

A Runway, Not a Cliff Successfully Transitioning to Adult Life

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November 19, 2025



Agenda - Thanks for Joining This Evening!

My Family

Adult Life - A New World

Step by Step

Some Final Thoughts

Thank You!

My Family

Neil and I have been happily married for 24 years

Our family lives in North Caldwell. Sean is 22 years old and Sam is 19 years old. We also have a sweet dog named Chloe

Neil runs a market research business from home and is a fully engaged dad

I work from home as an advocate and a transition coordinator consultant, and I'm also a dedicated mom



More about Sean

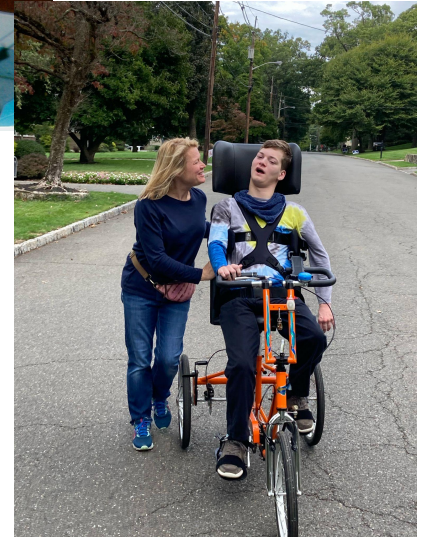
Sean is a sensitive and caring young man. He loves his family, music, Disney movies and being in nature. He was a Scout for 10 years and loves giving back to his community. He also thrives on new experiences.

Sean was a beautiful full-term baby.

Sean began having significant difficulties soon after his birth, including feeding issues and low muscle tone.

Sean was diagnosed with spastic quadriplegic cerebral palsy in the profound range, and later with GERD and an intractable seizure disorder.

Sean has many abilities - and many challenges



More About Sam

Sam is a high-energy, funny and earnest 19 year old. He loves Pump It Up, karaoke, and making people laugh. Sam is an Eagle Scout and a Freshman at Ramapo College.

Sam was a hard-to-settle baby who did not sleep much. He did not engage with others around him, and he was diagnosed with PDD-NOS at the age of 18 months. Later, he was diagnosed with Level I Autism

Early Intervention and inclusive preschool made a big difference, and Sam has responded to a lifetime of support.

Sam has many strengths, gifts and challenges.



Adult Life - A New World

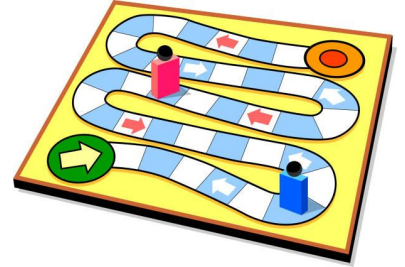
The system of supports for individuals over 21 differs from school-age supports in some important ways:

- Children under 21 with disabilities are supported by the Department of Education (DOE). Education is an **entitlement**, and there are legally binding structures to support and enforce it - like IEP's.
- Adults over the age of 21 are supported by the Division of Developmental Disabilities (DDD), and they are **eligible** for supports and services. This means people can access services and supports that are available, but they are not guaranteed.
- Planning is **recommended** and **beneficial** for children under 21 with disabilities, but it is **essential** for planning for adult life.



Step By Step

	Description	Timeframe
1	Work with your young adult to identify their hopes, dreams, goals and support needs - as well as what doesn't work for them.	Lifelong process - start now!
2	Use the IEP process to develop transition goals and plans.	Age 14-21
3	Utilize DVRS for Pre-ETS (Pre Employment Training Services)	Pre-ETS: age 14-21 DVRS: 21 and older
4	Apply for guardianship or build a supported decision-making plan.	Age 18
5	Apply for SSI (Supplemental Security Income)	Age 18

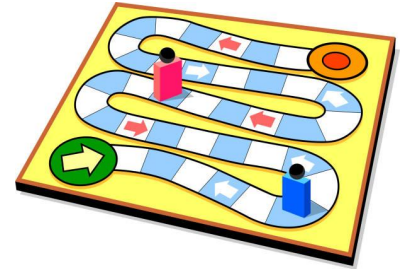


Some steps can happen at the same time, others are in sequence.

You can focus on one or two steps at a time.

Step by Step, Continued

	Description	Timeframe
6	Apply for DDD services	As early as 18, begin using at 21
7	Transition to adult medical providers	As early as 18
8	Select a support coordinator	Upon DDD approval
9	Build your young adult's plan based on their goals and priorities, and update as their goals and needs change.	Ongoing



1. Helping Your Young Adult Identify their Strengths, Goals and Needs

Notice what makes your young adult happy and engaged - and what upsets them or causes them to tune out.

- Be specific and descriptive - the details matter!

Talk with teachers, therapists, and friends to get their perspectives

Use the Charting the Lifecourse tools

- Good Life Board
- Integrated Supports Star



Coffee - it's all in the details!

Sean's Good Life Poster

Sean chose his favorite pictures to reflect what's important to him - what makes his good life.

We shared Sean's poster with his IEP team, his support coordinator and the staff at his day program.

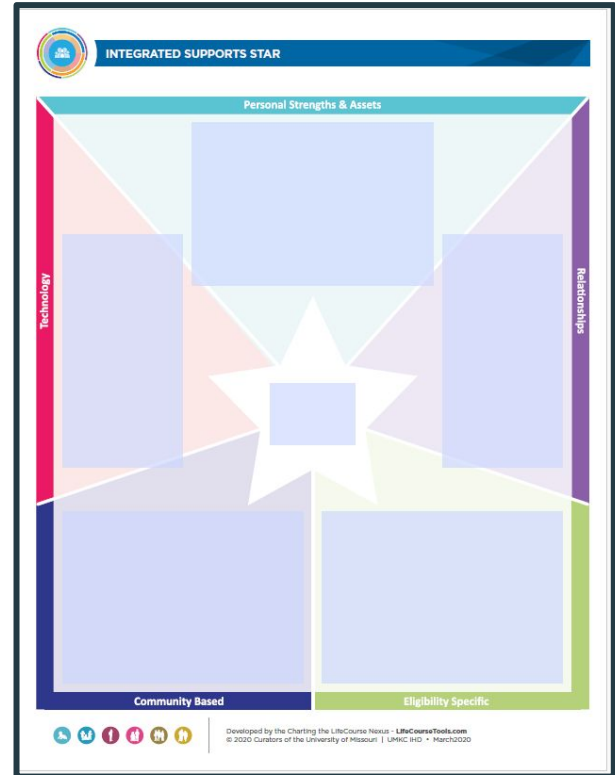
Each member of my family made a Good Life board.



Integrated Supports Star - A Great Planning Tool

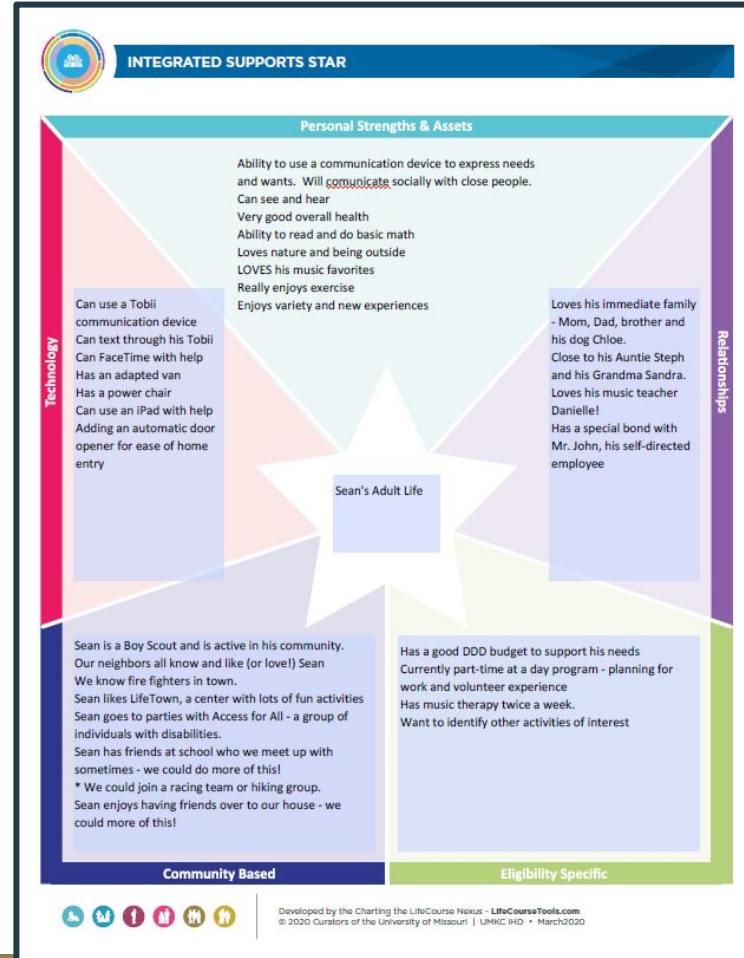
Gives a format to explore all areas of support in a young person's life - not just paid supports:

- Personal Strengths and Assets
- Relationships
- Eligibility-Specific - from your DDD budget
- Community-Based
- Technology



Sean's Adult Life Support Star Highlights

- Personal Strengths and Assets
 - Enjoys and benefits from exercise
- Relationships
 - Special relationship with John, Sean's self-directed employee. Need more time with him!
- Eligibility-Specific - from your DDD budget
 - Sean has the CCP waiver, which includes a good budget
 - Sean attends a day program part-time and would like vocational support to work
- Community-Based
 - We could join a chair racing team or a hiking group
- Technology
 - Sean can use his Tobii to text and control his environment



2. Using the IEP Process

The IEP contains specific information to help families plan for adult life. Transition begins in New Jersey at the age of 14, and future education, employment, and other areas of adult life are considered and planned for.

Many private schools offer 18-21 programs to support transition to adult life.

Work with your school to help you prepare

[NJ Transition Toolkit](#)

[Search results for "transition" | SPAN Parent Advocacy Network](#)

3. DVRS - Division of Vocational and Rehabilitative Services

DVRS can offer skills assessment, assistance finding jobs, job coaching and other resources

Pre-ETS (Pre Employment Training Services), a part of DVRS that serves young people under the age of 21, can teach job readiness skills and provide internships to young people with disabilities

If your young person is in school, their Child Study Team can make a referral for pre-ETS. Alternatively, you can complete the online application: [New Jersey Division of Vocational Rehabilitation Services Confidential Referral Form](#)

If your young person is over 21, apply for DVRS services at your county office. [Career Services | Vocational Rehabilitation Services](#)



Sam at his paid REI internship, coordinated by Pre-ETS and Community Options

4. Guardianship and Supported Decision-Making

Sean has a limited guardianship - he retained some of his rights - including the right to vote. We worked with Deb Guston of Guston and Guston, and we were happy with their support.

[Guston Home - Guston & Guston, LLP](#)

Sam does not have a guardian

Guardianship makes the guardian the decision-maker, but our young adults can still be involved as much as possible. We discuss medical and life decisions with Sean in plain language

Supported decision-making is an alternative to guardianship. The young adult is the decision-maker, supported by a group of trusted adults. More Information:

[Decision-Making-Supports-Center-for-Future-Planning-1.pdf](#)

5. SSI (Supplemental Security Income)

SSI is a monthly benefit paid by the federal government to adults with disabilities who have limited income, work history and resources (no more than \$2,000).

Individuals with a disability who are over the age of 18 may apply. Tip: Wait until your child is 18 to apply, so that your family's income won't be included.

[Apply for Supplemental Security Income \(SSI\) | SSA](#)

[Adult Disability Starter Kit](#)

Applications may be started online and are currently taking 7 -8 months to complete

If your adult child is approved, they will receive a monthly payment to help cover their living expenses. The maximum monthly payment is \$967. Sean's current monthly payment is \$688.98

Medicaid - Much More Than Insurance

When your adult child is approved for SSI, they will also receive Medicaid

Medicaid covers

- Medical care and prescriptions
- Equipment and Supplies
- Private Duty Nursing
- Day Programs
- Residential Supports, like group homes

Another way to receive Medicaid

- NJ Family Care Aged, Blind and Disabled program - apply through your county Medicaid office
 - [Department of Human Services | The NJ FamilyCare Aged, Blind, Disabled Programs](#)

6. NJ DDD - Division of Developmental Disabilities

DDD provides services to more than 25,000 individuals in NJ through the Community Care Program (CCP) and Supports Program (SP) waivers.

- CCP waiver includes a budget for employment/day habilitation, individual/family supports, and residential support
- Supports waiver includes a budget for employment/day habilitation and individual/family supports

Families can apply for DDD when their young adult is 18, and services begin at 21.

If the young person was accepted on PerformCare, the short application may be used

<https://www.nj.gov/humanservices/ddd/assets/documents/individuals/application-for-eligibility-short.pdf>

If the young person was not approved for PerformCare, the full application is required

<https://www.nj.gov/humanservices/ddd/assets/documents/individuals/application-for-eligibility-full.pdf>

If you need help, email DDD.BeforeYouApply@dhs.nj.gov with questions

DDD Budgets by Tier

After a young adult is approved by DDD, they take an assessment called the NJCAT (New Jersey Comprehensive Assessment Tool).

The NJCAT quantifies the amount of support a young adult needs in three functional areas (self-care, behavioral, and medical) and assigns a tier between A and E.

If the person needs a high level of behavioral or medical support, they will have an acuity added to their tier. The acuity means a higher support budget.

Date: December 27, 2023

Topic: Quick Guide to Updated Fee-for-Service Program Budgets Effective January 1, 2024

Supports Program			
Tier	Employment/Day	Ind/Family Supports	Total
A	\$20,564	\$7,442	\$28,006
Aa	\$28,628	\$7,442	\$36,070
B	\$26,208	\$14,883	\$41,091
Ba	\$36,519	\$14,883	\$51,402
C	\$32,429	\$14,883	\$47,312
Ca	\$45,159	\$14,883	\$60,042
D	\$48,096	\$22,324	\$70,420
Da	\$66,932	\$22,324	\$89,256
E	\$63,821	\$22,324	\$86,145
Ea	\$88,820	\$22,324	\$111,144

Community Care Program				
Tier	Employment/Day	Ind/Family Supports	Individual Supports	Total
A	\$20,564	\$7,442	\$ 36,792	\$ 64,798
Aa	\$28,628	\$7,442	\$ 67,847	\$ 103,917
B	\$26,208	\$14,883	\$ 73,584	\$ 114,675
Ba	\$36,519	\$14,883	\$ 135,693	\$ 187,095
C	\$32,429	\$14,883	\$ 122,640	\$ 169,952
Ca	\$45,159	\$14,883	\$ 226,154	\$ 286,196
D	\$48,096	\$22,324	\$ 171,696	\$ 242,116
Da	\$66,932	\$22,324	\$ 316,616	\$ 405,872
E	\$63,821	\$22,324	\$ 220,752	\$ 306,897
Ea	\$88,820	\$22,324	\$ 407,078	\$ 518,222

7. Transition to Adult Medical Providers

Pediatric providers will need to transition your young adult out of their practice, usually between 18 and 21

Some practitioners will allow you to remain - always ask if you'd like to stay

- Sean's neurologists allowed him to remain a patient, as well as his dentist
- We found a great GI - Dr. Coburn at GANJ Hackensack

Ask your friends for recommendations

Make one change at a time, and start with the easiest ones

Sean transitioned to the Developmental Disabilities Center in Cedar Knolls for primary care - we are happy with his NP Catherine Thompson. The office spacious and has a lift and exam tables to accommodate a wheelchair user.

[Developmental Disabilities Centers - Atlantic Health](#)



Developmental Disabilities Center
Exam Room

8. Support Coordination

Your young adult's support coordinator

- Listens to their goals and needs
- Identifies supports funded by your DDD budget
- Coordinates payments for your young adult's services and supports

A total of 130 Support Coordination Agencies work with DDD and its recipients

Ask friends about their experiences - a great Support Coordinator makes all the difference!

You can change support coordination agencies if you're not satisfied - Sean is on his third agency

Support Coordination Agencies with happy clients whom I personally know

- Breaking Barriers - Natalie DeLeon - ndeleon@bbsnj.com
- Infinity Today - [Infinity Today](#)
- Spectrum Care Management - Claudia Antoci
 - [Care Management, Support Coordination | New Jersey | Spectrum Care](#)

9. Building Your Young Adult's Plan

Along with your support coordinator, you and your young adult will develop an ISP (Individual Service Plan).

The ISP replaces the IEP and includes information about the young adult's medical history and needs, as well as the written details of the supports, activities, and resources required for the individual to achieve personal goals.

Some areas to consider

- Day Programs - Full-time or part-time
- College with the Think College program
- Employment and Training
- Leisure and Recreation

Day Programs

A high-quality program can help meet your young adult's goals

Part-time status could allow time for more exploration and development

Visit programs to determine if they can meet your young adult's needs:

- Transportation
- Nursing Staff
- Do they allow private duty nursing if your young adult needs it?
- Ratio of staff to participants
- Availability of therapies
- Time in Community
- Does the program feel right to you and your young adult?

Northern NJ Day Programs

Name	Location	Website	Visited?	Know Someone there?
Community Choices - ARC of Bergen & Passaic	Fair Lawn	Day Programs, Day Hab	Y	N
The Felician School 21 & Older Program	Lodi	21 and Over	Y	N
NJEDDA	Clifton	Adult Services – North Jersey Elks Developmental Disabilities Agency	Y	N
New Concepts for Living	Paramus	Special Needs Adult Housing NJ Residential Living Special Needs Adults NJ New Concepts For Living	Y	Y

Northern NJ Day Programs, Continued

Name	Location	Website	Visited?	Know Someone There?
Red Ribbon Academy	Wayne and Hillsborough	Red Ribbon Academy Community Options, Inc.	Y	Y
Second Home	Totowa	Home - Second Home Day Habilitation Center	Y	Y
Spectrum for Living	Teaneck and Ringwood	Our Services - Spectrum For Living	Y	N
Universal Institute	Livingston	Structured Day Program - UI Rehab - New Jersey	Y	Y

Think College

College programs for individuals with IDD (intellectual and developmental disabilities)

Non-degree programs that allow young adults to continue their education and have a college experience. Participants do not have to meet requirements for a degree program.

Students earn a certificate

13 programs in New Jersey [College Search | Think College](#)

<https://youtu.be/ZtAa9ACRPZk?si=Cc8fscFqA5yVJ5fP>

Leisure and Recreation

Many high-quality options are available

- Music therapy - example: Muzique
- Cooking and swimming classes - example: Lifetown, Livingston, NJ
- Gym memberships and personal training - example: GymGuyz

Mahwah Access for All - free community activities

Support Coordinators can be an excellent source of ideas and

Don't forget accessible organizations for the general public

- Liberty Science Center
- Bronx Zoo
- NY Botanical Gardens



Mahwah Access for All Bowling



Giraffe Encounter - Bronx Zoo



Music Therapy - Muzique



Swimming at LifeTown

Some final thoughts

Begin early to give yourself time to learn. It's also never too late - just get started!

Begin with your young adult's goals, strengths and needs

Identify the support needs of your young adult, and identify natural supports and supports from their budget to meet their needs. Your support coordinator can help!

Revisit your plan at least once a year - New Years is a great time

Join or form a group for brainstorming and support
*African Proverb - "If you want to go fast, go alone.
If you want to go far, go together."*



Thank You!
Questions?
Comments?



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Appendix: Funding Support and Low-Cost/No-Cost Options for Equipment

Goodwill Home Medical - Bellmawr

- Huge Inventory of Refurbished Medical Equipment [Used Home Medical Equipment | Goodwill Home Medical Equipment](#)
- We purchased a electronic life and a bath chair

Patrick's Pals - Funds equipment not covered by insurance for individuals up to age 26 [Patrick's Pals - Home](#)

McLindon Family Foundation - Funds adaptive bikes for children and young adults

[Adaptive Bikes for Children with Special Needs](#)

Julia's Butterfly Foundation Funds equipment and other needs for chronically ill children

[Julias' Butterfly Foundation](#)



Appendix: Funding Support and Low-Cost/No-Cost Options for Equipment

Pluckemin Medical Equipment Ministry - Offers medical equipment free of charge

[Pluckemin Medical Equipment Ministry | Home](#)

From We Can't to We Can - offers gently used medical equipment free of charge

[From We Can't to We Can - Home](#)

Also search Facebook for the group Resource Recycler