

THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF JOURNALISM

A LIFE

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SPRING 2019

A thesis
submitted in partial fulfillment
of the requirements
for a baccalaureate degree
in Journalism
with honors in Journalism

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ABSTRACT

This entire journalistic project including videos, audios and pictures could be found on <http://commmedia.psu.edu/news/preview-story/a-life1>

In the 2016-2017 school year 24,819 students left of special education programs in Pennsylvania public schools. More than half of them graduated with a high school diploma and 2,284 went to college or trade schools. (Special Education Statistical Summary 2016-2017)

In today's economy it's difficult for students with a bachelor's degree to find jobs and make a basic living. For special education students who are unable to graduate from high school with a diploma, the barriers to success are much greater. They may never be able to secure a minimum wage job or live independently.

What is the best way to help these people?

In this project we will follow two families with special needs children who have aged out of public schools or face the prospect of aging out in the near future.

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ACKNOWLEDGEMENTS

I would like to thank all of my subjects for their participation in this multimedia piece who supported my work in many ways and helped me get the material with high quality. I am so grateful to everyone for their patience and support in overcoming numerous obstacles I have been facing through my research.

More than that, I would like to thank my thesis supervisor Curt Chandler and my honor advisor Ford Risley who offered me tremendous advice and help throughout the whole project. Special thanks to Curt Chandler for supervising my project during my entire senior year.

Chapter 1

Everything Begins

Kimberly Capenos is raising her daughters by herself. All three have been diagnosed with different levels of autism. The oldest daughter, Marabeth Capenos-Stiffler, 25, has Level 2 [link] autism spectrum disorder (ASD). Her youngest daughter Kashmir Paige Capenos-Paolucci, 15, and middle daughter Lavender Capenos-Paolucci, 17, have Level 1 [link] ASD. Each of the girls eats, sleeps and lives on their unique schedule. As a result, Capenos says she gets about four hours of sleep a night. She says she depends on outside support to make her family function.

People with autism experience life differently. They may be much more sensitive to subtle changes in sound, light and texture. For example, Capenos says few people understand why her daughters won't sleep on sheets. They do not like the way wrinkles in the sheets feel on their skin. All three girls prefer to sleep on a bare mattress, without sheets. They have similar objections to switching from long sleeves to short sleeves and back again when the weather changes every year. Marabeth has struggled the most. Capenos said it took her a couple of months to wearing a bra when she became a teenager.

Dealing with the girls acting out in public can be a particular challenge. Every time Capenos brings her daughters to the restaurant, they draw stares if one of the girls does something unusual. She said that one time when the family went out to eat, Kashmir Paige reacted to the new environment by wiggling her fingers in front of her face and screaming.

Another diner began complaining about the situation while Campenos tried to calm her daughter down.

After many experiences like that, Campenos says she has started carrying Autism 101 cards that explain what autism is and the actions autistic kids may have in the public. The family still goes out for dinner, just not a lot. According to the mom, they usually prefer to order takeout food and eat at home.

Although she was married to the fathers of the three girls, the men moved out when the girls were still young. Campenos says life is easier, when she only has to deal with the girls, because their fathers offered mostly complaints and little help.

Chapter 2

Plunging off a cliff at 21

Public schools provide special education support services and a therapist for autistic children like Campenos' daughters. Those benefits disappear when a disabled person becomes a legal adult. So, home life got even more complicated when her oldest daughter, Marabeth Campenos-Stiffler, turned 21 and aged out of the public-school system.

In Marabeth's case, autism is just one of her physical challenges. She is diabetic, and it's been much more difficult to control her condition without the support services from the school. She's also lost her social network, because she isn't able to interact with her peers at school. Her mom says she's bored. This has resulted in erratic behavior, including temper tantrums and a hunger strike.

Chapter 3

Future Plans

At this point, Marabeth isn't able to live on her own like other people her age. She is unwilling to live away from her family in a group home. Campenos says Marabeth's doctor has told her that because she is Level 2 ASD, Marabeth will probably never gain total independence, which will require guardianship for the rest of her entire life. She needs a structured schedule that includes taking at least five insulin shots a day. This breaks up the day so much for Marabeth that she needs the company of her mother and sisters to fill the gaps.

Campenos says that Marabeth can do things that are organized and repeatable, but she doesn't understand the logic behind it. Sometime Marabeth prepares meals for the family. Her sisters compliment her cooking all the time.

One of Marabeth's biggest challenges is understanding cause and effect. Campenos says her daughter doesn't fully comprehend the relationship between being tired and sleeping; or eating and drinking to bathroom functions. She says her daughter also has difficulty being social. Marabeth never makes phone calls and most of her conversations end in two sentences.

Marabeth has had a boyfriend, however. Campenos said a schoolmate who also has autism fell in love with Marabeth during high school. His parents were wealthier than the Campenos family and it would have been possible for them to support their son and Marabeth if they chose to live independently. The relationship did not end pleasantly as the boy's parents felt that he needed to find more capable partner and forced them to break up. Even not for a romantic relationship, Campenos said it is still nice to actual have a friend to talk to her daughter.

Since she is reluctant to live in a group setting and may never get married, it falls on the family to provide for Marabeth's long term care. Her sisters have promised they will become her guardians once they reach legal age, but their mom still worries. This is a life-long promise that will restrict the younger sisters' lives.

Marabeth has worked as often as three times a week as a music teacher, but lost support for doing the classes after she turned 21. Since then her mother has occasionally helped her to conduct classes, but doesn't have the time to help Marabeth to work regularly. Her sisters Kashmir Paige and Lavender plan to travel from Tyrone to study at Penn State Altoona. Although they are beginning to explore a wider world, if they commit to caring for Marabeth, they must stay in Pennsylvania. Marabeth's government support funding is state-based. If she moves outside of Pennsylvania she will have to start applying for support again, without knowing whether she will have the same benefits or when they will begin.

Chapter 4

Possibility

Jackie, 20, was born with Down's syndrome. Like Marabeth, when Jackie turns 21 it will dramatically change her support system.

To help make the transition, Jackie participates in the Lifelink PSU program operated by State College Area School District and Penn State University. Lifelink PSU helps special needs students in the school district who are over 18 years old but under 21 to gain more living and social skills in the university environment with their same age group. The goal is to help the students function in the least restrictive environment possible.

Jackie's father is a professor in Penn state 's Smeal Business College. He says he still has concerns about who is going to take care of Jackie after she turns 21, where she will be able to get financial support and how to make that financial support sustainable.

Chapter 5

Carry on

In programs like Lifelink students are taught to live as independently as possible. They are trained in how to use the public transportation system so they can go out to work. After learning these skills, as adults they should be able to do simple tasks, like folding boxes, shredding paper or packing mail inserts. But most of time, these jobs don't produce enough income for a person to live independently.

Since 1986, the Fair Labor Standards Act allows employer to pay sub-minimum wage to any worker with a physical or mental disability that affects the amount and/or quality of their work. In another words, the pay of a disabled worker may be prorated to reflect their productivity. This means they may earn much less than minimum wage (which is \$7.25/hour in Pennsylvania, the Federal minimum). This act was trying to make disabled employees more attractive to employers. According to Public Source, a non-profit news organization based in Pittsburgh, about 13,000 disabled Pennsylvanians are earning an average of \$2.40 an hour in a legal use of subminimum wages, a third of the federal minimum hourly wage. If the goal is to help disabled adults to live independently, and able-bodied workers struggle to get by on minimum wage, the Public Source investigation showed that paying them a subminimum amount makes it virtually impossible.

Even with incentives like reduced wages and targeted tax incentives, State College Area High School Transition Coordinator Lydia Everhart says it's very difficult to convince employers to hire disabled employees.

As disabled children become adults, the inability to earn a living wage, combined with the elimination of financial support at age 21, makes it especially difficult for them to live independently. In Marabeth's case, her mother says she has filled out more than 15 different forms to apply for supplemental funding, which is a never-ending process. Campenos says she worries about the future because her daughter will never be able to file those documents herself.

Chapter 6

The Long Run

Kimberly Capenos knows she will not be around forever to care for her daughters. She suspects that Kashmir Paige and Lavender may have second thoughts about caring for their older sister after they graduate from college. A wealthier family might be able to set up a trust fund. For middle class households, a more likely outcome may be for Marabeth to transition from family life into an institution, an outcome Campenos dreads, but may not be able to avoid.

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Pennsylvania State University **University Park, PA**

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EXPERIENCE

Vanguard Inc.

Strategic Service Intern (College to Corporate Finance)

Greater Philadelphia Area, PA

May 2018 - August 2018

- Set up threshold for return and refund to improve efficiency of accounting year-end close
- Measured and analyzed various aspects of journal entries to enable team problem solving
- Participated and reported on bi-weekly project update to stakeholders
- Assisted in drafting internal communications and survey related to process improvement of accounting monthly close

The Daily Collegian

Business Operation representative

State College, PA

September 2017-May 2018

- Communicated with local and national clients to provide advertising strategies for the paper to increase revenue
- Processed incoming payments and associated client issue resolution

Pennsylvania State University

Orientation Leader

Abington, PA

March 2017 - August 2017

- Implemented orientation programs for new and transfer students, as well as parents
- Arranged guided tours for over 500 students and participate in bi-weekly faculty group meetings
- Offered academic advising to over 200 first year students under professional adviser supervision

Peer Assistant

August 2016 - December 2016

- Presented weekly workshops focusing on study skills for more than 50 first year students
- Proposed new approach to incrementally assess writing assignments to address freshman writing challenges difficulties
- Instructed 12 students on advanced academic planning and registration for upcoming semesters

CollegeDaily.cn

Managing Editor

Beijing, China

February 2014 - October 2016

- Responsible for weekly content that achieved Top 2 amount of visitor week over week
- Managed and edited 14 team members' weekly columns, and facilitated team bi-weekly meetings
- Created marketing strategies for MasterCard China and IELTS to increase brand awareness

China Construction Bank

Global Business Department Intern

Fuzhou, China

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- Connected the local companies with foreign financial groups to facilitate the steady cash flow
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Abington Jazz Ensemble

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Children's Hospital of Philadelphia

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