



I Love My Life: Journey to Independence

By Rachel Nicole Mast





Who I Am...

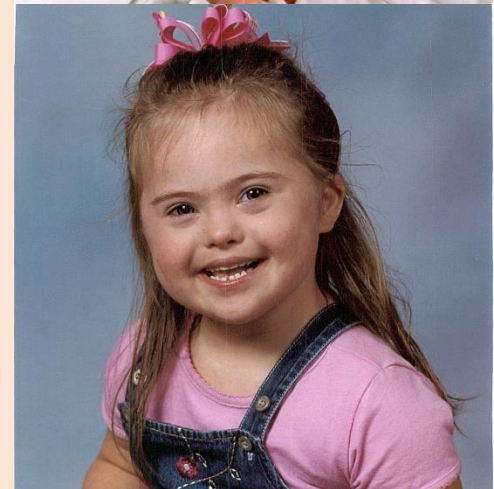
- I am Rachel Nicole Mast.
- I am 24 years old.
- I love to tell people about my life, my hopes and my dreams.
- I am a self-advocate
- I am proud to be a voice for others with Down syndrome and different abilities.

Independence Starts Early

When I was born in Memphis, Tennessee, people told my parents all kinds of things I would not be able to do.

- My parents did not listen to them.
- I went to:
 - The same activities as my friends
 - The same school as my friends
 - I went to all of my IEP meetings. I didn't stay for long because I did not like to miss class.
 - My parents wanted to be sure that plans were about me and what I wanted
 - The same classes as my friends
 - The same church activities as my friends

Mom
Thought



Just Like You

- When I was 13, I was cast in the “Just Like You – Down Syndrome” video.
- This is my friend Savanna. She was in the video with me.
- If you watch the video, you will see that I am Just Like You!
- That’s when my parents helped me make a Power Point to use in my speeches.
- I wanted to name it “I Love My Life.”
- I wanted people to know I have a great life.
- I have shared in 14 states and with lots of people.
- I also presented the Power Point at my IEP meetings and included all my hopes and dreams.



Mom Thought

I am a Self-advocate

- There is a silly law that won't let people with disabilities save money. So, I started going to Washington DC to tell my elected officials why that needed to change.
- I told Congressman Yoder, Senator Moran, and Senator Roberts my story.
- Guess what? They told their friends, and they passed the ABLE Act.



I am a Self-advocate



- Then, I spoke to the Kansas legislature, and they liked what I said.
- They passed the Kansas ABLER Act.
- I opened the 1st Kansas ABLER Savings Account.
- Now, I can save some money for my dreams, for my pink house.
- I try to save half of the money I make at my jobs in my ABLER account.

The Achieving a Better Life Experience (ABLE) Act allows people with disabilities to save money in a 529 type accounts without losing their means tested government benefits. There are rules and limits to govern these accounts that allow individuals with disabilities to save money above the \$2,000 Social Security asset limit.

A Diploma like my Friends

I graduated from Olathe South High School on May 20, 2018.

I received a diploma just like my friends.

People also gave money to my ABLA Account for my graduation gifts



Mom Thought

You are Hired!

- After high school and before I started college, I got my first job as a hostess at Olive Garden.
- I went through the same process as everyone else to get my job.
- Then, I worked when I was home in the summer and holidays.
- I put money in my ABLÉ Account and saved spending money for college.

Mom Thought





I am a College Girl

- Since I was a little girl, I dreamed of going to college like my parents and my friends.
- I started the Missouri State Bear POWER program in January 2019.
- I was in the first Bear POWER Class.
- We lived in suites in a dorm called Hutchens House.



I loved being a college girl.

- I really liked my classes and making new friends.
- I loved to stay up late and watch Netflix and YouTube and eat snacks.
- I love the eating in the cafeteria and socializing with friends.
- I worked on becoming an independent woman.

Rachel's Thoughts



Mom Thought

- I had roommate challenges and had to move into a room and live by myself one semester.
- It was hard to stay organized and understand my syllabus. I had some help from my ambassadors.
- I cannot drive. Sometimes it was hard to find someone to take me to do things especially on weekends.
- Some weekends I was kind of lonely.
- It was really hard to watch what I eat because I could eat whatever I wanted and as much as I wanted in the cafeteria. The pasta and desserts were really good.
- I have never liked for people to help me. I did learn to be better at asking for help when I felt overwhelmed.

Rachel in the Workplace

- After three semesters of college, Covid hit.
 - I came home and did not return to college.
- Then, I did an internship program called Project Search.
- My jobs there were:
 - Hospital Dining Services
 - Embassy Suites Houseman
 - Price Chopper Courtesy Clerk
- I have had four jobs
 - Olive Garden hostess, three years
 - Sporting KC ticket taker, six month
 - HyVee Courtesy Clerk, four months



Patient Greeter University of Kansas Health System



Now, I am a patient greeter at the University of Kansas Health Center.

- I did an online interview.
- Then, I did an in-person interview.
- Then, I applied for my position on the portal just like other people.
- I do not have a job coach. I am part of the team. My mom works with the manager on some of my paperwork .

What do I do?

- I greet people at the front door
- Help transport people to rooms
- Assist with sanitizing/cleaning areas near the front

I LOVE MY JOB!

About my work:

- I have worked there for 18 months.
- I get paid time off and holidays.
- I work 24 hours per week.

What I love:

- I love being part of a team.
- I love meeting people.
- I love greeting people with my smile.
- I love eating in the cafeteria
- I love being independent.
- I love being able to save money in my ABLE Account.

Challenges:

- It is hard to be on my feet all day.
- It gets hot going in and out in the summer.
- It is harder to watch what I eat in the cafeteria.
- Transportation



Mom Thought

Journey to Independence

- Person Centered Planning
- Circle of Support
- Allow to make own decisions and mistakes
- Don't over prompt
- Everyone has different strengths, abilities and needs different supports
- Seek to provide the minimum supports that will pave the path to the most independence



Journey to Independence

- Kansas Medicaid Home and Community Based Waiver Services
 - Home and Community Based Waiver (HCBS) differs in every state.
 - Most states have a waitlist
- Supplemental Security Income – DS automatically qualify at 18
 - Apply
 - Take needed documents
 - Keep assets under \$2,000
 - Keep updated on reporting
- Rachel has worked enough to get Social Security Disability Insurance which is good because the asset limit does not apply, and she has now qualified for Medicare.
 - SGA limit on amount of money you can make;
 - Also, limits may apply to state waiver and Medicaid
- Because of the amount of money she makes, she will soon be transitioning to a program called Working Healthy



Journey to Independence

Housing

- Limited options
- Group homes (not really what we want) all have waiting lists.
- She could have supports in an apartment of her own if we could find a safe one she could afford. Biggest challenge is actually transportation would be an even bigger issues with this.
- Section 8 Housing
- There are a few more options in our community that aren't options just yet.
- We don't have a local residential type place and that is not our top choice. Often, these are private pay and very expensive.
- Sometimes do not meet criteria for HCBS services because they are segregated.
- We continue to save, learn about options, and work with our Case Manager to find affordable, accessible, housing



Rachel's Thoughts



- I have the same kinds of hopes and dreams as everyone else.
- I want to do the same things that other people do and be included with friends in
 - Church
 - Community
 - Jobs
- Sometimes, I need different help though.
- For example, I can't drive. It is hard to always have to ask for a ride.
- It is nice when people just offer.
- Money and time are hard for me, so I need people who love and care about me to help me with that.
- There are other people in our community who want to be included and treated like everyone else, too.



I am Rachel

- I have Down syndrome.
- But, I am not called Down syndrome.
- I am Rachel.
- And I REALLY love my life.

Contact info

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Resources

- ABLE National Resource Center - <https://www.ablenrc.org/>
- NDSC Guardianship Position Paper chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.ndsccenter.org/wp-content/uploads/NDSC-Policy-Position-on-Guardianship-for-Individuals-with-Disabilities_Final.pdf
- College
 - Think College - <https://thinkcollege.net/>
 - Ruby's Rainbow - <https://rubysrainbow.org/>
 - Vocational Rehab - <https://www2.ed.gov/about/offices/list/osers/rsa/index.html>
- Medicaid Waiver <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>
- Health Insurance Premium Payment Program - <chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.dol.gov/sites/dolgov/files/ebsa/laws-and-regulations/laws/chipra/model-notice.pdf>
- Supported Decision-Making - <https://supporteddecisionmaking.org/>
- <https://acl.gov/programs/consumer-control/supported-decision-making-program>
- Working Healthy – Kansas <https://kancare.ks.gov/consumers/working-healthy/wh-details>

NDAC Graphic with QR Code



The National Down Syndrome Advocacy Coalition (NDAC) is the National Down Syndrome Congress' (NDSC) grassroots advocacy program designed to educate individuals with Down syndrome, their family members, and other allies about policy issues and give them the advocacy tools and techniques they need to effectively engage with lawmakers, agencies, and other key decision makers to advocate for policy change.

NDAC works to involve and engage more advocates, including individuals with Down syndrome, their family members, and other allies who support our Down syndrome community. If you or someone you know wants to impact change for individuals with Down syndrome, NDAC is for you!

NDAC membership grants access to:

- Quarterly webinars, resources, and information
- Private Facebook group
- Networking opportunities and more!



Ready to Join or Learn More?

Scan the QR code or visit www.ndscenter.org/political-advocacy/national-down-syndrome-advocacy-coalition for the NDAC FAQ and online application.



Action Alerts

<https://www.ndscenter.org/political-advocacy/take-action-stay-informed/>

Congressional Public Policy Agenda

National Down Syndrome Congress
**Congressional Public Policy
Agenda for the 118th Congress
(2023-2025)**

QR code links to
our Congressional
Agenda!

