

ACRONYMS

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorders
CART	Clinical Administrative Review Team
CILA	Community Integrated Living Arrangement
CMS	Center for Medicaid & Medicare Services
DCFS	Department of Children and Family Services
DD	Developmental Disabilities
DDD	Division of Developmental Disabilities
DHS	Department of Human Services
DMH	Division of Mental Health
DPH	Department of Public Health
DRS	Division of Rehabilitation Services
DSCC	Division of Specialized Care for Children
DT	Developmental Training Day Program for adults

EI Early Intervention (birth to 3)

FICA Federal Insurance Contribution Act

HBS Home Based Services

HFS Department of Health Care and &
Family Services (Public Aid)

HUD Housing & Urban Development

ICAP Inventory for Client and Agency
Planning

ICD – DD Intermediate Care Facility for
Individuals with
Developmental Disabilities

IDEA Individual with Disabilities
Education Act

IDPH Illinois Department of Public
Health

IEP Individual Education Plan

ISBE Illinois State Board of Education

ISC Individual Service Coordination

ISP Individual Support Plan

ISSA Individual Service and Support
Advocacy

OIG Office of the Inspector General

PACKET Information on paper going to
Network Facilitator advocating
your need for help

PAS Pre-Admission Screening
PDD Pervasive Developmental Disorders
POS Purchase of Service funding method – fee for service
PUNS Prioritization of Urgency of Need of Services (waiting list)
QA Quality Assurance
QSP Qualified Support Professional
SEP Supported Employment Program
SNAP Supplemental Nutritional Assistance Program (food stamps)
SNT Special Needs Trust
SODC State Operated Developmental Center
SSA Social Security Administration
SSDI Social Security Disability Insurance
SSI Supplemental Security Income
SST Support Service Team
UCP United Cerebral Palsy

EARNING FICA CREDITS FOR SSDI

- The credits are based on the amount of your earnings. Your work history determines your eligibility for disability benefits.
- In 2020, you receive one credit for each \$ 1410 of earnings up to a maximum of four credits per year.
- The number of credits you need to be eligible for benefits depends on your age and the type of benefit.
- How many credits you need for disability benefits depends on how old you are when you become disabled:
 - If you become disabled before age 24, you generally need 1½ years of work (six credits) in the three years before you became disabled.
 - If you are 24 through 30, you generally need credits for half of the time between age 21 and the time you became disabled.
 - If you are disabled at age 31 or older, you generally need at least 20 credits in the 10 years immediately before you became disabled

Monthly substantial gainful activity amounts by disability type

Year	Blind	Non-blind	Year	Blind	Non-blind	Year	Blind	Non-blind
1975	\$200	\$200	1995	\$940	\$500	2015	\$1,820	\$1,090
1976	230	230	1996	960	500	2016	1,820	1,130
1977	240	240	1997	1,000	500	2017	1,950	1,170
1978	334	260	1998	1,050	500	2018	1,970	1,180
1979	375	280	1999	1,110	700	2019	2,040	1,220
1980	417	300	2000	1,170	700	2020	1260	2110
1981	459	300	2001	1,240	740			
1982	500	300	2002	1,300	780			
1983	550	300	2003	1,330	800			
1984	580	300	2004	1,350	810			
1985	610	300	2005	1,380	830			
1986	650	300	2006	1,450	860			
1987	680	300	2007	1,500	900			
1988	700	300	2008	1,570	940			
1989	740	300	2009	1,640	980			
1990	780	500	2010	1,640	1,000			
1991	810	500	2011	1,640	1,000			
1992	850	500	2012	1,690	1,010			
1993	880	500	2013	1,740	1,040			
1994	930	500	2014	1,800	1,070			

FAIR SHARE

Social Security will lower someone's check if they are not paying their full share of household expenses.

Household Expenses for Renters

For renters, household expenses are

- rent
- gas/heat
- electricity
- water, sewer
- garbage

Household Expenses for Homeowners

For homeowners, household expenses are

- mortgage
- property tax
- property insurance (only if required by mortgage)
- gas/heat
- electricity
- water, sewer
- garbage

ADDITIONAL HOUSEHOLD EXPENSE

Food is also considered a household expense. It can be included in your lease or in a written agreement as an expense. Or you can simply pay for your own food yourself and not have any kind of written agreement. Social Security does not ask for written proof of food. Most people on SSI choose to keep their food separate from other people in the household, since this generally will lead to higher amount of food stamps, according to the Food Stamps Regulations.

NOT HOUSEHOLD EXPENSES

- Everything else!

What About Other Expenses in My House?

According to the Social Security regulations, Social Security DOES NOT CARE who pays your phone bill, internet, medical bills, lawn care, appliances, pet care, or car insurance or any other bills other than those listed above, as long as the money does not go directly to you.

PUNS - THE BASICS

From The Arc of Illinois

Family to Family Health Information & Education Center

- PUNS stands for Prioritization of Urgency of Need for Services.
- PUNS is a list of the people in Illinois with developmental disabilities who need services.
- PUNS is for everyone who may need help from the government to pay for developmental disability services now or in the future.
- PUNS is the first step toward getting services in Illinois. If you are not on the PUNS list, you are not on the waiting list for services.
- To get on PUNS, you need to set up a date to meet with a Pre-Admission Screener. These screeners will ask questions about you and your needs. These questions are part of the PUNS survey. All screeners work for Independent Service Coordination Agencies or ISC's. To get on the PUNS list, you must have a developmental disability. If you don't know if you have a developmental disability, the screener will help you.
- To find your ISC, you can call Illinois Life Span at 1-800-588-7002. You can also call DHS at 1-888-DD-PLANS.
- When your PUNS survey is done, you are on the list. This doesn't mean that you will get the services you need. It just means that you have made the first step.
- Some of the services that people may need are:
 - In-Home Supports
 - Respite Care
 - Job Coaches
 - Group Homes
 - And many others
- There is not enough money to give everyone in Illinois the services they need. Right now, many people are working on a fair way to choose who gets services.
- Don't forget to update your PUNS form every year. Only people (families) who have completed the PUNS - and keep it updated - have a chance of getting "picked" to receive services.
- If you have questions or need help, you can call Illinois Life Span at 1-800-588-7002.
- If you want more information about PUNS or Home-Based Services, go to the Family Support Network website at www.familysupportnetwork.org

PUNS

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If age 18 or older - When will I be selected??

dhs.dddd.puns@Illinois.gov

- Name
- Address
- Birthdate
- Social Security number

QUESTIONS FOR POTENTIAL SPECIAL NEEDS TRUST ATTORNEY

- 1) How many Illinois special needs trusts have you done? Third Party?
D4a/OBRA 93/First Party?
- 2) Do you keep up with the rule changes? If yes, how?
- 3) Do you let your clients know when their trust needs updating?
- 4) Has your trust been denied by SSI or Medicaid? If yes, why?
- 5) If mine gets denied, will you file the appeal with Social Security / IL
Medicaid - and will the appeal cost me more money?
- 6) Has your trust been submitted with an actual case for someone
applying for SSI and/or Medicaid or have they mostly been prepared
for younger clients?
- 7) Has your trust been pre-approved by SSI? By Medicaid?
- 8) Has your trust been approved by Regional Staff?
- 9) Is your trust compliant with the clarified POMS 1/1/09 and 2010?
- 10) Is your trust compliant with the new trust regulations beginning
January 2020?
- 11) Do you charge for questions after the documents have been
signed? If yes, at what cost?
- 12) How long is the first consultation? Do you have a consultation
fee? If yes, does this fee count toward a contract with you?

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. The Arc of Illinois lists their presentations on their website. If you would like support from fellow parents, you can reference IPADD Unite on Facebook. You can also attend a work group in your area. www.iacdd.org

- 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 and, if not already selected from the PUNS list, a Vineland test.

- In Illinois, special education can end the day before your child turns 22. 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.

- At 18 years old:

- Apply for SSI
- Apply for Medicaid
- Consider the need for Guardianship –vs- Powers of Attorney 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