

Below is a “To Do” list that will be helpful as a step-by-step guide:

- Keep all documents received from Division of Developmental Disabilities (DDD), as well as copies of your letters to DDD, on file for reference.
- While your child is still in school, ask your child study team case manager to gather adult service information and discuss it with you at an Individual Educational Program (IEP) meeting during your child’s transition years (age 14 and up).
- When DDD offers a placement or service, examine it carefully to make sure it fully meets the needs of the individual. For example, a generic workshop program would not be appropriate for an individual who requires a structured-based program or who has been successfully employed in the community.
- Invite DDD staff to participate in the transition planning process.
- Families should insist that the Individual Habilitation Plan (IHP) fully describes all of an individual’s needs, and the goals and objectives needed to meet and address the individual’s potential.
- Be sure your son or daughter is on the DDD waiting list for day services well in advance of graduation from school. DDD regulations permit a person to be placed on a waiting list for day services five years prior to graduation.
Day Programs and Vocational Services DDD also use a waiting list for adult day services. DDD regulations permit a person to be added to a waiting list for day services five years prior to graduation. Therefore, for families of school-age children who have planned well, a waiting list should not be a problem. However, for individuals who are still on a waiting list upon graduation at age 21, it may be illegal for DDD to refuse immediate services despite its waiting list, particularly if serious regression is likely.
- Although case managers undergo training, the level of knowledge and experience widely varies. Ask your case manager about his or her experience with adults with autism. Refer him or her to COSAC for free training and information.
- Whenever possible, have a family member serve as guardian. Talk to family members about assuming this role.
- Waiting lists exist for most DDD services; therefore, it is important to make sure that your child, regardless of age, is in the appropriate waiting list category.
- Your request to be placed on the waiting list should be made in writing, through a dated letter sent with delivery confirmation (return receipt requested).
- Division of Vocational Rehabilitation Services (DVRS) involvement should begin while a student is still receiving special education services. Therefore, parents should request that the Child Study Team case manager contacts DVRS during the student’s transition years.
- Funding for long-term follow-up support services should be explored at the time of the initial IPE. If an individual is eligible for services through he or she can receive follow-up support services through a DDD-funded provider agency.
- COSAC recommends that families establish a special needs trust in order to protect assets and ensure continued eligibility for important Medicaid benefits.
- Talk to family members and loved ones who may be planning to leave money to your child with autism. Advise them on the need to put any gifts for your child into a special needs trust.
- Parents and other family members should not place assets in excess of \$2,000 in the name of the person with autism.
- If the person with autism has assets in his or her name in excess of \$2,000, and the value is modest, spend them or reimburse the family for expenses already incurred.
- Inheritance and lifetime gifts should be made to a special needs trust and not the individual with autism.