

Lost in Transition: Understanding “Failure to Thrive” in Teens and Young Adults with IDD

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The Family Institute



- Provides families with the necessary resources and education to access the appropriate supports and services for their loved one with an intellectual and developmental disability. We offer:
- <http://www.thearcfamilyinstitute.org>
- Advocacy
- Education
- Resources
- Community Support



We Offer



- **Information**

- ○ Email updates about important issues and action alerts for upcoming legislation
- ○ Fact sheets, Go Bags, Navigation at a Clip
- ○ Monthly e-newsletters
- ○ Resources and referrals

- **Individual and Systems Advocacy**

- ○ Creating changes on the local and state level that will benefit people with IDD and their families
- ○ Providing one to one assistance to help families with NJ service systems and special education

We Offer



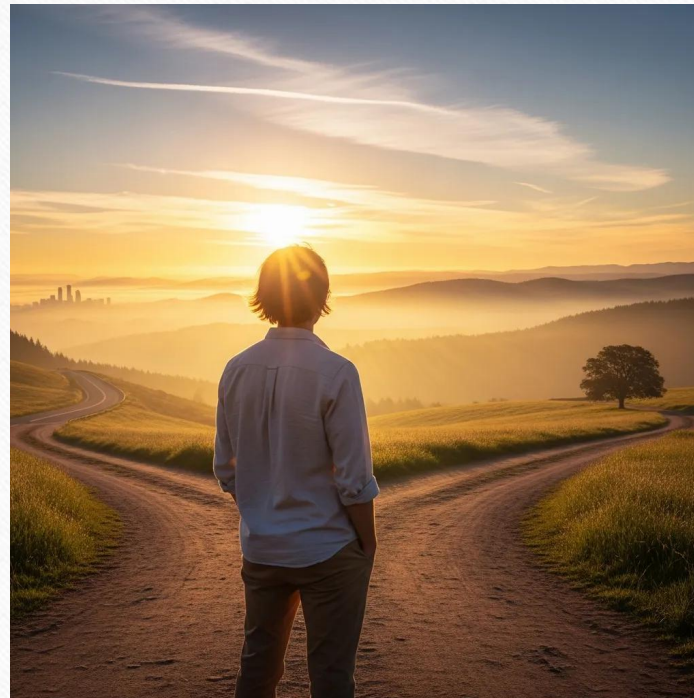
- **Engagement**

- ○ Facebook - @thearcofnjfamilyinstitute
- ○ X & Instagram - @TheArcNJFI
- ○ Attendance at resource fairs

- **Training & Education**

- ○ Webinars
- ○ Podcasts
- ○ In-person workshops and presentations

What is Transition?



Transition to Adulthood

The transition to adulthood for teens and young adults with IDD involves a critical shift from school-based support to community services that focuses on developing:

- Independence in Education
- Employment
- Housing
- Finances
- Health Care
- Social Life

It often requires personalized long-term planning ,often starting around age 14 to build life skills, self-advocacy, and access tailored resources for success.

It's a multi-faceted process, moving from pediatric to adult systems, navigating new challenges like social integration and mental health, and making informed choices about their future, often with support from families, educators, and agencies.



Key Areas of Transition

- **Education & Employment:** Exploring career paths, technical training, job skills, internships, and securing accommodations for college or work.
- **Independent Living:** Learning daily living skills (cooking, cleaning, money management), finding housing, and connecting to community resources.
- **Health Care:** Transitioning from pediatric to adult healthcare providers, understanding benefits, and managing appointments.
- **Financial Management:** Budgeting, understanding benefits (like SSI), and managing bank accounts.
- **Social & Self-Advocacy:** Developing social skills, understanding rights (civil rights), and learning to speak up for one's own needs.

* NJ Self Advocacy Program (NJSAP) is one way a person with IDD can speak up for themselves and gain a better understanding of their civil rights. For more information about how to get involved with this program visit: https://www.arcnj.org/programs/njsap/self_advocacy.html

Common Challenges Around Transition to Adulthood



- **System Navigation:** Moving from the familiar K-12 special education system to disconnected adult service agencies.
- **Social Isolation:** Difficulty forming and maintaining friendships and feeling integrated in the community.
- **Skill Gaps:** Overwhelmed with tasks like managing finances, medical care, or household responsibilities.
- **Mental Health:** Increased stress can heighten anxiety or depression.
- Our Planning for Adult Life program provides detailed information on transition and offers various training opportunities for individuals and their families as they move into adulthood. For more information visit: <https://planningforadulthood.org/>

Successful Transition Strategies



- **Early, Integrated Planning:** Start planning at age 14. This involves the student, parents, and school staff.
- **Focus on Self-Determination:** Involve students in decisions about their goals and services.
- **Skill Building:** Practice life skills (laundry, calling to make appointments, money) at home before they leave school.
- **Connect to Resources:** Get connected to adult service agencies (e.g. DVRS, DDD).
- **Explore Support Options:** Consider supported decision-making, and research financial supports like SSI.



Lost in Transition

Overview



- Sometimes it can feel like a teen or young adult with intellectual and developmental disabilities (IDD) has stopped moving forward.
- They may lose interest in activities they once enjoyed, struggle with motivation, or appear stuck in routines that no longer serve them.



Why Does This Topic Matter?



- When teens and young adults experience failure to thrive and it goes untreated, the impact can last well into adulthood.
- It's important to recognize that mental health issues like anxiety, depression, or ADHD can worsen over time, leading to ongoing challenges and a lower quality of life. Additionally, some may turn to unhealthy coping strategies, like social withdrawal, as a way to manage their feelings. It's crucial to address these issues early on to help ensure a healthier, happier future!

Goals for This Webinar



- During this presentation we will discuss failing to thrive in teens and young adults, a stage where growth may appear different and sometimes more fragile than anticipated.
- Together, we will examine why this happens, how to recognize early warning signs, and what families, educators, and support teams can do to help young people re-engage, rebuild confidence, and discover new paths forward.
- My goal is for you to leave with **practical tools, renewed hope, and a deeper understanding of how to support continued growth during this complex and transitional stage of life.**

Learning Outcomes



Hopefully after this presentation, you will be able to:

- Identify common signs of failure to thrive in teens and young adults with IDD.
- Understand factors that contribute to stalled progress during this life stage.
- Apply supportive strategies to re-engage motivation and confidence.
- Support continued growth through collaboration and individualized approaches.

What Does Failure to Thrive Mean?



Traditionally, failure to thrive (FTT) was a medical diagnosis applied to infants who were not gaining weight or meeting physical growth milestones.

In recent years, the term has also been used to describe older adolescents and young adults who show delays in emotional and psychological development.

- So, *what does failure to thrive mean* for teens and young adults? Instead of focusing on weight and height, it involves difficulties in areas like:
- **Mental health conditions** such as anxiety, depression, or ADHD.
- **Motivation and perseverance** – difficulty sustaining effort in school, work, or personal goals.
- **Executive function challenges** – procrastination, disorganization, and avoidance behaviors.
- **Social skills and relationships** – struggles with identity, secure attachments, and autonomy.
- **Life skills and independence** – difficulty managing money, or handling responsibilities of adulthood.

Common Signs and Red Flags

Recognizing the symptoms of failure to thrive in teens and young adults is critical for early support.

Some of the signs may include:

- Persistent low self-esteem and negative self-worth.
- Difficulty managing mental health issues such as anxiety, depression, or attention-deficit disorders.
- Frequent procrastination and avoidance behaviors when facing responsibilities.
- Struggles with identity development leaving the individual unsure of who they are or what direction to pursue.
- Regressions in skills or independence.
- Loss of interest in things that once interested the person.
- Reliance on parents or caregivers for responsibilities typical of adulthood, such as financial independence.
- Lack of motivation and difficulty setting or achieving long-term goals.
- Withdrawal from social settings due to poor social skills or fear of failure.
- While some of these symptoms overlap with normal adolescent struggles, persistent patterns may signal that a young person is experiencing failure to thrive in a psychological sense.
- Loss of interest in things that once interested the person.
- Increased rigidity and unhelpful routines.

What it is not?

- Laziness
- Defiance
- Lack of Potential



Early Signs of Failing to Thrive

Physical and Nutritional Signs



- Weight Loss: Unintended weight loss or not gaining weight appropriately.
- Poor Appetite: Decreased interest in eating or food preferences.
- Fatigue: Significantly reduced energy or increased sleepiness, less tolerance for activity.
- Frequent Illnesses: Increased susceptibility to infections due to weakened immunity.
- Self-Neglect: Lack of interest or ability in personal hygiene

Early Signs of Failure to Thrive: Behavioral and Cognitive Signs

- Social Withdrawal: Lack of interest in people or social activities, isolating themselves.
- Mood Changes: Depression, irritability, excessive crying, or mood swings.
- Cognitive Decline: Memory loss, trouble thinking, or difficulty managing tasks (finances, planning)
- Decline in Skills: Losing previously mastered abilities in cognition, motor skills, or daily living skills.
- Decreased Activity: Engaging in less activity, staying in their room more.

The Cost of Missing the Signs



- Long term disengagement
- Reduced confidence and self- efficacy
- Fewer opportunities for independence
- Increased stress for families and caregivers



Addressing Failure to Thrive



- Conduct comprehensive assessments to identify underlying health issues.
- Ensure a balanced diet tailored to individual nutritional needs.
- Monitor growth and development regularly to track progress.
- Provide appropriate therapies and interventions to support physical and cognitive development.
- Foster a supportive environment that encourages social interaction and engagement.
- Collaborate with healthcare professionals for ongoing support and guidance.

Why Does Progress Sometimes Stall?



- Mismatch between supports and current needs
- Mental health factors (anxiety, depression, burnout)
- Communication challenges
- Limited choice, autonomy, or meaningful roles

Environmental and Systemic Factors can Contribute to a Failure to Thrive



- Over structured or under-stimulating environments
- Repetitive programming with no pathway to grow
- Low expectations
- Learned helplessness
- Lack of coordination across support systems

Re-Engaging With Motivation and Confidence



- Start by rebuilding psychological safety.
- Shift the questions from what's wrong to what's draining you?
- Restore a sense of control (even if it's small)
- Focus on strengths that feel real
- Take it one step, one win, at a time
- Focus on what the individual cares about
- Identify loss
- Build confidence through belonging
- Support without taking over- Coaching, not rescuing
- Make sure to screen for mental health needs
- Reintroduce choice and autonomy
- Update goals to match current interests
- Offering safe risk-taking
- Build success through small wins

Strategies



- In this next section, we will explore strategies that can help individuals with IDD build **social skills and relationships**, actively **participate in community activities and programs**, and create **supportive networks**.



How can Families and Advocates help?



- Collaboration and shared language
- Consistency across environments
- Avoid “doing for” when “supporting” is possible



The Importance of Independence for Adults with IDD



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- Independence plays a vital role in the lives of teens and young adults with IDD.
 - By fostering independence, individuals can gain a sense of empowerment, dignity, and self-worth. It allows individuals to make choices, pursue their goals, and actively participate in their communities.

Support Services are Important



- Support services play a huge role in enhancing independence for teens and young adults in need of support when transitioning to adulthood.
- Some services can provide assistance with daily living skills, access to healthcare and mental health services, and community opportunities.
- Understanding and accessing available support services is key to helping all individuals lead fulfilling and independent lives.

Self-Advocacy and Decision Making



Encouraging self-advocacy skills is essential to people looking to assert their rights, express their needs, and make informed decisions about their lives.

- Self-advocacy involves developing effective communication skills, understanding personal strengths and limitations, and actively participating in decision-making processes.
- By fostering self-advocacy, individuals can have a voice in matters that affect their lives. They can actively participate in their own care, express preferences, and make choices that align with their goals and aspirations.

Building Life Skills



Life skills encompass a wide range of abilities that enable individuals to navigate daily tasks, manage their personal affairs, and engage in meaningful activities.

These skills can include:

Basic self-care

Household management

Financial literacy

Employment readiness

- By providing opportunities for skill development and offering appropriate supports, individuals can gain the necessary skills to lead more independent lives.

Promoting Social Inclusion and Community Engagement is vital



- Developing strong social skills and nurturing meaningful relationships play a vital role in the lives of all adults. By building social skills, individuals can increase their confidence, communication abilities, and overall social interactions.

Some effective strategies to foster social skills and relationships include:

- **Group activities and therapy:** Encouraging participation in group activities, such as group therapy sessions or social skills classes, can provide opportunities for individuals to practice social interactions and learn essential skills.
- **Role-playing and social scripts:** Engaging in role-playing exercises and using social scripts can help individuals with IDD navigate various social situations and develop effective communication strategies. This could be helpful to an individual who is non verbal. (Visual supports with social stories.)
- **Community-based social groups:** Connecting individuals with community-based social groups or clubs that share common interests can facilitate social connections and create a sense of belonging.

Participate in Community Activities

Participating in community activities is an excellent way for individuals to develop new interests, and form connections with others.

Community organizations, recreational centers, and local support services often offer a range of activities tailored to the needs and preferences of individuals with IDD.

These may include:

- **Sports and fitness programs:** Engaging in sports and fitness activities designed for individuals with promote physical well-being, boost confidence, and provide opportunities for social interaction.
- **Art and creative programs:** Art workshops, music classes, and other creative programs can help individuals with IDD express themselves, explore their talents, and connect with others who share similar interests.
- **Volunteering opportunities:** Volunteering not only benefits the community but also provides individuals a chance to contribute, develop new skills, and build social connections.
- One resource available on our website is the recreation page. To learn more about community activities, please visit: <https://www.thearcfamilyinstitute.org/resources/recreation.html>

Build Supportive Networks

- Building a network of support is crucial for adults with IDD to thrive in their communities. Creating supportive networks can involve a combination of family members, friends, professionals, and other individuals who understand and champion the unique needs and abilities of those with IDD.
- Supported Decision Making is one way to build a solid network! We have created a fact sheet around this topic and you can find it in our Guardianship Go Bag:

<https://www.thearcfamilyinstitute.org/resources/guardianship-go-bag.html>

Employment and Education Opportunities



- For teens and young adults with Intellectual and Developmental Disabilities (IDD), accessing meaningful **employment and education opportunities** plays a crucial role in enhancing their independence and overall quality of life.
- The Division of Vocational and Rehabilitations Services (DVRS) assist individuals with IDD in finding suitable employment opportunities. These services often involve vocational counselors who work closely with individuals to identify their skills, interests, and goals. Job placement services help match individuals with employers who value diversity and inclusivity, ensuring a supportive work environment.
- Additionally, supported employment programs provide ongoing assistance and job coaching to individuals with IDD, helps with navigating the workplace and succeed in their chosen careers. These programs offer the necessary support to individuals as they adjust to their new work settings. By providing job placement and supported employment opportunities, individuals can gain financial independence and a sense of purpose.
- We have a DVRS Go Bag: <https://www.thearcfamilyinstitute.org/resources/dvrs-go-bag.html>

Lifelong Learning



- Education is a lifelong journey, and students can benefit from college and education programs.
- Lifelong learning provides personal growth, skill development, and intellectual stimulation. Continuing education can take various forms, including adult education classes, online courses, and workshops.
- These programs provide young adults the chance to expand their knowledge, explore new interests, and develop new skills.
- By engaging in continuing education and lifelong learning, individuals with IDD can continue to grow and build their independence throughout their lives.
- Please visit our college page to find out about different college opportunities here in NJ:
<https://www.thearcfamilyinstitute.org/advocacyawareness/college-programs/>

Enhance Physical and Emotional Well-Being



- Ensuring the physical and emotional well-being of teens and adults is crucial for their overall quality of life.
- Regular physical activity and exercise have numerous benefits including improved physical health, increased strength and flexibility, and enhanced overall well-being.
- Engaging in activities such as walking, swimming, dancing, or adapted sports can help individuals maintain a healthy lifestyle and manage their weight. It is important to consider the individual's abilities and preferences when determining suitable physical activities.
- By participating in physical activities, individuals can also experience social interaction, increased self-confidence, and a sense of accomplishment. Encouraging and supporting their involvement in recreational activities can contribute to their overall well-being.
- Special Olympics of New Jersey is a great option to help when individuals are looking to engage in physical activities: <https://www.sonj.org/>



Access to Healthcare and Mental Health Services is Important

- Access to healthcare and mental health services is essential for all individuals. Regular check-ups, preventive care, and timely interventions can help address medical or mental health concerns.
- It is important for all individuals to have access to healthcare providers who are knowledgeable about their specific needs and can provide appropriate support.
- Additionally, mental health services play a crucial role in promoting emotional well-being. These services can include counseling, therapy, and support groups. It is important to address any mental health challenges that individuals may face and provide them with the necessary resources and support.
- We have a Go Bag to help with Health Care questions:
<https://www.thearcfamilyinstitute.org/resources/health-care-go-bag.html>
- If you have any questions around Health Care you can reach out to Connor Griffin. Connor is the Director of our Health Care Advocacy Program. T: 732.246.2567 E: cgriffin@arcnj.org

Self-Care



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- Promoting emotional resilience and self-care is essential for individuals to cope with daily challenges and maintain a positive outlook.
 - Encouraging individuals to express their emotions, providing a supportive environment, and teaching coping strategies can help enhance their emotional well-being.
 - Some examples of coping strategies include mindfulness, deep breathing, and journaling.

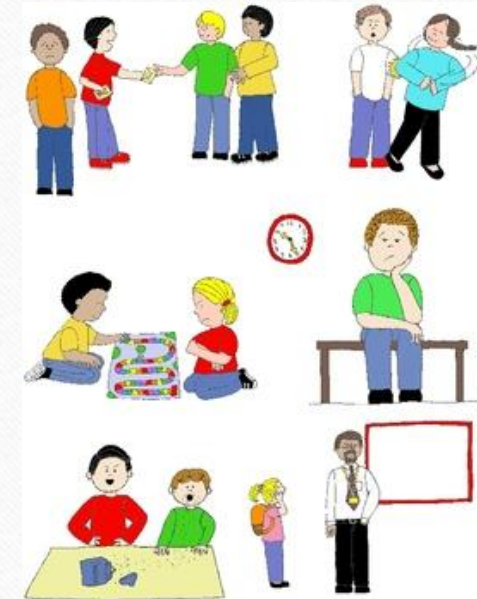
Social Skills By County



The Family Institute has created a page to assist individuals and their families in finding social opportunities by county. Please check back frequently as we continually add new agencies.

Visit:

<https://www.thearcfamilyinstitute.org/resources/social-skills-by-county.html>



Key Takeaways



- Transitions are hard.
- Failure to Thrive is rarely due to lack of effort or ability by the individual.
- Loss of support drives decline.
- Adult systems aren't always accommodating or coordinated.
- Early transition planning is vital.
- Families need better support.
- Prevention is possible.
- The Arc of New Jersey is here to help!



Next Steps



- Start transition planning at 14 years of age.
- Prioritize mental health and social belonging.
- Practice daily living skills and self- determination.
- Ensure continuity of Health Care.
- Talk about education and employment opportunities.
- Act on early warning signs that someone might be struggling to thrive.
- If one strategy doesn't work, try a different one.
- It's ok to ask for help!



Go Bags



What's In Your Go Bag?

The Go Bag was created to help you be the best ADVOCATE you can be for your loved one with an intellectual or developmental disability. A Go Bag is a simple collection of necessary resources about a specific topic. The topics will vary but the message is the same. Be Prepared!

Visit: <https://www.thearcfamilyinstitute.org/resources/go-bags.html>



County Roadmaps



Your map for county based resources. We have one for every county.

Visit:

<https://www.thearcfamilyinstitute.org/resources/county-roadmaps.html>

A ROADMAP TO YOUR COUNTY RESOURCES

ALL AGES

The Arc of New Jersey Family Institute
www.thearcfamilyinstitute.org

Lisa Ford - (732) 828-2022
The Arc of Atlantic County
www.arcatlantic.org

Rebecca Reed, Support
Coordination Supervisor, (609) 485-
0800 x175 or
reed@thearcatlantic.org

Health Care Advocacy
<https://bit.ly/healthcare-advocacy>
Connor Griffin
cgriffin@arcnj.org
(732) 246-2567

Special Olympics New Jersey
www.sojn.org
(609) 896-8000

UNDER 21

PerformCare

State services for children with
intellectual and developmental
disabilities under 21. Call 24/7
www.performcarenj.org
1-877-652-7624

Atlantic Cape Family Support Organization (FSO)

FSOs provide peer support, education,
advocacy and other services to family
members of children with emotional and
behavioral needs, substance abuse
issues and/or developmental disabilities.
<https://www.acfamsupport.org/>
(609) 485-0575

Planning For Adult Life

www.planningforadulthood.org
helpdesk@planningforadulthood.org
(732) 828-0972

Special Child Health Services (SCHS) Of Atlantic County

Case management services
for children from birth to age
21 who have a disability or
pre-disabling condition. This
program is administered by
Atlantic County Special
Services School District.
bit.ly/schscasemangers
Cindy Hause, Unit Coordinator,
chause@childrenspecialized.org
(609) 909-9269

Office of Special Education

www.nj.gov/education/special-ed/ (609) 376-9060

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Division of Vocational and
Rehabilitation
Services (DVRS)
<https://bit.ly/3sscyv8>

DVRS Field Office of Atlantic
County
(609) 813-3933

Learning Resource Centers (LRC)

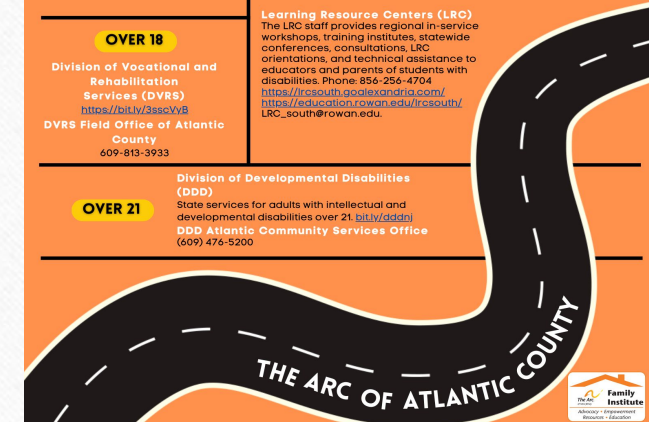
The LRC staff provides regional in-service
workshops, training institutes, statewide
conferences, consultations, LRC
orientations, and technical assistance to
educators and parents of students with
disabilities. Phone: 856-256-4704
<https://lrcsouth.golexandria.com/>
<https://education.rowan.edu/lrcsouth/>
LRC_south@rowan.edu

OVER 21

Division of Developmental Disabilities (DDD)

State services for adults with intellectual and
developmental disabilities over 21. bit.ly/ddnj

DDD Atlantic Community Services Office
(609) 476-5200



Questions

