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TO DO LIST FOR PARENTS WITH A DISABLED CHILD

1. Get your child's name on the State of Illinois "Waiting List" for services even if you don't need services now. (Waiting List is formally called PUNS - "Prioritization of Urgency of Need for Services") (State of Illinois wrote on January 4, 2008 that one of the factors for families getting funding for services is "length of time on the [PUNS] database") Contact your local Pre-Admission Screening Agency / Independent Service

Contact your local Pre-Admission Screening Agency / Independent Service Coordination Agency to get on "Waiting List."

If you live in Peoria or Tazewell County, then contact Central Illinois Service Access at 217-732-4731

- 2. What Services are Available For Your Child (outside of the school system) from the State of Illinois because of your child's disability. Contact your local Screening Agency / Service Coordination Agency listed above.
 - a) Children's Services including but not limited to, personal support; respite; behavior intervention; therapies; modifications for home vehicle and adaptive equipment; and residential.
 - b) Adult Services -including but not limited to, personal support; day programming services; residential; respite; behavior intervention, therapies; transportation; and modifications for home, vehicle and adaptive equipment.

(All programs for developmentally disabled children and adults are Medicaid funded and if your child has more than \$2,000 or inherits money, then he/she may have to spend down all the funds to pay for the services)

- 3. Your Child should not have more than \$2,000 in their name, including any custodial account or bonds held by you.
- **4.** Establish a "Special Needs Trust." Your disabled child will be the beneficiary of the trust and the funds in the trust can exceed \$2,000 and all the funds will not count as your child's asset by Social Security and Medicaid.
 - Your Will would not give money directly to your disabled child but would give the money to the "Special Needs Trust."
 - Life insurance beneficiary and retirement fund beneficiary would not be the disabled child but would designate the "Special Needs Trust" or your Estate, so that the monies would flow to the Trust.
- 5. At age 18, apply for SSI (Supplemental Security Income) Your child may be eligible for approximately \$674 per month.
 - Your child's payment will be reduced 1/3rd if you do not charge your child rent for food and shelter costs.
 - Your child will not be eligible for SSI if he/she has more than \$2,000)
- 6. On or before age 18, consider Guardianship for your child.
 - Does your child need assistance making decisions affecting their health, personal welfare and financial matters?