



Linda LaCourse

A FAMILY TRADITION OF ADVOCACY

by Maryann B. Hunsberger

Fifty seven years ago when they learned that their new-born daughter had a developmental disability, Linda LaCourse's parents showed no hesitation.

"They will not take her away from us."

At that time that was an unusual and courageous stand to take.

LaCourse never lived in an institution. She watched her parents championing the rights of people with disabilities. And, as a result, she has spent her life doing the same.

“They advocated a lot for all people with disabilities, but I was their inspiration,” LaCourse says. “That taught me what advocacy was and what the rewards were.”

Seeking to walk the same trail her parents had blazed, the Fairlawn resident became active in New Jersey’s Self-Advocacy Project. She worked on the task force Governor Thomas Kean established for people with disabilities in the mid-1980s, working on the passage of the Americans with Disabilities Act (ADA), testifying before the US Senate, and attending two international People-First conferences where she gave workshops on limitations and abilities.

Because of her passion for advocacy, LaCourse was chosen to be the New Jersey Congressional Advocate in 2001. She trained for two weeks in Washington, DC to advocate for people with disabilities on the federal level.

“It was an intense two week training on Capitol Hill, but it was rewarding and fun. It’s a life-long appointment.”

LaCourse works with both houses of Congress, supporting federal legislation affecting adults and children with disabilities. She is now working to change the last presidential administration’s method of Social Security reform and seeking to increase funding and support for higher education in New Jersey. She is also working on the ADA Restoration Act and the Rehabilitation Act of 1973 to be sure they remain intact.

“Whenever federal funding is needed for disability projects for the state of New Jersey, we do our best to get what is needed.”

Since the Congressional Advocate must persuade the federal government to provide funding for state disability-related programs and advise the state on handling federal funding, LaCourse wanted to learn more about working on the state level. Therefore, she attended the NJ Council on Developmental Disabilities’ Partners

in Policymaking (PIP) Program from April until November of last year.

Despite her advocacy experience, LaCourse said, there is always more to learn.

“It (PIP) helped me learn even more about the federal government. It also helped me learn how state government has to work with the federal government.”

LaCourse discovered agencies, programs and advocacy services that she never knew were available in the New Jersey.

On Election Day, she put some of that knowledge into action when she and three friends found the voting site inaccessible for some people with disabilities.

“It (PIP) helped me learn even more about the federal government. It also helped me learn how state government has to work with the federal government.”

“I brought the materials from PIP with me in case there was any problem. So I had the number of the Public Advocate’s office with me. My roommate called the Public Advocate from her cell phone. They said to stay where we were. In ten minutes, people showed up from the County Sheriff’s office, the Board of Freeholders, the County Board of Elections and the voting machine office. They closed the polls and moved everything to the gymnasium, which is accessible. That’s going to be the permanent location now. Thank God I had the PIP materials with me.”

LaCourse is now working on a project called Banning Further Institutionalization of People

with Developmental Disabilities. She began working on it as part of her PIP training. She and Krystal Odell of Allies, Inc. have written a proposal to suggest to state legislators. The ban would create more community placements and would bar the state from using developmental centers for people who need residential services.

“Some people who were living with aging parents need emergency community placement due to their parents’ health or age. Other family members can’t take care of them. Since the state had no community placements available, they were placed in developmental centers against their families’ wishes. We don’t want to see this happen. These people’s families are very upset that they are in developmental centers. If someone’s family wants to keep them in the community, they should be able to stay.”

The proposed legislation would also decrease the population in the developmental centers.

“This will make the situation more comfortable for those who can’t live in the community, so they will get better care and treatment by the workers in the developmental centers. Right now, there are so many people in the centers that the workers and staff are overworked and overburdened. This ban will make the work conditions more desirable, as they will have a smaller population to work with. The state can take the money they used for institutions to create community placements.”

LaCourse gathered up-to-date data to show how this legislation would benefit people with disabilities. To obtain the data, she talked with various individuals in the developmental disability system of services. Some were former developmental center residents who now reside in the community. Others had been placed in institutions due to lack of community placements. Some had always lived in developmental centers and were on a waiting list for community placement.

LaCourse and Odell are working with Kenneth W. Ritchie, assistant commissioner for the Department of Human Services in charge of its Division of Developmental Disabilities (DDD) and with the

SWOT Team on reducing the numbers of people living in the state’s developmental centers.

“They (the SWOT Team) are a group of former developmental center residents who counsel people wanting to leave institutions,” said LaCourse. “Since they have left institutions, they can tell people what it’s like. They are doing an excellent job and we’d be lost without them.”

They have not yet met with resistance, but are anticipating that this will occur when they go to public hearings and talk to legislators.

“We expect the resistance to come from the public and from families who want their family members in institutions.

LaCourse and Odell will be meeting with their legislative representatives. Then, they will hold a conference for all state legislators. They also are putting together a training session for legislators on the importance of passing this legislation. “We will go to any public hearings or legislators’ committees on this matter. We’re hoping it will get a vote of approval in both Houses.”

LaCourse used her legislative education from PIP while putting this proposal together.

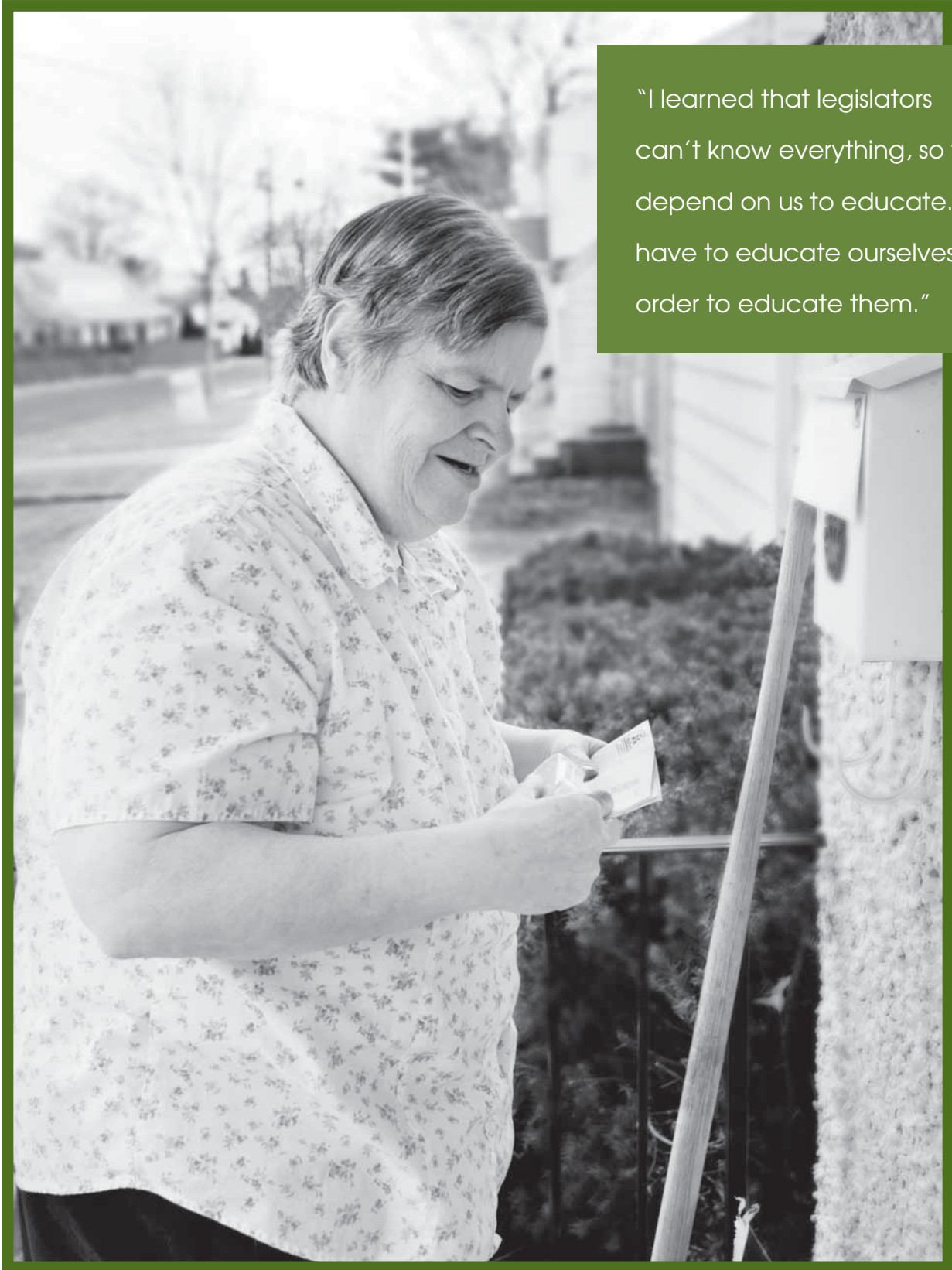
“When we wrote our own testimony for mock hearings at PIP, we did role playing where we pretended to meet with a legislator. One homework assignment was to write and phone our elected officials.

“I learned that legislators can’t know everything, so they depend on us to educate. We have to educate ourselves in order to educate them.”

LaCourse feels she was lucky to stay in the community after her mother died in 1998 and her father died in 2000. She stayed with her sister until June 2001 and then tried a supportive living apartment. Support staff tended to her needs 25 hours a week, but she lived alone. She found it too difficult, so she moved into a group home in 2003.

“I’ve been there five-and-a-half years. Four other women live there. I see my brothers and sisters frequently and I am very happy there,” she says.

“I’d like to see others given these choices instead of placing them in institutions against their families’ wishes. The ban will give them this opportunity.” **P&F**



"I learned that legislators can't know everything, so they depend on us to educate. We have to educate ourselves in order to educate them."

Stephanie Rosati-Pratico



It's Empowering

by Maryann B. Hunsberger

Recent Partners in Policymaking (PIP) graduate Stephanie Rosati-Pratico read about the Council's advocacy training program right here in the pages of "People & Families" magazine.

And now here she is with her story.

"I read about a self-advocate who participated in the course and thought it would be a good way to expand my knowledge base. What better way to learn about the New Jersey system than through a course like that?"

Rosati-Pratico already had experience with advocacy as the mother of two children, John, 15, and Sara, 10, Rosati, who both have Down syndrome.

"I've been an advocate since they were born. Parents of children with disabilities have no choice but to advocate. I've learned from my children's experiences how to help other families, so my advocacy has expanded over the years."

Last year—as she was full engaged in PIP's eight month, one weekend a month, training—Rosati-Pratico faced a challenge that would test her existing advocacy skills as well as the ones she was learning.

In September 2008, the family's health insurance carrier, Horizon Blue Cross and Blue Shield of New Jersey, announced that they were dropping Children's Hospital of Philadelphia (CHOP) from their network of providers as of April 2009.

Since Rosati-Pratico had Horizon's blue card plan, her family would be covered but only if they made the trip to Philadelphia. CHOP's New Jersey satellite doctor's offices would no longer be an option.

Even worse, Rosati-Pratico felt, individual members without the blue card plan could no longer obtain any medical care for their children from CHOP, not even in Philadelphia.

Rosati-Pratico knew how important CHOP was to her family. Her daughter Sara was born without an airway and spent her first six months at CHOP. She has sleep apnea, lung disease, reflux, asthma, chronic intestinal problems, an immune dysfunction and chronic ear infections.

Sara is tube fed. She receives intravenous immunoglobulins every four weeks at CHOP. She has also had a melanoma.

Rosati-Pratico's son John has bilateral hearing aids, reflux, asthma and muscle tightness in his legs which causes them to stay bent.

Both children are susceptible to infections and John recently developed pneumonia.

Twenty-six thousand children in New Jersey use CHOP's services through Horizon. Rosati-Pratico knew something had to be done. Too many vulnerable children depended on the help of the medical expertise at CHOP. It was time to mount a campaign and her experience at PIP provided her with right vehicle to focus those efforts.

During the fall sessions of PIP, participants prepare testimony to present before a mock legislative committee at the State House in Trenton. The committee includes legislators and other officials who volunteer their time to allow PIP participants to hone their skills in selecting important issues and making the case for action to address those issues.

"It was wonderful timing," said Rosati-Pratico, who worked with her group to present the issue of Horizon's decision to drop coverage. "These mock hearings were a great way to educate the five legislators who participated and as a way to help train us."

But for Rosati-Pratico that was just the beginning.

She also called other elected officials to let them know how important an issue this was for many of their constituents.

Since 1994, Rosati-Pratico has been a member of the Down Syndrome Association and has served on the board of directors for the ARC of Mercer County. She has belonged to the Children's Hospital's Family Advisory Council since 2005.

“I didn’t know what would happen to all of these children. Horizon said the children could access care at New Jersey hospitals, but these are the same hospitals that transferred our kids to CHOP in the first place. They had no idea how to handle their care. I tried to make the legislators understand that when you end up at CHOP, you need to be there.”

Rosati-Pratico also presented the issue to a panel of state agency directors.

“Many people hadn’t realized what a critical issue this was to the people of New Jersey. Since Horizon is one of the healthcare providers for state employees, this interested them. I told people that they may not have disabled children right now, but a healthy child can become disabled at any time and need CHOP’s services.”

Rosati-Pratico began pooling a network of people together to bring attention to the matter.

“I knew we had to publicize how monumental the effect of this change would be. I sent mass emails and rallied people.”

She contacted the Trenton Times, which ran a story about the effect the contract termination would have on families.

“That had an impact. So many people saw it, including other parents who have this insurance.”

If she hadn’t attended PIP, Rosati-Pratico said her advocacy efforts wouldn’t have been as effective. “PIP cut out a lot of wasted effort, since it taught me who to talk to and how to talk to them. My team partners gave me their perspective and worked on this with me. They all testified before the legislators about how detrimental this would be.”

The hard work paid off. On January 15, CHOP signed a contract extension through June 30, 2014 with Horizon Blue Cross Blue Shield of New Jersey.

Since 1994, Rosati-Pratico has been a member of the Down Syndrome Association and has served on the board of directors for the ARC of Mercer County. She has belonged to the Children’s Hospital’s Family Advisory Council since 2005.

One year ago, she joined the hospital’s Family Faculty. In that capacity, she teaches hospital employees about family-centered care from her

personal experience. She has been a state-wide Parent-to-Parent support person since 2006. She traveled to Washington, DC with Children’s Hospital in 2007 with her husband and her two children to advocate on Capitol Hill.

Rosati-Pratico and her family—her husband Michael and the two children—live in Hamilton. She graduated from the eight-weekend PIP course in November 2008 and says she never walked away from any presentation without gaining something.

“I walked away with a ton of knowledge and contacts for networking. PIP enhanced abilities that were already there and added new skills.”

She also learned to look at things from a new perspective.

“Listening to self-advocates talking about their feelings, issues, concerns and perspectives was immeasurable. I felt they put into words the things my children feel and experience. We laughed and cried and advocated and celebrated together. I struggled over seeing self-advocates who have no family. My children are my



John and Sara Rosati

first priority, but my advocacy work is not just about them.”

The knowledge she received at PIP made Rosati-Pratico feel confident enough to take on another project.

At PIP, she met Krystal Odell from Allies, Inc., who spoke about adults with developmental disabilities living in the community. Rosati-Pratico’s Aunt Cathy, 63, has lived at Vineland Developmental Center for 45 years.

“For a long time, I had wanted her in the community, since there are better options now. She only got to come home to peace and quiet four times a year, but I thought she should have that chance every day. PIP made me realize it was possible. My Aunt Adrienne and I are co-guardians and she agreed.”

She approached the developmental center and told them she wanted a community placement for her aunt.

“Brenda Brown from Vineland Developmental Center is wonderful. She helped my aunt transition into the community. State employees get a bad rap, but Brenda kept me up to date every step of the way.”

Her aunt made the move to the group home in January.

“My Aunt Cathy loves living in the community. She is as happy as can be. In Vineland, we couldn’t visit with her where she lived. We had to take her out to the park and then take her back the same day. Now, we can visit her at her own home and spend the day. This represents hope for my children because I believe the options will get better every year.”

Rosati-Pratico said her children enjoy visiting their great-aunt at her new home.

“The doctor said giving birth to two children with Down syndrome is as likely as being struck by lightning or hitting the lottery, but I realize how lucky I really am. My children have a unique and awesome relationship. They have two different personalities and are very close. Their strengths and weaknesses complement each other. She is bubbly and he is protective. Sara loves life. She does track and field in Special Olympics, plays basketball through the Hamilton YMCA and plays baseball for Miracle League of Mercer



County. She loves to dance and sing, watch High School Musical and listen to the Jonas Brothers and Hannah Montana. John plays basketball and track and field for Special Olympics, plays baseball with Miracle League and likes to lift weights. He’s a very physical kid.”

As for her PIP experiences?

“It energized me. I’d be frazzled and tired when I’d get there, but the weekend would always renew my strength and my fighting spirit. It would give me the power I needed to continue fighting the fight. We all rallied for each other. It’s a great team building experience. We were all brought together by disability, so nobody was divided by disability. It was really awesome.” **P&F**

HOW'S YOUR NEWS?



I don't know what your life's been like lately. But the odds are that you haven't been having nearly as much fun as the engaging, talented team of reporters with intellectual and developmental disabilities that contribute to *How's Your News?* (HYN).

Last year, they surfed the waves in Venice Beach in Los Angeles; covered the Grammy Awards; interviewed Jimmy Kimmel, Sarah Silverman, Ben Affleck and other celebrities; made cheese balls with Amy Sedaris; and performed at the SXSW music festival in Texas.

This winter, the 30-minute, weekly TV show aired for six weeks on MTV. It is the first show to

be hosted by people with intellectual disabilities on a major TV network.

The *How's Your News?* style is by turns lovable, rebellious and refreshing. The HYN reporters aren't "inspirational" in the traditional way that this term often is used to describe people with disabilities. They aren't wide-eyed innocents, endearing, or any other type.

The News team is simply a group of reporters, interviewing—in admittedly off-beat styles—famous entertainers and politicians, as well as ordinary people. The range of topics can be a bit all-over-the-place—sexuality, voting, sweat and whether marijuana should be legalized. But the



energy and candor is refreshing—for interviewees and audiences alike.

Jeremy Vest, 21, who has Williams syndrome, has been an avid drummer since age 13. He lives in Gaithersburg, Maryland. A graduate of Quince Oxford High School, Vest has been the drummer for the *How's Your News?* band since joining the news team in 2004.

Vest, confronting a musician who's just performed, asks: "Were you sweaty?"

Susan Harrington, 41, is legally blind and has a cognitive disability. She lives in assisted living in Massachusetts. Harrington works as a receptionist, manning a 16-phone line for the state Department

of Mental Retardation, and has an avid interest in politics and an operatic singing voice.

She's not shy about expressing her editorial opinion in the middle of a man-on-the-street interview championing the benefits of marijuana for people with some illnesses.

"Medical marijuana, my foot!" she says in the middle of one interview.

Yet, the tone of *How's Your News?* isn't overly opinionated.

In one scene the *HYN* team is surprised and delighted when musician and "Full House" star John Stamos hitchhikes a ride on their traveling tour bus.

Vest and Stamos, who had met previously, are buddies.

“You and I will hang out one night,” Stamos says to Vest. “And we’ll chase girls. I’ll be your wingman.”

Arthur Bradford, director of HYN, calls the team’s MTV show a “docu-comedy.” Bradford helped the show come into being with co-producers Matt Stone and Trey Parker of South Park.

The shows cover a broad range of moods.

Reporter Bobby Bird, 51, has Down syndrome and his speech is impaired. At times he struggles to make himself understood, but perseveres. He understands more than “he’s able to tell,” his sister says, as he interviews her for one segment.

Using the quick cuts that MTV is known for, the next segment finds Harrington on her way to go surfing for the first time, looking a little goofy all suited up.

“I feel like a bleached wail,” she says, laughing.

The *How’s Your News?* team is made up of seven reporters, who receive support from their close-knit families and crew. HYN began 10 years ago at a summer camp for people with disabilities in Massachusetts.

Bradford discovered through teaching video classes that the campers both enjoyed and were skilled at making news videos. Video tapes of their man-on-the-street interviews circulated among Bradford’s family and friends.

Eventually, Parker and Stone, before they made the big time with “South Park,” saw the videos. They liked what they saw, and after “South Park” became a huge hit, provided some funding.

In 2002, a road-trip movie was released, which won several film festival awards and has been shown on HBO, PBS and on Channel Four England. In 2004, HYN released a half-hour documentary about their trips to the Republican and Democratic conventions. In 2007, they got the go-ahead to make the MTV show. Episodes of the MTV show are available on www.howsyournews.mtv.com.

For more information about *How’s Your News?*, go to www.howsyournews.com.

Tom Shales, “The Washington Post” TV critic, praised *How’s Your News?*. “MTV’s new ‘*How’s Your News?*’ show can be seen not as exploitation of people who have mental disabilities,” Shales wrote, “but rather as the expression of a subculture that has much to contribute to the mainstream but never had much of an opportunity.”

In January, a few weeks before the group’s MTV show aired, I interviewed Bradford by e-mail and HYN reporter Jeremy Vest by telephone.

Following are excerpts from the interviews.

KW: *Why did you decide to make videos of news?*

AB: When we first began making these videos the goal was to find a format in which everyone, regardless of their level of disability, could participate. Producing a news show turned out to be a great format. It allowed us to play around with something in which everyone was familiar.

At first we began interviewing each other. Then we did reports about the goings on at the camp. Really, anything can be considered news if you teach it as such. The big step was when we decided to go downtown and interview people on the street. That’s when we started making videos which had a wider appeal.

KW: *Do you have a disability?*

AB: That’s an interesting question because many people would say that everyone has some kind of disability. But, in the traditional sense of the word, no, I do not have any severe disability. I have dyslexia and poor organizational skills, those are my strongest disabilities.

KW: *Do people without disabilities assist your reporters?*

AB: Yes, we have a very dedicated crew who travel with us whenever we go anywhere. This is a group of people who have known the reporters and their families for many years. Each reporter usually has a “counselor” (a term left over from the summer camp days) who helps him/her keep



their stuff organized, get dressed, take meds, etc. We help support each other emotionally and talk over the challenges facing the crew before and after each day of shooting.

We go over the questions we'd like to ask the people we are planning to interview. It's very important that the questions originate from the reporters and don't appear canned.

KW: *On your website, you say that some people find it offensive to hear about HYN. Why?*

AB: I think the concern is that HYN is a humorous show. Often people think that there is nothing funny about life with a disability. This is a major misconception. Humor is essential. I think too, that people worry that the reporters are somehow being taken advantage of, that they may be unaware of how they are being portrayed in the show.

I see where this concern comes from. But, I want to assure everyone that this is a project built on many years of close friendship and trust. All of the reporters, and their families, are very aware, and proud, of their roles on the show.

KW: *How do interview subjects react to being interviewed by HYN reporters?*

AB: Most people are very friendly and let down their guard to a refreshing degree. Every so often we encounter someone who is very uncomfortable and won't really look our reporter in the eye. This can reveal a lot about that person's character. We rarely include interviews that have a negative vibe though. They just aren't enjoyable to watch.

KW: *How do you chose which stories to cover, and how do you assign stories?*

AB: We try to assign stories based on the reporter's interest. We can't really force them to be interested in subjects which they have no feelings about. Because we've all known each other for such a long time we have a good sense of what might make a good HYN story.

KW: *Do you think HYN improves media depictions of people with intellectual disabilities?*

AB: Yes. Too often people with disabilities are only seen in the media in a certain, well, sappy light. The "heart warming" stories are nice, but

they are kind of getting old, and sometimes they encourage us to simply feel sorry for people with disabilities. My experience has been that they don't want our pity. Hopefully, HYN gives a fuller picture, one with humor, awkwardness, rebelliousness, etc.

She also talked with Jeremy Vest.

KW: *Were you scared to interview people? Did you like doing that right away?*

JV: I just thought, what if I interviewed people. Would they accept me for who I am? Would they like my interviews? Would they be Okay talking to me? Sometimes people weren't. But thank God.

KW: *People were generally cool?*

JV: Oh yeah! Oh yeah!

KW: *Who did you like interviewing the best?*

JV: John Stamos.

KW: *Were you surprised when he hitchhiked on to your bus?*

JV: I was very surprised! I didn't know he was going to be hitchhiking!

KW: *How did you decide what to ask people?*

JV: I don't know. I think we thought of the questions, wrote them down, and then we said what we thought would be the best questions to ask. Such as, 'Who are you going to vote for in the presidential election?'

KW: *You play the drums?*

JV: Yes. It's a lot of fun!

KW: *HYN has a band?*

JV: We do! I've performed with the band at a festival in Texas. We played our hearts out for a lot of people!

KW: *How did people react to HYN at the political conventions in 2004?*

JV: There's one scene where Bobby Bird, another HYN reporter, talks. You know how he talks. Bird's speech is difficult to understand. He does this interview with this guy. And the guy looks really disgusted. He doesn't want to be there. It's rude to be laughing at somebody we like. But what are you going to do?

KW: *Are you going to be doing more shows?*

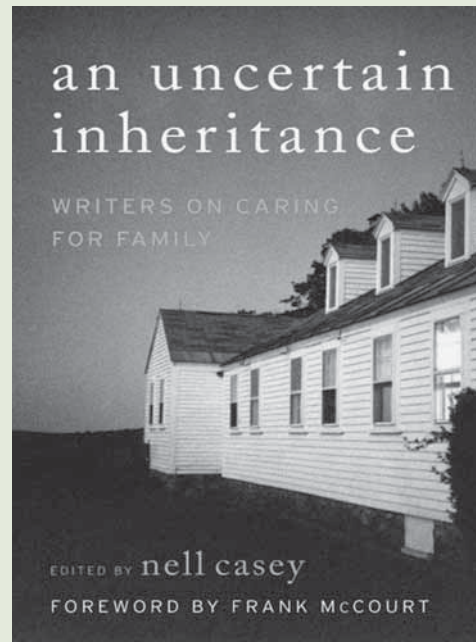
JV: Oh my God! If I get to do more shows, I would be so excited. **P&F**

Book Review

*“An Uncertain Inheritance:
Writers on Caring for Family.”*

Edited by Nell Casey. Harper Perennial.

Paperback. \$14.99. 304 Pages



Disability rights advocates often talk about autonomy, the independent living movement and self-advocacy. Yet, the frequently unspoken secret is that many of us need some form of care-giving. Some of us need round-the-clock personal care assistants. Others require periodic (say, a few hours a week or an hour a day) help with things like dressing, reading or, maybe a job coach.

Whatever the amount, care-giving—obtaining and accepting help—is a part of independent living; and though most people would rather not depend on (or burden) loved ones, most caregivers are family members.

In “An Uncertain Inheritance: Writers on Caring for Family,” edited by Nell Casey, released in paperback at the end of last year, a wide variety of writers offer up an illuminating collection of essays on care-giving. The essayists write

poignantly, angrily, and, occasionally humorously (the humor grows out of their sadness) about caring for family members (parents, children and spouses) with illnesses and disabilities ranging from multiple sclerosis to cancer to depression to autism.

Despite the fact that care-giving, and being cared for, will at some point be a part of nearly all of our lives, the topic is largely off the radar screen.

“Seeing a family member through a health crisis is an experience that nearly everyone must face—even if it’s only to make arrangements for someone else to do it,” Casey writes in the introduction. “Yet care-giving, as a rite of passage, is only just beginning to enter our cultural and literary consciousness.”

Diseases may either end in death, go into remission or become cured. Yet many illnesses and disabilities are long-lasting or life-long.

Care-giving sometimes entails helping a family member through a time-limited health crisis, such as an acute episode of depression. In other situations—say, a parent of a child with autism, or a spouse with a spinal cord injury—it can mean being a care-giver for the rest of your or your family member's life.

Our culture—particularly, in movies and TV shows (where family members are frequently portrayed as constantly loving and selfless)—romanticizes both people with disabilities and caregivers.

“An Uncertain Inheritance” dispenses with this. The writers in this collection (which includes both caregivers and people who need care-giving) have a refreshingly down-to-earth perspective.

In the essay “Death in Slow Motion,” Eleanor Cooney writes about the frustration, misery and anger she feels as she cares for her once loving and charming 75-year-old mother, who has Alzheimer's.

“I felt hard and mean and full of sorrow all at once, and it drove me truly mad,” Cooney recalls. “Drove me, in fact, to drink.

When she came to the end of her rope, Cooney moved her mother into an assisted living center. Then, she was told that her mother was too “high maintenance” for the facility to cope with.

“What would you do?” Cooney asked, “I'm still waiting for the answer.”

Though the disability community rightly prefers having people live in the community whenever possible, sometimes living in an institution such as a nursing home is the best alternative. Ann Harleman writes about what it was like to be the caregiver for her husband Bruce as his multiple sclerosis progressed.

Ann found that their relationship deteriorated when she provided the care-giving for her spouse. Bruce became angry, and, at times, unloving towards her. They got along better, after she decided, after much soul-searching, to place Bruce in a non-profit nursing home.

“I'm no longer his physical caregiver,” Ann Harleman writes, “I'm no longer implicated in his illness. Because our bodies don't connect, our hearts can.”

Scot Sea's piece “Planet Autism” is a searing take on what it's like for him and his wife to care 24/7 for their teenage daughter with autism. Care-giving for the Seas is described as a living hell. Their child throws things—like glass against walls)—doesn't use the toilet or know how to dress herself.

The media may “mythologize” characters like Rainman, Sea says, but this has no relation to the reality of life of most families of people with autism.

“Celestial metaphors do little to temper the exhaustion you struggle with as your daughter, still going strong at 3:30 a.m., cranks out her version of the diagnostic handbook for developmental disabilities greatest hits,” Sea writes, as he recounts how his youngster stays up all night endlessly playing the same “Sesame Street” video—repeatedly clutching objects from a hairbrush to a coaster, dropping them—then picking them up again.

Receiving care or assistance can be as difficult as being a caregiver.

“One of the most trying aspects of being sick is being cared for—as counterintuitive and thankless as that may sound,” writes Amanda Fortini, who was ill for many months. “Nothing makes a person feel out of control—and illness is by definition a loss of control—like having to cede it to another person.”

I wish “An Uncertain Inheritance” had more of a disability rights or disability culture consciousness. By that I mean, I kept looking for more pieces by authors such as the late Harriet McBryde Johnson and her ilk. Johnson, and others with severe disabilities, have written (see books such as Johnson's memoir “Too Late to Die Young”) from a somewhat different perspective than the writers of this volume. Johnson, for example, needed a good deal of assistance—in everything from eating to dressing. Yet, she, not her caregivers, managed her care.

But, of course, some of us (such as Sea's daughter or Cooney's mother) aren't capable of managing our care. So this isn't a major quibble.

“An Uncertain Inheritance” is a must read for anyone who has or will be either a caregiver or in need of care. Which is all of us. **P&F**



Bernard Krakowsky