

# Navigate to Advocate: DDS 101 A Primer for Transitioning Families

#### Did You Know?

- Services and supports for your adult child with I/DD are not an entitlement
- In order to become eligible for DDS services, you must PROVE that your child or loved one meets the DDS eligibility criteria of an IQ of 69 or below. Proof of IQ must be provided prior to the age of 18.
- Your child with I/DD becomes a legal adult regardless of disability at age 18. If you have concerns that he/she cannot make healthy choices about their futures, you need to explore guardianship/conservatorship you're your probate court.
- Most DDS services are provided through Medicaid waivers. In order to become eligible for DDS services, your
  adult child must apply for and receive Medicaid funding through the Department of Social Services (DSS). You
  must do this when your child turns 18.
- All funding for DDS services is determined through the state budget process.
- Services and supports your adult child over the age of 21 with I/DD will rely on, are funded at the discretion of DDS, Governor and the Connecticut General Assembly. They are NOT an entitlement.

#### To Apply for DDS Services:

DDS is divided into 3 regions. Each of the DDS Regions has a Help Line to assist families who do not have a case
manager to help access services. Help Line staff will assist you to apply for DDS Family Support Services or refer
you to appropriate community resources and services. A list of towns in each region is available on the DDS
website (<a href="http://www.ct.gov/dds">http://www.ct.gov/dds</a>)

North Region - 1-877-437-4577 or email: dds.nr.ifshelpline@ct.gov

**South Region -** 1-877-437-4567 or email: dds.sr.ifshelpline@ct.gov

West Region - 1-877-491-2720 or email: <a href="mailto:dds.wr.ifshelpline@ct.gov">dds.wr.ifshelpline@ct.gov</a>

## Once Your Child Has Been Deemed Eligible for DDS Services:

- The DDS region you live in will be notified.
- If your child is on Medicaid, he/she should be assigned a Case Manager.
- If your child is not on Medicaid, you will most likely need to wait until there is room on a Case Manager's
  caseload to start receiving services. THIS WHY YOU SHOULD APPLY FOR MEDICAID ONCE YOUR CHILD TURNS
  18.

#### Case Manager's Role and Responsibilities:

- The DDS case manager is the primary contact for persons who are eligible for DDS supports and services.
- The case manager is the person you should contact with questions and information about your family member.
- The case manager should assist you in:
  - Identifying your child's needs through the level of need assessment (LON) and planning process
  - Gaining access to supports and services to meet those needs.
  - Monitoring progress and evaluating the quality of supports and services.
- Your case manager also maintains the master file which contains the important record of information about your family member.

It is strongly recommended that you build a relationship with your case manager and do so when your family is not in crisis so they are better informed and better able to assist you if a crisis occurs.

### Once you have been assigned a Case Manager:

- DDS policy indicates you'll be contacted by the Case Manager (CM) to set up an initial visit to share and gather information.
- DDS policy indicates that within 2 months of your initial visit, your CM should meet with you to develop a plan of services called "An Individual Plan" or (IP).
- Following that meeting the CM will make referrals for services based on a complete assessment of you family's needs.
- The frequency of CM visits depends on a variety of circumstances but a minimum of 1 visit per year is the policy. You can request that regularly scheduled CM meetings be implemented in your child's IP.

#### Completing the Level of Need (LON) Assessment Tool:

- THIS TOOL IS EXTREMELY IMPORTANT because your child's Level of Need score will determine the funding for services your family receives.
- LON scores range from level 1 being the lowest level or need to a level 8 being the highest.
- When you fill out the LON assessment you must focus on how your child would be able to function without any supports at all in place no prompts, no medication, and no assistance at all from parents or staff. This is difficult for parents, especially because you are used to focusing on your child's strengths but it is critical because the level of support and funding you have access to is directly related to their LON score.
- DO NOT allow a CM or anyone else to fill out a LON assessment without your input.
- You are NOT required and you should NOT sign a LON assessment that has been completed without your input.
- You can and should consult others you trust, who know and or have worked with your child when filling out the LON assessment like teachers, coaches, community members, etc..

#### Things to know about accessing DDS services once the LON and IP are complete:

- Your IP will detail the services that you need, but remember DDS SERVICES ARE NOT AN ENTITLEMENT.
   Being eligible for services does not mean you will get them.
- CT has historically been one of the only states in the country that gives day services to young adults as they graduate or age out of the school system. There is currently a waiting list for Day & Employment Services.
- DDS IS NOT OFFERING OUT OF HOME RESIDENTIAL SERVICES UNLESS THERE IS AN EXTREME EMERGENCY.
- Even in the absence of services you should work with your CM to be placed on the DDS Waiting and Planning Lists.
- Your CM will help you complete a priority checklist for residential services. Based on the department's assessment of your urgency for services, you will be placed either the Residential Waiting list or The Residential Planning List. There is currently no funding for residential placements on either list.
- If your child is still in high school, your CM will begin discussing employment or day supports. Hopefully your school initiated the transition process beginning at age 16 and this is all not brand new to you.

#### If you are awarded DDS funding:

- Funding is provided directly to the family so you are in charge of deciding how best to meet your child's needs. You can hire a provider or you can hire your own staff. You also have "portability" of your funds which means you can make changes in providers or staff.
- Your CM will discuss the options you have.
- Ask your CM for a listing of vendors approved by DDS in your area and also ask for a list of Medicaid eligible services that are offered through the Medicaid Waiver.
- DDS Funding Allocation Team will notify your CM that you are being given funds based on your LON. You will work with your CM to refine your plan and create an Individuals Budget which will then need to be approved by your region.
- You will also be required to apply for Medicaid (if you have not done so) and required to apply for one of DDS's HCBS Waivers.

#### **Frequently Asked Questions**

### Why apply for Medicaid?

- Most DDS services are offered through Medicaid waivers. These waivers are offered by the federal
  government through the Medicaid program. Connecticut receives a federal reimbursement of 50 cents on
  every dollar spent on waiver services. To be eligible for a Medicaid Waiver, one must be a Medicaid
  Recipient.
- State law requires individuals to enroll in one of the waivers if they receive significant services in or out of their homes.
- Day & Employment services and Community Residential services are all covered under Medicaid waivers. If you wish to receive these services you must apply for Medicaid through the Department of Social Services (DSS).

#### What is a Medicaid Waiver?

- Years ago services through DDS were provided paid for almost exclusively in large institutions. Waivers allow people to receive Medicaid reimbursement for community supports by "waiving" the requirement that services be provided in institutions.
- Day & Employment and Community Residential are waiver services, as are most services you will be eligible for through DDS.

# What is Portability?

- You have control over your individual budget, aka your DDS funding.
- This means you can make your budget "portable" or you can change service providers at any time.
- Your CM will help you through this process.

# Navigating the system is an ongoing, learning process. To be the best advocate for your child or loved one we recommend that you:

- Build a relationship with your Case Manager.
- Stay informed and use the resources available to you: DDS website, The Arc Connecticut, other parent groups.
- If you are still in school, access the DDS transitional coordinators.
- Remember you have due process through DDS if you are unhappy with your services or decisions made about level of services.
- Remember there are no guarantees for adult services. To secure and protect services get involved with family advocacy through The Arc Connecticut and stay involved!

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