



Families for Families:

After the Cap & Gown



THE ARC CONNECTICUT

FAMILIES FOR FAMILIES

The Arc Connecticut is a 64-year-old advocacy organization. We are committed to protecting the rights of people with intellectual and developmental disabilities and to promoting opportunities for their full inclusion in the life of their communities.

***Families for Families* is our grassroots group of parents, family members and caregivers dedicated to making sure that all people with I/DD in Connecticut have access to the vital services and supports they need to live and participate in their communities.**

Purpose

This workshop is for families who have teen or young adult children with intellectual and developmental disabilities (I/DD) who will be eligible for either DDS services (meaning IQ's of 69 or lower) or qualified for the Autism Waiver program.

This presentation is designed to give you a snapshot of the state of funding for services for people with I/DD and how that will impact your child or loved one when they graduate.

Overview

- School Years: Most of you are here with school-aged children, who are currently protected by federal education laws.
- DDS Years: After age 21, your children (if eligible) will receive services from the Department of Developmental Services (DDS), a CT agency. These services are not guaranteed, but depend on budget availability.
- Furthermore, because of state budget problems, funding for DDS has been dramatically cut over the years, leaving the agency unable to provide much for our children.
- The Future: There are things you can and should do, both to help your own family and to support better funding for all CT families.

School Years: Services Up To Age 21 Are Guaranteed

- Educational services for people with disabilities from age 3 to 21 are covered under the Individuals with Disabilities Education Act (IDEA). This is a federally-mandated law, so services covered by IDEA are entitlements.
- The purpose of the IDEA to provide special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living ...
- IDEA services end after the school year when the child turns 21.

While Your Child Is Still In School, There Are Things You Should Do

- Set your child up for post-21 success by advocating for good transition services while in school
- By age 16, your child must have comprehensive transition planning done - this should be reflected in IEP goals and objectives, and services provided
- Get (and read) a copy of the Transition Bill of Rights (provided by the CT State Department of Education)
- Pay attention to the areas of your child's IEP that are about transition



Transition Bill of Rights

For Parents of Students Receiving Special Education Services

A student with an individualized education program (IEP) has certain rights under both federal and state laws. This *Transition Bill of Rights* for parents of students receiving special education will help parents and students understand a student's rights related to getting an education and other important issues regarding the transition to life after high school. School districts will provide this document annually at a planning and placement team (PPT) meeting to all parents, guardians, and surrogate parents of students who are receiving special education services in Grades 6-12 as well as to students who are 18 years of age or older.

Students, parents, guardians, and surrogate parents are important members of the PPT. Parents, guardians, surrogate parents, and students 18 years of age or older have the right to receive a copy of *Procedural Safeguards in Special Education* which explains the rights and responsibilities in the federal law called the Individuals with Disabilities Education Act (IDEA). These procedural safeguards are provided at least annually at a PPT meeting by each school district. This publication describes a student's right to a free and appropriate public education (FAPE) in the least restrictive environment (LRE) through specialized instruction and related services in a student's IEP.

Students with an IEP have a right to:

1. Receive secondary transition services through their IEP starting at least at age 16, or younger if desired and recommended by the student's PPT.
2. Receive appropriate individualized education services through the end of the school year in which they turn 21 OR until graduation with a regular high school diploma. The school year is defined as July 1 through June 30. This decision is typically recommended by a student's PPT.
3. Attend all PPT meetings, including those related to transition planning, to represent their education/training, employment, and independent living interests, preferences, and strengths.
4. Assist in the development of their IEP with accommodations and modifications designed to meet their unique needs.
5. Develop realistic and specific post-school outcome goal statements (PSOGS) that are measurable, based on their individualized needs and interests, and reviewed annually as part of their IEP.
6. Receive secondary transition services and related supports to help them prepare to meet their post-school goals in postsecondary education/training AND employment, and independent living skills if appropriate.
7. Assist in developing annual goals and objectives to include but not be limited to those areas in the Connecticut *CORE Transition Skills*, such as health care, transportation, self-determination, and social skills.
8. Identify, explore, and connect with outside agencies as appropriate, including but not limited to the following adult service agencies: Department of Developmental Services (DDS), Department of Mental Health and Addiction Services (DMHAS), Department of Public Health (DPH), and the Department of Rehabilitation Services (DORS), which includes the Bureau of Education and Services for the Blind (BESB) and Bureau of Rehabilitation Services (BRS) (see *Easing into Secondary Transition*).
9. Be informed on or before their 17th birthday that all parental rights will transition to the student when he or she reaches the age of 18. Under Connecticut law, students may notify the school district (in writing) that their parents, guardian, or surrogate parent shall continue to have the right to make educational decisions with the students when they turn 18.

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Dianna Wentzell
Commissioner

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Secondary Transition Resources



- [Post-School Outcomes Goal Statements](#)
- [Post-School Outcomes Survey Reports](#)
- [Special Education Publications](#)
- [Back to BSE Home](#)

(all documents are pdf unless noted)

Community-Based Transition Services (18-21)

- [Approved Transition/Vocational Programs \(Bureau Bulletin 2009\)](#)
- [Community-Based, College, University Transition Services SURVEY](#)
- [Directory of Transition Services in College, University and Community-Based Settings \(2010\)](#)
- [Directory of Transition/Vocational Service Providers \(2014\)](#)
 - [Map of RESC areas](#)
- **Minimum Wage Waiver** - Department of Labor Agreement
 - [Community-Based Career and Tech Ed Unpaid Career Exploration Experiences for Students Receiving Special Education \[DOC\]](#)

Guidance Documents

- [Connecticut's Transition Training Manual and Resource Directory \(2004\)](#)
- [Building a Bridge: A Transition Manual for Students \(2009\)](#)
- [Building a Bridge: A Transition Manual for Students - Spanish](#)
- [Easing into Secondary Transition: A Comprehensive Guide to services and Resources in Connecticut \(2015\)](#)
- [Educational Journey for Self-Discovery and Advocacy A Handbook for Students \(2003\) - Spanish](#)
- [Providing Transition Services - Flow Chart](#)
- [Secondary Transition Planning Process](#)
- [Stepping Forward: A Self-Advocacy Guide for Middle and High School Students \(2013\)](#)
- [Summary of Performance \(SOP\) Frequently Asked Questions - Topic Brief](#)

Research and Apply for Appropriate Agency Services

- DDS or Autism Waiver (*Department of Developmental Services/Department of Social Services*)
- Social Security (SSI or SSDI) (*Social Security Administration*)
- Title 19/Medicaid (*DSS*)
- Community First Choice (*DSS*)
- Financial/estate planning - consider special needs trust and/or ABLE account (private financial advisor)

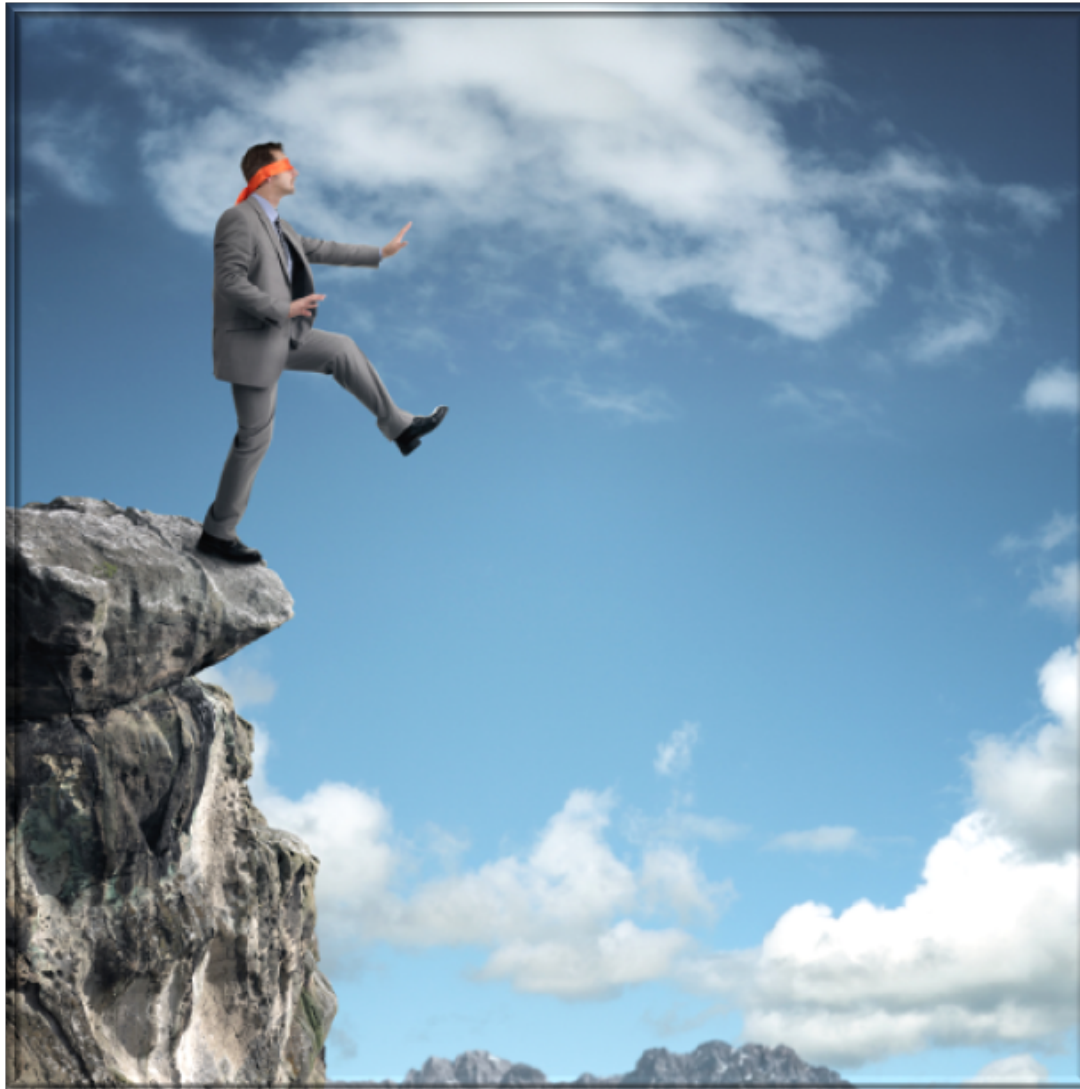


We are not going to cover these in detail, but are happy to talk further after the presentation

Graduation Comes - Then What?



Transitioning from School to Adult Services



DDS Services Are Not Guaranteed

To qualify for DDS services your child must have an IQ of 69 or below, or qualify under the DSS Autism Waiver guidelines. However, even if he/she is found eligible, currently there are waiting lists for all DDS services:

- DDS services are not guaranteed by law, and supports for your adult child with I/DD are not an entitlement
- Individuals who need and are eligible for DDS services can be, and routinely are, denied funding for services
- Services and supports for people with I/DD are funded solely at the discretion of the Governor and the Connecticut General Assembly, and implemented by DDS and DSS

DDS Budget Facts

- DDS services are funded through the state budget
- There have been tens of millions in cuts to the DDS budget every year for the past several years, due to challenging state budgets

For the State of CT, legislative analysts are projecting deficits in the billions for the next three budget cycles.

Budget Challenges Lead To Waiting Lists

Residential

- There are over 2,000 people on the “waiting list” for DDS residential services
 - ✧ Some on the list have waited years, or even decades
- DDS currently awards residential placements only in cases of emergency - abuse, neglect, homelessness, or usually the death or disability of both parents or caregivers
- In 2012, former DDS Commissioner Terry Macy admitted to families, “There is no waiting list because there is nothing to wait for.”

New Waiting Lists Are Forming

Day Programs (Day & Employment Services)

- DDS has historically offered day budgets to all young adults graduating from the school system.
- That funding has been put on the chopping block year after year.
- Last year there was no funding in the budget at all until the last minute. 2017 grads did not start getting funding until November, some as late as January.
- **There is currently a waiting list for Day & Employment Services**

New Waiting Lists Are Forming

Respite

- Respite centers have been closed, and individual respite budgets have been decreased

Behavioral Support Program (BSP)

- This part of DDS, which serves individuals with severe behavior issues, has a waiting list

Family Grants

- One-time grants available to help families with in-home supports or therapeutic items - this budget is also decreased

These services are often lifelines for families waiting for residential supports.

What Does This Mean for Your Family?

Given the state's current budget projections, you should be very concerned that the services your loved one needs may not be available when he or she graduates

What's Happening Right Now?

1. The 2018 legislative session began Wednesday, February 7, 2018.
2. Arc Legislation: An Act Establishing a Pilot to Serve People Seeking Residential Services from the Department of Developmental Services.
3. Arc Watchlist:
 - Funding for 2018 Graduates
 - Funding for Emergency Placements
 - Community First Choice
 - Bills that would create a segregated healthcare system for people with I/DD

What Should You Be Doing?

Work to secure
what your child
needs



Work for the
greater good

For Your Child - Make Sure You've Done These Things

- Make sure you have all of the school-based transition services your child needs. Get an independent transition evaluation if needed.
- If you haven't yet applied to DDS, or for the Autism Waiver (for IQ above 69), do it now
- Learn about the other agency funding that you may need to apply for:
 - ✧ SSI (*Social Security Administration*)
 - ✧ Title 19/Medicaid (*Department of Social Services*)
 - ✧ Home Health Aide supports (*DSS*)
 - ✧ Community First Choice - some uncertainty here, but more applicants could help keep it (*DSS*)

For Your Child - Make Sure You've Done These Things

- Go to every meeting you can find about Adult Services, Transitions, Housing, etc.
- Consider a financial planner with special needs expertise, who can help you work through the various ways you can protect your child's services (e.g., special needs trusts, ABLE accounts)
- Get to know your legislators - if you're not on a first-name basis with your state Senator and Representative, you're making a mistake
 - ✧ Invite them to your house, and let them meet your child and see your life. Attend town meetings and raise questions about DDS funding. Bring your friends. Bring your kids.

For The Greater Good - Get Involved

- Legislators respond to pressure from many voices. Help all families, including your own, by being part of this.
- Throughout history every service and advancement for people with I/DD came because families fought for more

Testify at Family Hearing Days



Attend Lobby Days



Testify In Front Of Committees (Appropriations, Public Health)



TAKE ACTION!

1. Email your legislator *tomorrow*.
 - Introduce yourself and your family. Tell them what your child's needs are now, and what they will need after graduation
 - Tell them you need them to fight for DDS funding and for your child
 - Host or attend face-to-face meetings in a family home or in the community with legislators and SPEAK UP!
2. Sign up for The Arc Connecticut's *Families for Families* budget updates and action alerts
3. Write a letter to the editor of your newspaper
4. Commit to going to the Capitol with other families at least once during the legislative session

Crisis Creates Opportunity

This crisis has woken families up and it presents us with a real opportunity to create a better system for ALL people with I/DD.

The efforts of a small group of families have brought us a long way, but with huge projected deficits we can expect more cuts and longer waiting lists for DDS services.

There are currently 18 states that have little to no wait for community based services. There is no reason why Connecticut can't be added to this list if families choose to make that happen.



The Arc[™]

Connecticut

Families for Families

“The people who are crazy enough to think they can change the world are the ones who do.” ~ Steve Jobs