

TIME LINE FOR ILLINOIS PARENTS WITH A SPECIAL NEEDS CHILD DIAGNOSED WITH DEVELOPMENTAL DISABILITIES OR AUTISM

(As seen in Chicago Parent Special Parent Magazine, The Daily Herald, and Special Olympics Newsletter)

Written by Sherri Schneider of Family Benefit Solutions

- If, at birth, your infant remains in the hospital for some time, apply for Supplemental Security Income (SSI) for this child. As long as the child remains in the hospital, parents' income and assets will not count. To apply, call 1-800-772-1213 and indicate that you are applying for SSI. If your child has no or limited health insurance, think about applying for Illinois Medicaid.
- At any age, the sooner the better, you will need to do some special needs estate planning to include (but not limited to): wills, special needs trust(s), powers of attorney, and change of beneficiary. It is vital that you use an attorney whose practice is limited to these issues and who keeps up with the ever-changing rules. To find an attorney in your area, you may reference the Special Needs Alliance website. Doing this planning will help to ensure that your child can obtain and maintain benefits for now and in the future.
- From birth to age 3, have your child evaluated for early intervention programs. There are several agencies that provide this program. To locate the agency for your area, you can call 217-782-1981.
- Do not open any assets in your child's name. Let others know this as well.
- At age 3, seek as much help from the school district as possible. You may need to hire a school advocate or attorney to get what your child needs.
- Continue to keep no assets in your child's name.
- If your child has the diagnosis of developmental disability or on the Autism Spectrum, you must do a PUNS (Prioritization of Urgency of Need for Services). Because there is not enough money to give everyone in Illinois the services they need, this is Illinois' waiting list for services that Illinois maintains. To do a PUNS, you will need to call your Independent Service Coordination Agency (ISC) which can be found by calling 1-800-588-7002 or 1-888-DDPLANS. You can request funding for services such as: respite, children's waiver, Home Base Service waiver, job coaches, and group homes.
- If your child is under 18 years old, most benefit programs will count the parents' income and/or assets against the child. Some programs do not. To find some programs that do not deem parents' income and assets, you may call: Case Management under Division of Specialized Care for Children 773-444-0043

- Attend as many conferences you can to obtain information for your child's future. The schools have presentations. If you would like support from fellow parents, you can reference IPADD Unite on Facebook.

- When your child turns 14 ½, the school should be starting transition planning. Ensure your child's IEP reflects realistic goals. Consult School Attorney or Advocate if necessary.

-Between 17-18, have your child take a WAIS test (if your child is verbal) or C-TONI or Leiter (if your child is not verbal) and, if not already selected from the PUNS list, a Vineland test.

- In Illinois, special education can end around your child's 22nd birthday. One year before this, do your due diligence to look at programs (day, residential) for where your child may attend when the school district is finished.

-Research ABLE accounts. Can have one in any state and is a great way to be able to save money and maintain benefits.

- At 18 years old:

- Apply for SSI
- Apply for Medicaid
- Ensure your child is in the "SEEKING SERVICES" category for PUNS.
- Consider the need for Guardianship -vs- Powers of Attorney -vs- Supportive Decision Making for your child – The same attorney doing your special needs planning may be able to do this
- Get a school Power of Attorney executed and given to the school
- Get an Illinois Disabled Identification Card
- Look into RTA Reduced Fare Permit and/or ADA Paratransit Service
- Males – Register for Selective Service
- Register to vote – if applicable

- ONGOING – establish and update a Letter of Intent