How to Support Individuals with Down Syndrome to Start Their Own Business: Turning Self-Employment Dreams into Reality

12.5.2024



NDSS Mission

NDSS empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions.



NDSS Core Programs

NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming:

- Resources & Support
- Advocacy & Policy
- Community Engagement



NDSS Core Programs

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving and more



ndss. Down Syndrome Regression Disorder

Down Syndrome Regression Disorder

Down syndrome regression disorder (DSRD) also referred to as regression, is a rare but stroload siloard that occurs in some adolecents and young adults with Nown syndrome. Regression is used to describe the loss of skills an individual has previously learned. These skills can be daily living, language, movement, or social skills. The loss is often sudden and occurs over a period of weeks to months. Since DSRD may be caused by a variety of factors, the first priority is to determine the most likely cause. Individuals who are younger than 10 years or older than 50 years are very rarely diagnosed with DSRD. If these individuals we experiencing regression like symptoms, a close look at all other factors must be taken before giving the diagnosis of DSRD.

In 2022, a group of medical experts with experience treating regression in patients with Down syndrome gathered to create the first criteria for diagnosing DSBD. These criteria provide guidance to physicians and families who do not have access to specialists in DSRD. There are eight clusters of symptoms linked to regression, and some are broken down into specific examples. Individuals who are experiencing four or more of the eight symptom clusters are considered 'possible' cases of DSRD, meaning further investigation is needed. Individuals who have seven or eight of the eight symptom clusters are considered 'probable' cases, meaning they are likely to receive a diagnosis of DSRD If no other cause can be found.

Testing

If you or your loved one are experiencing symptoms in the checklist (see page 3). It is recommended that you make an appointment with your primary care doctor or neurologist as soon as possible. The diagnosis of DSR0 is mostly based on symptoms, but your doctor may order some of the following medical tests as part of the evaluation.

- Blood work
- Urine tests (if necessary)
- Lumbar puncture (also known as a spinal tap)
 Electroencephalogram (EEG)
- Genetic or metabolic testing (if necessary)
- Polysomnogram (sleep study)

For more detailed testing recommendations, you and your doctor can read the Assessment and Diagnosis of Regression in Down Syndrome (Santoro et al., Front Neurol, 2022). https://www.frontiersin.org/articles/10/3389/fneur.2022.940175/full





Entrepreneurship Guide



national down syndrome society **INCLOSE** .









The NDSS Entrepreneurship Guide is designed to help individuals with Down syndrome and their families learn more about entrepreneurship as a pathway to employment and what it takes to start a business.

This resource was developed in partnership with:





NDSS Holiday Gift Guide



Looking for the perfect gift this holiday season? Check out our Holiday Gift Guide!

Take our quiz to discover unique products from businesses owned and operated by individuals with Down syndrome and find the perfect presents for everyone on your list!

Shop with purpose this season—spread joy and make a difference!

Visit: <u>https://ndss.org/holiday_gift_guide</u> or scan the QR code



NDSS Core Programs

Advocacy & Policy

- Federal, state and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome







NDSS Core Programs

Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk[®] Program
- Times Square Video presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!











NDSS Events



NDSS Gala & Auction February 27, 2025 New York, New York



Down Syndrome Advocacy Conference April 28-30, 2025 Washington D.C.



Racing For 3.21 March 21, 2025 Virtual



Times Square Video and New York City Buddy Walk[®] September 6, 2025



Speaker Bio

Sue Babin

- Sue has been working in the developmental disabilities field for 40+ years.
- She was the administrator of the Office of Quality Assurance for the RI State Division of Developmental Disabilities for 32 years advocating for the human rights of people with disabilities and overseeing investigations on abuse, neglect and mistreatment.
- Sue has also served as an administrator for supported employment statewide grants; program manager for RI's Home and Community-Based Services (HCBS) waiver; and responsible for designing monitoring and quality improvement programs for DD community agencies.
- For the last 14 years she has been a Special Projects Coordinator for the RI Developmental Disabilities Council (RIDDC), staff to the Systems Advocacy Committee (SAC), and founder and Project Director for RI's Self-Employment Business Incubator.



Project Director

RI's Self-Employment Business Incubator Initiative



Speaker Bios

Claudia and Lowe



Business Specialist

RI's Self-Employment Business Incubator Initiative

Former Coordinator for Down Syndrome Society of RI Co-Founder of the <u>RI Self-Direct Coalition</u> Owner Cheetah Greetings



Rhode Island's Self-Employment Business Incubator Initiative

Agenda

- RI Self-Employment Overview
- Why Self-Employment?
- Benefits of Self-Employment
- Program Components
- Funding and Leveraging State Services
- Tips/Recommendations





How and *Why* We Started a Self-Employment Project

- People/Families asked for assistance with starting their businesses
- They couldn't get business supports from DD or VR
- Started taking local Business Classes from SBA entities
- Partnered with SBA to adapt/utilize their business training curriculums
- 2018-present ...continuous work to build the ongoing business development support people need as successful entrepreneurs. Funding from DLT.







Why Self-Employment?

- Some people apply for jobs but do not get the position, or even an interview sometimes, which is very discouraging.
- Barriers can prevent a person from obtaining the job they want, e.g. transportation.
- Person makes the choice to work at something really meaningful to them and spend time with doing work that is their passion and work at their own pace.
- Opportunity to demonstrate the value/contributions people can make to improve their financial futures and their local economy





Benefits of Self-Employment & Entrepreneurial Education

- People work in a job they really *love* and can control, themselves...
- Opportunities to network, meet people, interact with customers and improve social skills and independence,
- Increased self-esteem by people who are proud to be the "BOSS" and a business owner,
- Set own business hours vs. time set by someone else, as little or as much time as you want to spend in the business





Program Components





Funding and Leveraging State Services

- Research and apply for funding from State Department of Labor and Training (Workforce Development Entity)
- Apply for funding from State DD, State VR, etc. for a selfemployment project... start with a small pilot
- Connect people as a participant of Vocational Rehabilitation for business start-up costs for equipment, supplies, materials, etc.
- Utilize Home and Community-Based Services (HCBS) under State Medicaid Waiver for Self-Directed Services to hire your own staff for support

Think Creatively!





Funding and Leveraging State Services (Cont.)

- Check out FREE Classes and resources from local and federal Small Business Administration (SBA) programs
- Research local foundations for grants for ongoing business support and mini-grants funding for entrepreneurs
- Request business start-up costs from State DD under "Goods and Services" under the Medicaid Waiver

Think Creatively!





Tips/Recommendations

Action Steps You Can Take...



Contact State Vocational Rehabilitation (VR) and complete an application for your family member to become eligible for their services. Ask about programs and funding for business classes and grants to purchase supplies, equipment and materials for a business start-up.





Research marketing and other important topics for business success. Check out **SCORE** for *FREE* classes and great information. <u>www.score.org</u>



Start small with your business. Get feedback from families, friends, and staff, on your products/services, what is good, and what can be improved. Then branch out!



Attend one of our "Entrepreneur's Forum" weekly meetings on Thursdays from 3 pm-4 pm EST and meet, talk with and learn from some of RI's small business owners.



Resources

Looking for more information about Self-Employment and Entrepreneurship? Don't forget to check out these resources!

1. Entrepreneurial Education Programs

- <u>RI's Self-Employment Business Incubator</u>
- <u>Celebrate EDU</u>
- Synergies Work

2. Business Resources and Support

- Small Business Administration
- <u>SCORE</u>
- Disability Employment TA Center
- Chamber of Commerce Networking + Support

3. Additional Resources

- <u>10 Questions About Self-Employment For People With Disabilities</u>
- <u>Quick Reference Guide: Entrepreneurship National Disability Institute</u>
- Plan for Achieving Self-Support (PASS) SSA
- Work Incentive Planning and Assistance (WIPA) SSA



Meet Katie Lowe

Owner and Designer of

Cheetah Greetings



Journey to Self Employment

- After High School
 - Katie had a variety of volunteer jobs
 - Katie expressed interest in becoming a DJ
 - DJing not as easy as it sounds
- Mom purchased a Cricut Electric Machine and I wanted to make cards
- At the beginning we made cards using stamps and patterned paper
- Graduated to Cricut Joy[®] during the pandemic
- In our efforts to keep Cheetah Greetings new & fresh we added buttons, magnets, and an About Me Portfolio to our inventory

What is Cheetah Greetings?

- I make personalized cards and buttons for a lot of different occasions
- The bulk of my cards are made using insert cards and the Cricut Joy(R).
- Some of the more custom designs, we use patterned card stock and stamps.













* A portion of sales from my adoption and pet sympathy cards are donated to local charities! For WDSD I create a unique card to sell to benefit NDSS and the NDSC, which makes me a Social Enterprise!

Why I Started My Business



- This was a perfect employment opportunity for me
- I enjoy making cards and making people happy
- I liked making cards for my family and friends and wanted to turn it into a business
- I like being my own boss and making my own schedule

How the RIDDC's Self-Employment Classes Helped Me

I've learned A LOT from the classes, including:

- How to market my business so people know about me
- How to use social media to promote my business
- Networking with other entrepreneurs
- How to come up with an elevator pitch and business plan



What I Got Out of the Classes and Other Support

- I understood the importance of being a social enterprise to give back to my community
- I received a grant which helped me purchase a variety of tools that I use when making my cards

Advice to Others Interested in Starting a Small Business:

- Think about something you do that can be a business
- Take the classes
- Follow your dreams, if you don't try something new, you'll never know how far you can go!



Questions?





Contact Information

If you have additional questions, please contact...

Sue Babin

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Post-Webinar Survey





Thank you for attending!

Questions? Send an email to employment@ndss.org

