has three screwdrivers (flat head, 2D phillips, micro flat), a wrench, a bottle opener, a letter opener, and more!

**Mario Badescu or Evian Facial Spray** is especially great when traveling or in an office where the heat or AC is blasting. This spray makes you feel refreshed and human again! An aloe or rose water base is my personal favorite.



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# FACING THE TRANSITION INTO ADULTHOOD

## Article by James Traylor

The transition from high school into adulthood is an anxious time for many of our friends and clients. Questions regarding adult services, benefits, health care, housing, college supports, wages and insurance are amplified by a generalized anxiety following an abrupt break in the school routine. Furthermore, the school district which once the conduit for information, is replaced by multiple sources of data and noise. Parents and young people alike are quickly lost. From our perspective the best way to eat an elephant is one bite at a time. To help you in your journey here is a laundry list of problems and solutions to ease that anxiety:

### Benefits

- Evaluate if Social Security may assist with supplemental income (see page 18)
- Confirm if a child can stay on the family health plan as an adult
- Engage a job coach either through a Care Coordinator, ACCESS-VR or local employment agency
- Consider SNAP (Foodstamps) or a Housing Subsidy to support independent living

### Financial

- If approved for Supplemental Security Income (SSI), tuition assistance may be available through NYS or ACCESS-VR
- Consider an ABLE Account to save for larger purchases
- Open a secured Credit Card to establish a credit history

### Legal

- Determine where to accumulate your paycheck (so it doesn't impact benefits)

- Discuss decision making and if an individual needs assistance (Guardianship or Supported Decision Making)

### Social

- Attend the Social Exchange or a similar meet-up program to maintain or develop social skills
- Establish rules around social media and screen time (it is easy to lose track of time online if you aren't in school 8 hours a day)
- Talk about sexuality and how to maintain healthy relationships
- Discuss independent living and the timeline for living outside the home



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# *Social Security Disability vs Supplemental Security Income A Primer*



## Article by Robert W. Clark, Esq.

Social Security Disability (SSD) and Supplemental Security Income (SSI) are both benefits provided by the federal government to assist individuals with a disability or other severe medical impairment that is expected to last or has lasted twelve consecutive months. Additionally, some family members of the disabled individual may also receive benefits under either program.

SSD benefits are an insurance based benefit payable to disabled individuals who have worked and paid Social Security taxes for a certain period of time prior to becoming disabled. Social Security refers to this requirement as "quarters of coverage." Generally, in order to qualify for SSD you must have worked twenty out of forty quarters or in other words, worked for five out of the past ten years. SSD benefits are intended to benefit disabled individuals who have worked long enough and paid taxes long enough in order to be insured and eligible to receive benefits under the program.

SSI benefits on the other hand are a needs based program payable to disabled individuals who meet certain financial criteria. Like SSD, the individual must be disabled and/or have a severe medical impairment. However, unlike SSD, SSI benefits may be payable to individuals with little or no work history so long as they meet SSI's financial guidelines or income limits. Generally, SSI imposes an asset limitation of \$2,000.00 for individuals and \$3,000.00 for married couples. Social Security classifies various types of income that they may or may not count towards the asset limitation for SSI benefits.

For both SSD and SSI, Social Security uses a five-step sequential evaluation process in order to determine eligibility. At step one, Social Security will see whether you are working and if your earnings are in excess of substantial gainful activity (SGA). What Social Security sets SGA at changes each year, so your eligibility at step-one will vary based upon whether you are working and what year you are claiming you became disabled, known as your alleged onset date.

At step two, Social Security will look to whether you have a "severe" medical impairment that is expected to last or has lasted twelve consecutive months. Severe medical impairments generally limit or preclude individuals from working on a competitive full-time basis.

At step three, Social Security will see if you meet one of their listing of impairments. Social Security has a published listing of impairments also known as the Social Security Blue Book which defines certain medical impairments. If your impairments meet or exceed Social Security's

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Blue Book listing then the evaluation process ends and you should be found eligible for disability benefits. However, meeting a listing is a rare occurrence and most claimant's will proceed to step four of the sequential evaluation process.

Prior to step four, Social Security will determine your residual functional capacity (RFC). Your RFC is a function of both exertional and non-exertional limitations you may have as a result of both physical and mental impairments. At step four, and after determining your RFC, Social Security will look to see if you are capable of performing your past relevant work.

If you cannot perform your past relevant work then Social Security will move on to step five and look to whether you can perform any other work available in the national economy on a competitive full-time basis.

I hope this information helps explain some of the basics associated with applying for both benefits for SSI and SSD. Depending on your circumstances it may make sense for you to apply for either or both SSI and SSD.

Robert Clark is an associate attorney at Connors & Ferris, LLP who helps disabled individuals with claims for workers' compensation and SSD/SSI.

## SUMMARY OF MAJOR SOCIAL SECURITY CHANGES IN 2018

### Article by James Traylor

Part of our consulting work is to keep informed regarding the constantly evolving benefits landscape. In 2018, the Social Security Administration (SSA) made some significant changes to the Program Operations Manual System (POMS) to clarify SSA policy surrounding Special Needs Trusts and SSI beneficiaries. The following updates I found to be most helpful:

#### SI 01120.201F.3.A

When a Special Needs Trusts that is considered a sole-benefit trust (self-settled) makes a payment to a third party for goods or services, SSA does not have to be so strict as to prevent anyone else from receiving an ancillary benefit. For example, a television purchased by the trust for a beneficiary doesn't have to be only located in the beneficiary's bedroom; it could be in the living room, where roommates may also use it.

#### SI 01120.201F.3.B

Travel expenses paid to a third party on behalf

of a support person, including a family member, are permissible as long as they are reasonable and the beneficiary could not safely travel without assistance.

#### SI 01120.201I.1.D

Payments out of a Special Needs Trust made to a third party credit card company are permissible as long as the beneficiary did not purchase food or shelter (For SSI Beneficiaries).

#### SI 01120.201I.1.E

Administrator-managed prepaid cards, such as True Link Financial, are permissible as long as the trustee restricts the beneficiary from purchasing food or shelter. The owner of the card needs to be the trustee not the beneficiary.

#### SI 01120.201I.1.H

Funds transferred from a Supplemental Needs Trust into an ABLE account are excluded from income to the trust beneficiary. However, this creates a situation where money may be payable to Medicaid after death of the beneficiary.

# WAYS TO recognize people IN YOUR CHILD'S LIFE

## Article by Nicole Traylor

It takes a village! Here are a few heartfelt ways to recognize the special people in your life that won't break the bank.

**'Why you're so awesome' fill in books** at Barnes & Nobles. They have ones for different occasions, such as holidays, birthdays, and more.

**Memory jar filled with favorite memories** or things you appreciate about the person. This one is easy and always well received. Pending on the size of your mason jar, you can do anywhere from 30 to 50 memories. Simply write your thoughts, fold the papers, and screw the top on. The comments do not need to be particularly long. Bonus points for a fun ribbon around the top or if you use different colored pens to write your cards. You can also add small mementos to the cards, such as a ticket stub or button, if you have some.

**Simple hand written cards** always make great impact! I typically go through my calendar once a month to look at what is coming up. I feel it's important to keep in touch with people. Hand-written notes are always welcome surprises.

Not sure what to say? Here are a few ways to start out:

- You did a remarkable job because...
- Thanks for being "on top of it," I have a lot of confidence in you because...
- You have such a unique way of dealing with (people, technology, conflict, etc.) because...
- Thank you for speaking up it took a lot of courage to...
- I admire your imagination and creativity because...
- It's exciting to work with you because...
- You mean a lot to this (department, division, company, etc.) because...
- I trust you because...
- The best thing you did (in that meeting today, on that trip, on that proposal today, etc.) was...



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# BROKER OWNER

## Article by Craig Schneider, Owner NORCHAR Real Estate

### What design elements are important when considering multi-generational living?

**Doorways and Openings:** Consider providing easier accessibility throughout the first floor by enlarging the doors to 34" or 36" doors. Focus also on hallways and openings within the home. Wider hallways provide an attractive aesthetic that also includes simple accessibility with a walker or wheelchair.

**Thresholds and Steps:** Reduce steps and thresholds at entrances to the home by replacing front lead walks steps with ramped front lead walks. Roll-in showers are also becoming very popular for multi-generational homes. A roll-in shower has no threshold to step or trip over while entering or exiting the shower stall.

**First-Floor Bedroom Suite:** If the family does not have an immediate need for a first-floor bedroom, this space can be repurposed as a family room, game room, music room, or study.

**Hard Surface Flooring:** Carpets reduce mobility when using a walker or wheel chair. When carpet is used, consider a low pile or commercial style product.

**Small Details:** Replacing items like doorknobs with lever handles and standard light switches with decorator push switches can make life

much easier for family members with arthritis or loss of strength or muscle control.

If a parent wants to purchase a home for an adult child what type of home should they look for?

We typically focus our search on new homes or homes that have been properly updated. Low maintenance is the goal here, as the most difficult factor of homeownership is keeping up with the maintenance. With a new home or a home that was extensively updated, a homeowner can enjoy (20-25) years of carefree living. When available in the clients target market, townhomes or condominiums can afford the leisure of low maintenance living though the Home Owners Association (HOA). The HOA collects a monthly fee that is used to pay a property management company to provide grounds and exterior building maintenance in most townhouse and condominium communities.

At what stage of the buying process should you engage a Realtor?

The sooner you're able to bring a local real estate expert, the better. This will enable them to help you create the proper timeline and explain the process in more detail. A true professional will also



# PLANNING FOR A SPOUSE WITH CHRONIC HEALTH NEEDS

## Article by James Traylor

Fulfilling the marital vows "In sickness and in health" can be challenging without direction. Following a discharge from a hospital or long term care rehab facility initial questions are around health care: establishing a medication regimen, following a Physical Therapy routine, adjusting to new chores or responsibilities. However, if the long term care event is unlikely to improve or require more complex care certain planning should be considered:

**1. Does the spouse need assistance handling financial or legal affairs?** Consider retitling assets to be jointly held and working with an estate planning attorney to establish an updated power of attorney. Being married does not necessarily mean you have the ability to handle a spouses financial or legal affairs.

**2. Evaluate the living space to avoid accidents.** Walk in showers, first floor bedrooms, kitchen ranges that are lower and lighting & security systems that are voice activated are not just for those that use a wheelchair. Accessibility and aging in place does not mean a sacrifice aesthetically and many builders, designers and real estate professionals can find or design a space to be comfortable but functional.

**3. Having candid conversations about money.** Everyone needs a long term care strategy. Assistance or care can be either purchased with private funds at between \$28-\$35 per hour, paid for with Long Term Care Insurance (which needs to be purchased BEFORE you are sick), or provided through State

Medicaid Programs (which require the transfer of assets). Many families are fortunate to have family and friends able to provide supports. Having upfront conversations about money, caregiving, time and expectations can reduce animosity between caregivers.

**4. Being realistic about respite.** Marriage does not mean you need to spend 24/7 together as spouse caregiver. Free time, exercise, and time away can often bring feelings of guilt as former activities may not be able to be enjoyed jointly. Our experience has been if the caregiver spouse does not have respite and rest, their quality of life can decline rapidly and lead to crisis. Taking a break from caregiving does not mean you don't love your spouse.

With appropriate supports and systems in place we have seen many families keep a loved one out of a nursing facility. Those that have difficult conversations early and often are able to maintain control and options. Those that pretend that nothing is wrong can end up in crisis.



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# PROS & CONS of an In-Law Apartment

## Article by James Traylor

Over the last two years we have observed an increase in clients purchasing homes with an in-law apartment or considering adding one to their existing home. Before committing the time and resources to a major capital project it is important to consider the advantages and disadvantages.

### Cons

- Many structures are not designed for an in-law space.
- What happens to the in-law space if the family caregiver dies or can no longer safely stay in the home?
- An in-law apartment may not add significant value to the property vs. the capital investment required.

### Pros

- A properly configured in-law apartment allows close proximity to caregivers while still allowing for privacy. Let's face it, staff does not want to see you in your bath robe at 7 am!
- The in-law apartment MAY be considered a separate space and therefore eligible for certain Self-Direction or State Funds if it meets certain criteria.
- For individuals with complex medical needs it allows the feeling of independence while still allowing appropriate nursing and family supports to be provided.



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# SPECIAL NEEDS TRUSTS

Article by Ryanlynn McCollum, CPA

It's estimated that 1 in every 5 Americans has a disability. Meanwhile, 90% of U.S. businesses are owned or controlled by families. Therefore, it's likely that you or someone you know owns a family business while also caring for someone with a disability.

If you're caring for someone with a disability, you've probably been advised to utilize a special needs trust to maximize government benefits for the disabled. What's often overlooked is the opportunity for family business, estate and succession planning in conjunction with your special needs planning. For instance, if your family business entity structure is an S-Corporation, it might make sense to have the special needs trust own part of the stock.

Special needs trusts are usually funded in one of two ways. First-party funded trusts are funded by the disabled beneficiary using assets they already own or hold legal title to. First-party funded trusts are considered grantor trusts for income tax purposes, thus all items of income earned in the trust are taxed to the beneficiary at their individual tax rates. Grantor trusts are eligible shareholders of an S-Corporation, therefore, if a first-party funded trust were to own shares in the family business, the income of the S-Corporation would be taxed at the beneficiary's tax rates. Upon the death of the beneficiary (who is also the grantor), the trust would lose its grantor trust status. The estate would be treated as the shareholder for S-Corporation eligibility purposes for up to two years post death. During that time, the trust should either dispose of the stock or the trustee should make the election to become an Electing Small Business Trust (ESBT). While ESBT's are eligible for S-Corporation status, they have a tax disadvantage in that the S-Corporation income

would become taxed using the more aggressive trust tax rates. To further complicate things, first-party funded trusts typically carry a "pay-back" provision which require Medicaid benefits received by the beneficiary to be repaid to the government upon the beneficiary's death.

Third-party funded trusts are funded with the assets of someone other than the disabled beneficiary, usually as part of an estate gifting or inheritance strategy. Third-party funded trusts can also be grantor trusts, which like the first-party funded trusts are taxed at individual tax rates. The difference is that the individual rates are those of the third-party funding the trust, not those of the beneficiary. The third-party individual funding the trust is typically in a higher tax bracket than that of the beneficiary, but still not as high as if the trust itself were paying the tax, which would be the case if the third-party funded trust was set up as an ESBT or another non-grantor trust. Like the first-party trust, upon the death of the grantor, the same two-year eligibility and election period is available for the special needs trust owning S-Corporation stock. Upon the death of the beneficiary, the assets in the trust can be passed onto other family members as directed by the party that funded the trust. Unlike the first-party funded trust, there is no "payback" provision requirement in a third-party funded trust.

While minimizing taxes, allowing for flexibility and mobility of trust assets, and preserving the government benefits of the disabled are all ideal, it's important to understand that every situation is different. This is only one example of how family business planning can be integrated with special needs planning. It is advised that you work with a team of specialized attorneys, financial advisors, and tax professionals to navigate through the complex laws to structure your plan specifically to fit your family's needs.



# The Dentist Will See You Now

## Article by Dr. Caitlin Hoffman

### What are some of the unique challenges providing dental care to those with sensory issues?

There are several challenges when providing dental care to those with sensory issues. We often use bright lights for visibility during treatment. Another very common challenge is the high pitch sounds that come from our dental handpieces. Lastly, patients with sensory issues may also have taste and texture aversions to many of our products. We are very fortunate at East Avenue Dentistry to have a board certified pediatric dentist, Dr. Lindsey Keck, in our office who is wonderful with children from all backgrounds.

### How do you create an environment to accommodate those with special needs?

There are many ways we accommodate those with special needs. We always create a friendly environment for the patient. One simple example is a "tell-show-do" method that works extremely well for patients. We simply tell the patient what we want to do, we will show them the instrument that we will use to do the treatment, and then we will walk the patient through it as we do the treatment. We always provide safety sunglasses that help with the bright lights or we simply will go without using our lights if it is very bothersome to the patient. Frequent breaks throughout the procedure are also very helpful. We offer earphones with calming music or will play a movie that cannot only help distract but cancel out noises associated with our instru-

ments. We take our time reviewing treatment, asking questions, and getting to know the patient ahead of time so we can make the patient most comfortable in our chair. If a weighted blanket is used as a comfort at home this can be used in the dental office or a lead x-ray apron can be used in its place for the same purpose. Wheelchair bound patients can often be seen in the comfort of their chair. Consistency is very important and we recommend whenever possible that they see the same provider and even be seen in the same room every time.

### Are there tips you could give to caregivers to help manage expectations for the trip to the dentist?

The most important thing is to acquaint your child with the dental office early on so it becomes a place of familiarity. The American Academy of Pediatric Dentistry recommends finding a dental home by age 1. The first visit at East Avenue Dentistry is mostly informative and involves only a short exam on a parents lap and the application of fluoride varnish. It's much easier to prevent children from developing decay if the parents are educated early on about homecare, diet, and overall expectations. Creating a social story about the dental visit can be very helpful for patients with autism. Autism Speaks has many good resources on their website for setting up successful dental visits. It's important for parents to maintain a calm and enthusiastic attitude throughout their child's dental visit. Children are very intuitive and can pick up on cues from their parents. Happy parents help dentists make happy children.



# Q & A

## WITH DR. LORI JEANNE PELOQUIN

**What age is appropriate to start psychological services?**

Psychological services can begin as early as parents suspect some type of developmental, emotional, social or behavioral challenges. I have worked with children as young as 9 months old. Some psychologists have not received training in working with very young children or adults with developmental disabilities. In working with very young children, work should always include parents in the session, as they are the most important therapist a child can have!

**How do psychological services integrate with other types of services a patient is receiving?**

Psychologists providing services are required to be in communication with the child or adult's medical provider, at least when first starting services and when any major changes occur. If a child is receiving counseling services at school, it is often helpful for the counselor and the psychologist to be coordinating care. Psychologists vary in how they work with parents. In my practice, parents are included in all sessions until the patient is old enough to want to meet by themselves or I believe it would be beneficial. Parents also come for parent sessions that do not include the child or adult, to discuss issues that should not be discussed in front of the individual, to provide training and support to parents, etc. If a patient meets with me separately, what they say is confidential, but may be discussed with parents in very general terms, unless they are a danger to themselves or to others.

**What advice would you give a parent who is wrestling with a child's behavior problems?**

It is critical to be a good detective to determine what is causing the problem. Is the child experiencing sensory challenges? Is the child anxious or overwhelmed? What negative experiences has the child had in this setting? What is triggering the problematic behavior? How does it feel to be in this child's body in this moment? How can we understand, rather than try to control how they are feeling? Remember children do well if they can! Be curious about what is getting in their way and remove barriers to success. I would also recommend limiting total screen and electronics to no more than one hour per day. Be sure to spend lots of time one on one, with your child engaged in play. The more limits you need to set, the more time you need to spend engaged directly and reciprocally with your child.

**What advice do you have for attaching labels for those with dual diagnosis and the impact on services?**

In my experience it is important for an individual to be assigned all appropriate diagnoses for which they qualify, with the most relevant diagnosis being listed first. In general, an individual with a primary developmental disability should be treated via OPWDD and related systems. It's important that mental health diagnoses for people with developmental disabilities be given by mental health practitioners skilled in working with people with dual diagnoses, to reduce the likelihood of mis-diagnosis.

# Pathways to employment

"a spotlight on the Arc of Monroe's JobPath program"



## Article by Alison Cundy

The Arc of Monroe's Job Path service provides supported employment for more than 400 people with a wide variety of disabilities including people with intellectual or developmental disabilities (I/DD), Autism Spectrum Disorders, and learning disabilities. It is the largest employment program in the region.

Supported Employment is a great option for those looking for hands-on employment training. People supported through Job Path get one-one-one attention. Each person is paired with an Employment Specialist who works with them every step of their employment journey. They work on skills like resume writing, job hunting and interview preparation. The Employment Specialist is there to mentor, help each person understand their responsibilities, and help resolve any workplace issues.

Once employed, Job Path provides assistance through on-the-job check-ins, communication with on-site supervisors, and individualized job coaching to ensure job satisfaction and success. The Arc of Monroe's Job Path also provides Adult Project SEARCH® in collaboration with Strong Center for Developmental Disabilities and the Del Monte Hotel Group. This is a one-year program that includes three 10-12 week internships in various departments throughout the hotel group. People who complete the program frequently work outside the hospitality field for employers such as Wegmans or the University of Rochester.

People in the above services learn transferable, real world skills like working with money, communication, self-advocacy, punctuality, and interacting with people. In addition, supported employment teaches people how to overcome obstacles, boost confidence, and create and grow friendships.

The perfect candidate is someone over 21 who may or may not have completed employment readiness training, be eligible for ACCES-VR, and can work independently in the community. The ultimate goal of the service is competitive employment.

Job Path helps people find jobs; but more than that, we work to find jobs that match their interests and passions, so people are excited and proud of their work. Working with over 200 businesses in Monroe County, in a wide variety of industries, we are able to find the right job for each person. If you have a dream job we'll help you get there!

More information can be found at [arcmonroe.org](http://arcmonroe.org) or by calling Outreach and Enrollment at 585-672-2222.





# SAFE@ HOME



## Article by Molly Clifford

To be safe at home, there are two main themes. One is knowing how to prevent something bad from happening, and the second is to be able to respond appropriately if something does.

Here are a few ways to prevent something from going wrong. First, stay in the kitchen while using the stove. Be sure to keep anything that can burn away from the stovetop. If you must use a space heater, do not put things on or too near it, and unplug it when you leave your home. Keep your dryer vent clean. Limit the use of extension cords and do not use them for appliances – plug those directly into an outlet. Use flameless candles whenever possible. If you must use candles that burn, make sure to blow them out when you leave the room!

Should something actually go wrong, keep these things in mind:

- Make sure you have the right number of smoke and carbon monoxide detectors and that they are installed properly throughout your home.
- Check alarms regularly to make sure they work and that you can hear them.

- Develop an exit plan with your family or roommates and make sure you know how to get out no matter what room you are in or what time of day it is.
- Be sure you identify a meeting place so that you will know that everyone is out and safe.
- Use nightlights and keep your phone and a flashlight near your bed. This way you can get out as quickly and safely as possible before calling 911.

For more safety information or to learn about Community Health Strategies' "Safe at Home" assessment and training program, visit us at [www.communityhealthstrategies.com](http://www.communityhealthstrategies.com).

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# CORNELL BOUND

## Article by Conan Gillis

My name is Conan Gillis. Barely a year ago, I started my college journey at Cornell University. But my road, like that of many, was hardly an easy one. I was born with a rare congenital disorder called Larsen's Syndrome which affects my muscular-skeletal system and has left me unable to walk. I require 24/7 nursing care, and assistance with many activities such as showering, preparing meals, and transferring onto the toilet. I was baptized the day I was born for fear that I would not survive the night.

Despite the roadblocks of my disability, I was able to succeed and even thrive academically, thanks to the hard and selfless work of my parents and countless others who have helped me throughout my life. I owe much to them. In the middle of my senior year of high school, I logged on to my applicant profile for Cornell University, and saw a message that changed my life. I got in! I had always dreamt of going to an old, prestigious school, and now my dream was finally realized. I was going to the Ivy League.

Fast forward to today, and I am now starting my second year at Cornell. I have declared my major in Mathematics, and I have become deeply involved in several organizations on campus, such as the Cornell Union for Disability Awareness and the Varsity Fencing team (and club). My academic success has continued with a current GPA of 3.8, and I have explored every bit of campus, in order to take advantage of the veritable cornucopia of opportunities on offer to students. Most important to me are the friends I have made along the way. In CUDA and the fencing team, as well as in my classes and my dorm, I have met so many interesting and wonderful people, quite a number of whom, I think, will be my friends for a very long time to come.

It hasn't all been easy, however. Before I even sent in my deposit, we had met with Student Disability Services (SDS) about how life at Cornell would look for me. How would I be able to live in a dorm? Where would the nurses go when I was in class? What would my testing accommodations look like? How on earth was I going to get up and down those hills every day (believe me, Cornell is VERY hilly)? Fortunately, they were able to put many of my concerns (and my parents') at ease. Within a few months, they decided to renovate a dorm room with a ceiling lift so I could live on campus. My testing accommodations are handled quite efficiently through SDS, and Cornell offers a program called CULift, which uses wheelchair vans to drive people anywhere on campus. Within a year, I was even able to work a summer job on-campus without much accessibility difficulties. The only major difficulty SDS was unable to help with was nursing, however I have managed (with the immense help of both my parents) to overcome that final barrier as well, although it certainly is an ongoing struggle. Nevertheless, I am very grateful that I have this opportunity, and for the people who have helped me earn it.

As for other students, applying and going to college can be a very stressful experience. To them, I would offer these pieces of advice: never give up, and find the college that's right for you. In my experience people are happiest at the college that is the most suited to them. I am extremely happy at Cornell, however many others are not. If at all possible, I would counsel students to visit the campus beforehand and, setting aside all concerns of accessibility or academics, ask themselves, "do I think I could be happy here?" If so, then everything else will fall into place. For Cornell in particular, I would definitely recommend applying early decision, if Cornell is definitely your top choice.



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