

Future Planning for a Youth with a Developmental Disability

If your teen has a developmental disability, look into the following:

- Illinois Division of Developmental Disabilities
- Registering for PUNS (Prioritization of Urgency of Need for Services)
- Education Plan
- Guardianship
- Supplemental Security Income (SSI) and Medicaid
- Special Needs Trust

Illinois Division of Developmental Disabilities

The Illinois Division of Developmental Disabilities provides services and support for individuals with developmental disabilities and their families.

- If you are interested in receiving services now or within the next five years, you must register in the PUNS system.
- This statewide database records information about individuals with developmental disabilities who are in need of services.
- Registering with PUNS does not guarantee the services, but lets the state know that you are in need.

Registering for PUNS (Prioritization of Urgency of Need for Services)

You can register with PUNS at your local coordination agency. Call 888-DD-PLANS or visit <http://www.dd.illinois.gov> to locate your local office.

- You must register to be considered for any of the following services:
 - In-home supports
 - Respite care
 - Life and work skills programs
 - Job coaches and vocational rehabilitation
 - Residential living arrangements
 - Adaptive equipment

Education Plan

If your child receives special education and has an Individualized Education Program (IEP), they can remain in high school up until the day before their 22nd birthday.

- Speak with the school regarding the education plan.
- If you want your child to stay in school until their 22 birthday, it must be written in the IEP ahead of time.
- Start early to make a plan for after high school and make sure your child is registered with PUNS so that he/she may be eligible for programs once they graduate.

Guardianship

If there are concerns about the ability of your son or daughter to make decisions independently, you may need to consider guardianship as a next step.

- You can file guardianship petitions once a teen turns 18 years old.
- There is full and partial guardianship, based on your child's needs.
- Without guardianship, parents may not have the right to decide about medical care, money, or future living plans.
- Your doctor will need to complete an assessment and paperwork during a visit within 3 months prior to submitting the petition.
- File your petition through your local circuit court. Visit <http://www.state.il.us/court/default.asp> to find your Circuit Court Clerk's contact information.

SSI (Supplemental Security Income) and Medicaid

Your son or daughter may also be eligible to apply for SSI and Medicaid.

- Once he/she turns 18 years old, the family's income is no longer considered when determining the financial status for these benefits.
- Many programs for adults with disabilities require the participant to be on Medicaid.
- For information on SSI contact the Social Security Office at 800-772-1213 or go to www.ssa.gov
- For information on Medicaid call 800-843-6154 or visit www.hfs.illinois.gov/medical.apply.html

Special Needs Trust

A Special Needs Trust allows a person with a physical or mental disability, or an individual with a chronic or acquired illness, to have an unlimited amount of assets.

- The amount of the individual's assets will not affect her/his eligibility for certain government benefits such as SSI (Supplemental Security Income), Medicaid, or vocational rehabilitation.
- Instead of leaving the assets directly to your son or daughter, you leave it to the special needs trust.
- You will choose someone to serve as the trustee, who will be in charge of spending money on your son/daughters' behalf.
- This trustee may be the parent, sibling, relative, or other trusted friend.
- Lawyers usually set up Special Needs Trust, which you can establish while your son or daughter is still a child.

Community Resources

- **Anixter Center**
773.973.7900
<http://www.anixter.org>
- **The Arc of Illinois**
800.588.7002

www.thearcofil.org

- **The Arc of Illinois Family Manual for Transition to Work and Adult Services**
<http://www.thearcofil.org/advocacykits/document.asp?did=119>

- **Family Resource Center on Disabilities**
800.952.4199
www.frcd.org

- **Independent Living Research Utilization (ILRU)**
713.520.0232
www.ilru.org
Search for your local Center of Independent Living

- **Special Recreation Programs**
Contact your local park district or visit <http://www.specialrecreation.org> for a list of Special Recreation Cooperatives

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